# Communications Manual

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AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF CANADA
SOCIÉTÉ CANADIENNE DE LA SCLÉROSE LATÉRALE AMYOTROPHIQUE

# Communications Manual

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# Introduction

*"We are constantly challenged with a growing number of people with ALS to maintain our priorities. Client and caregiver support come before all else. After that, if time and resources are available, we worry about public awareness."*

*"It's the job of ALS Canada, from our perspective, to raise awareness of the illness and funds for research."*

In this section

## ALS and public awareness: The challenge

These comments about public awareness and media relations reveal the dilemma of many ALS Society volunteers and staff. When ALS strikes, its course is so rapid and devastating that the needs of people with ALS and those around them consume all the family's available resources — physical, emotional, financial. At our Unit and Chapter levels, public awareness and media relations activities are secondary to the human needs so dire and immediate. Also, the volunteers we rely on so often do not have the experience or skills to confidently engage in awareness activities.

### Public awareness

Media relations and public awareness work are too important to overlook. At the National level, the ALS Society of Canada is well positioned in many areas, including promotion of our understanding of the disease and of the need for research funding. But the organization can't mobilize local resources nearly as effectively as someone within that community. It is those on the spot who can assess and access whatever resources the community has to offer. And stories about a local person with ALS in local papers or on local radio, news items in company newsletters, and speeches to local service clubs and community groups are effective ways of drawing attention to the disease and the organization.

## Goals, objectives, strategies

ALS Canada has developed a Communications Plan to clarify its goals and objectives and communicate the strategies it will undertake to achieve these intentions.

### Goals for ALS Society communications program

- Maximize awareness opportunities
- Create awareness opportunities
- Communicate accurate messages
- Build understanding of ALS
- Increase the visibility of ALS and the work of the Society at all levels
- Support fundraising, advocacy and all other initiatives of the ALS Society

### Communications objectives

- Communicate the specific messages of the ALS Society with each of its audiences, both internal and external
- Increase recognition of ALS and the ALS Society of Canada with the wider public. Hone and deepen our image and "brand" through new strategic initiatives
- Support awareness activities nationally and locally, building on the momentum that is growing as a result of local efforts
- Attract donors and volunteers to the work of the Society

### Communications strategies

- Build corporate identity to increase recognition of the ALS acronym
- Strengthen existing communications tools and create new ones to meet the needs of our internal and external audiences
- With corporate partnerships, gain wider distribution of additional awareness tools: print and video PSAs, media and transit advertising, etc.
- Offer communications support to programs like the WALK for ALS, June ALS awareness month, March of Faces, and other awareness activities

# Getting started

This manual is intended to provide guidance to ALS Society volunteers. With the correct tools and some experience, volunteers will be able to increase visibility in

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their communities and promote our common cause. It is intended as a toolkit and a stimulant to your own creativity in the awareness challenge. As well as advice and information, it contains resources from ALS Canada, which are also available on our web site (www.als.ca) and are updated regularly.

## Purpose of the Communications Manual

### Checklist

- Provide an overview of what communications involves and its various components
- Clarify the interconnecting roles of national, regional and local communications programs
- Encourage local volunteers to increase ALS Society visibility in the community
- Provide useful resources to those volunteers
- Provide guidance re: crisis communications

We hope you find it helpful.

## The message

### Growing awareness of who we are

The ALS Society of Canada is more than a collection of dedicated local societies. It is a multi-level partnership in which local, unit and national organizations work to create a strong, unified message. It is a relationship in which consultation and communication are essential. One of the goals of this manual is to empower and enliven the partnerships within the ALS community. If we can build solid communications among ourselves, we will be able to support each other in the critical work of raising visibility and enhancing public awareness of ALS and the work of the organization.

### Who is our target audience?

Our target audience includes the ALS community, i.e., circles of influence emanating from the person with ALS at the centre, including:

- Family, friends, neighbours, work associates, community connections
- Health-care professionals who treat people with ALS
- Donors
- Media at the national, provincial and local levels
- Potential funders and sponsors

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- Policy makers at the federal, provincial and local levels
- General public

### About ALS

Fact

- ALS is a rapidly progressive and fatal neurological disease
- ALS can strike anyone, regardless of age, sex or ethnic origin
- Two to three Canadians a day die of ALS
- Approximately 3,000 Canadians currently live with ALS
- ALS affects the whole family
- ALS is costly — economically, physically and emotionally

### ALS Canada mission statement

Founded in 1977 as a national voluntary organization, the ALS Society of Canada funds research towards a cure for ALS, supports provincial ALS societies in their provision of quality care for persons with ALS and provides information to build awareness about the disease.

### ALS Canada vision statement

In the fall of 2004, the Board of Directors of ALS Canada approved a new vision statement, which is: “the ALS Society envisions a cure for ALS.”

### Tag lines

Quote

- "ALS. Three letters that change people’s lives. FOREVER.”
- "What would you do, while you still could?”

## Audiences and messages

Following are the series of messages that ALS Canada has developed aimed at specific target audiences.

### Messages for people with ALS, caregivers and network of supporters

- We are your source for reliable information about ALS and the ALS network in Canada
- We raise money for ALS research

- We collaborate with partner units to help provide support
- We raise awareness about the disease
- We advocate on behalf of and with people affected by ALS

## Messages for health-care professionals

- *Those unfamiliar with ALS:* We can direct you to resources and people who can answer your questions
- *Those familiar with ALS:* We are part of the team supporting those affected by ALS

## Messages for the research community

- We fund research through the Neuromuscular Research Partnership (NRP) and the CIHR
- We are part of the team supporting those affected by ALS
- We can share your news — drug trials and other research

## Messages for policy makers

- We will work with you to help create solutions to problems within your jurisdiction
- We are an organization that works collaboratively to maximize resources
- It is crucial for us to ensure that neuromuscular research is sustained and strengthened. The reasons for having the NRP are as important as ever — to improve the lives of Canadians, to promote Canadian research, and to fulfill the mandate of our respective organizations (ALS Canada and Muscular Dystrophy Canada) — fund research for a cure, as effectively as possible
- Funding for a cure for ALS remains a top priority for the Canadian government
- Only you can make it happen. We need you to be our voice in Parliament
- ALS researchers indicate that they are getting closer to understanding the cause of ALS, which will lead to treatment and ultimately a cure for this devastating disease. ALS researchers need secure funding to accomplish this goal
- ALS is a costly disease — emotionally, physically and financially
- It is very difficult to treat and cure diseases such as ALS
- There is no cure — yet
- Increased funding for research into the causes, cures and treatments for chronic diseases — such as ALS — will help reduce the tremendous burdens placed on our health-care system

## Messages for the community and health media

- We are the source for news about ALS
- We provide accurate and timely information
- We can connect you with people in the ALS network to profile or respond to an issue

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- We can provide sources for larger issues that relate to ALS – homecare, health-care reform, stem cell research etc.

### Messages for other media

- We are the source for news about ALS
- We provide accurate and timely information
- We can provide local human-interest stories

### Messages for donors

- Your donation makes a difference
- Research is our only hope for finding a cure
- We have many ways for you to contribute

## Educating Ourselves

As participants in this conversation with the public, we need to be able to answer these basic questions. Education is the first task in any increased awareness.

Our message is more than just facts and scientific data. It is about drawing people into a community of concern. The society in which we live is highly visual. In thinking about the ALS message, we also have to visualize it if we want to make the conversation more effective.

In an organization as complex as the ALS Society family, it is important to clarify which area is responsible for what task. The chart below shows how Partner Units and the ALS Society of Canada have agreed to divide the tasks in our communications program.

The media — newspapers, magazines, radio and television — help us to get our story out. In seeking to raise visibility, we have to focus on the needs of the person who is encountering ALS for the first time: as a person with an ALS diagnosis, as a family member, as a possible donor, even as a media person.

We have agreed to divide the communications/public awareness roles between the ALS Society of Canada and local partner units. The specific roles are outlined in this chart.

## Public awareness/communication

### ALS Society of Canada

- Develops an annual report for the public and provides Units with bulk copies for distribution
- Manages crisis communications process to deal with any issue that affects more than one Unit; offers support in crisis communications to Units
- Enhances and utilizes relations for the benefit of ALS Societies with media
- Develops material for use by Units, after consultation and involvement with the Units
- Produces and distributes news releases on key Canada-wide topics
- Produces appropriate communication tools — newsletter/web site/list serve/etc. and distributes to Units, media, people with ALS, donors, etc.
- Establishes and implements a strategic public awareness and communications plan in conjunction with Units
- Involves stakeholders in the development of awareness materials
- Provides materials to Units at cost or less
- Responds to public inquiries with pertinent information and compassion; provides no medical advice
- Co-ordinates communications strategies on an annual basis

### Unit

- Develops an annual report for the public; sends partners copies
- Responds to public inquiries with pertinent information and compassion; provides no medical advice
- Informs ALS Canada in confidence of issues which may lead to potentially damaging publicity/legal action
- May have a Unit newsletter
- Provides input to awareness material development
- Ensures that logo and corporate identity are being used properly
- Provides materials to Chapters and/or Support Groups at cost or less
- Co-ordinates communications strategies on an annual basis

# Volunteers

Volunteers play a vital role in enabling the ALS Society to mount communications activities. For instance, volunteers make presentations to community groups, arrange displays at health fairs, and manage media relations programs.

This section of our Manual provides some guidance for how volunteers can maximize their involvement in a media relations program.

In this section

- Media relations working group
    - Goals for the working group
    - Next steps

## Media relations working group

Consider forming a Media Relations Working Group to co-ordinate the media relations activities and provide continuity from one year to the next. One of the great frustrations in small and medium-sized organizations is the feeling of "reinventing the wheel" each time there are leadership changes.

If good work has been done the previous year, it needs to be available so that its successes can be built on. Two or three people should be able to do this work effectively.

### Goals for the working group

Checklist

- Purchase a binder and put copies of all press releases you issue to the media in it
- Keep lists of media contacts (divided by print, radio and television)
- Maintain archival files of promotional material developed by the local ALS Society
- Maintain copies of all local media coverage of ALS
- Maintain files of materials received from the ALS Society of Canada and the ALS Unit
- Annually update the lists of local media contacts

- Maintain an updated profile of the local ALS Society; keep extra copies for distribution
- Keep contacts with client groups
- Develop an annual calendar with events and media deadlines
- Develop a bio for your Unit President and Executive Director
- Develop a critical path for special events and assign responsibilities. Have a chair and co-chair for sub-committees so the person next in line will be able to identify specific promotional tasks and recruit volunteers to take them on
- For reference, keep copies of *Coast to Coast* (the ALS Canada newsletter), *Research News* (ALS Canada's research newsletter) and *The Northern Neuron* (ALS Canada's research publication)

If this structure is being put in place for the first time, consider holding a one-time consultation to help focus staff and volunteers on media work. Invitees could include:

- Local staff and volunteers who have worked on media
- Representatives of other partner health organizations
- Media personnel: e.g., a reporter who writes on health issues in a local newspaper, a public service announcement director from a local radio station, a producer from a television station
- People with ALS
- Representatives of the Unit and ALS Society of Canada office

The goal of the consultation is to raise awareness within the local organization — not to make specific plans. The following questions might guide the discussion:

- What is the present media profile of ALS in this community? Give us a snapshot
- How can the local Society improve its media profile?
- How do local activities connect with the national strategy of the ALS Society of Canada?

Encourage participants to tell success stories and brainstorm fresh strategies. Make sure to take detailed notes so that examples and suggestions can be followed up, especially if particular names and organizations come up. The notes from this consultation will help the Working Group assess and prioritize its work with the media.

## Next steps

Have your media relations working group review the Media Relations section of this Communications Manual that contains guidelines for planning and implementing an effective media relations program.

# Media Relations

The Media Relations section of this Manual includes a wealth of information. After you have reviewed this section, you will have the tools you need to implement an effective Media Relations program for your Unit.

In this section

## Creating a media plan

The goal in all communications activities is to increase the visibility of the ALS Society and the disease to bring about public awareness, understanding and willingness to support our cause and fundraising activities.

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We recommend the development of a plan for each segment of the communications activity.

### When you are creating a media plan you will:

- Determine why you are doing media outreach
  - Who is the target audience?
  - What media outlets will you use?
- Develop a media timetable/critical path (determine what will happen when and by whom)

A media plan takes time to develop, but it can be an effective tool to organize your media relations efforts. Be creative; media relations is often a simple matter of finding an angle to the news that makes it interesting.

Plan something for every quarter so that you can establish a rhythm and maintain momentum.

The media timetable can be mapped out on a spreadsheet with the months of the year going down the left column and some headings across the top, for instance, timing, topic, target, responsibility and results.

## Effective media coverage of ALS means strong local coverage

Media attention is essential to raise public awareness of ALS. With greater public awareness, we will be better positioned to educate and offer resources to individuals and families. Effective fundraising relies on increased public awareness. Each local ALS Society needs to make media relations one of its primary goals and build the function into its ongoing operations.

### The first step

The first step in building a media relations program is knowing clearly what message we want to convey. The media are overwhelmed with a thousand competing ideas and facts every day. If we can articulate the ALS message, then we will be able to persuade the media that this is an issue that needs to come to the public's attention.

The ALS message needs to be delivered with clarity, compassion and conviction.

### Thinking about ALS and the media

As the baby boomers age, media coverage of health and health-related issues has increased enormously. Yet ALS Society staff and volunteers, even those with formal media relations training and substantial experience as communicators, lament the difficulty of placing stories about ALS.

Several major stories about ALS and people with ALS have appeared in the national media recently. Despite these successes, the basic challenge remains.

“Media outlets get inundated, and ALS is not news. It is hard to compete,” said one seasoned communicator in our ranks.

Fact

The media is most likely to pick up on a health story when:

- there is a medical or scientific breakthrough such as
    - a dramatic increase in its incidence
    - a new drug/therapy for ALS or
- a celebrity has contracted it

Since Sue Rodriguez’s highly publicized fights for the right to end her battle with ALS through assisted suicide, there have been few ALS-related events that a Canadian editor or producer would consider newsworthy on a busy day.

### Media awareness and the local ALS Society

We tend to think of media coverage as a “hot” phenomenon: national news stories that happen in cities with high-profile people and events. However, being newsworthy can often mean that the story is out of our control. The media, especially television, are looking for the angle that makes the story interesting, and this often focuses on negative aspects.

ALS has one great “hot” news story ahead in the future: the announcement of the cure for the disease. But until that day, the media coverage of ALS will rely on strong background coverage of the people and programs that are working to defeat the disease.

## How to be newsworthy

To get coverage, you must be newsworthy. Being newsworthy means you meet one of the media’s three objectives. You inform, educate or entertain. Your story must also be timely. Before pursuing a story, editors, reporters and producers ask themselves, why would our readers, viewers or listeners be interested in this now?

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### A checklist to figure out your news angle

To answer the question above, identify what journalists call the “angle” of your story. Ask yourself the following questions to help figure out how your activity or event can be newsworthy:

Checklist

You should answer "Yes” to the first question and to at least one other question.

- Is it timely?
- Is it innovative?
- Is it different or distinctive?
- Will it instigate a change that will affect many people in your community (local hook/angle)?
- Could it impact the public’s health and safety?
- Is this something that has never been done before (for example, a new fundraising initiative), or has never been done before in your community (for example, a new walk, hike)?
- If it has been done before, how is it being done differently this time?
- Does it tie in with a current item in the news?
- Does it tie in with a particular season, ALS Awareness Month in June, or holiday?
- Is it information that previously did not exist (such as result of a survey or study)?
- Does it have emotional appeal? Is it moving or inspiring? Is there a human interest angle?

Units’ annual WALK for ALS is an example of a newsworthy event. The media do a story about the event. Check to see who would like to be interviewed about why they are participating in the Walk. If you need assistance with media training, contact the national office.

# The media: An overview

## Television

Television is the most important and pervasive medium in Canadian society. It is where we go for information, entertainment and even consumer shopping. Television has the capacity to reach everyone making it the most valuable medium for public awareness. However, it is also both the most expensive and the most competitive medium.

Television stations are either *affiliates* of a network such as the CBC or *independents* such as CITY-TV in Toronto or AChannel in Alberta. Affiliates are part of a national network with substantial resources. A broadcast segment, which is developed by the local station, may be shown on the national network. Independent stations, on the other hand, usually have a mandate to promote local news and issues.

There has also been a dramatic development of lifestyle-related cable programming such as the LIFE cable network. Remember also that neighbouring American stations increasingly aim to serve their Canadian viewers. Health stories cross boundaries easily.

Fact

Health-related stories on television tend to fall into two categories:

- **News stories:** e.g., a dramatic breakthrough in research, a celebrity with the disease, a crisis or scandal in the health organization. These stories will be accompanied by topical footage and short interviews with key players in the story
- **Background stories:** e.g., overviews of medical research, an "ordinary" person's account, or "inspirational" stories of community experiences. These will almost always be profile segments that use personal interviews (the human interest angle) as a means of talking about the issue

## Key people

It helps to know the players in TV and the role they play, for instance:

- **Planning editor:** Reviews all news information received prior to an event, and often arranges for an interview to take place before the event. Most network affiliates have a planning editor but only some independent stations do
- **Assignment editor:** Determines what stories will be covered on a particular day. There may be several who work on a rotating basis
- **Reporter:** Actually covers the story. Reporters usually work on assignments and cover stories assigned by the assignment editor, but may also suggest ideas
- **Producer:** Schedules interviews for talk show hosts
- **Researcher:** Develops background information on a story for the producer and host

## Radio

With the exception of the CBC, most radio stations are independent in Canada. Local profiles are important to the independents and health-related stories are broadcast on these stations more frequently than on network television.

Fact

Health-related stories have more opportunities on radio than on television.

- **News stories:** As on television, are topical and may be shaped by circumstances beyond the control of the health organization
- **Background stories:** Are nearly always an interview with a person with the disease, or with an activist or professional in the field

The rise of so-called "talk-radio" has dramatically opened up new possibilities for access to public forums on health issues.

Over the next few years there will be an increase in the number of radio stations that are only broadcast on the Internet. Many of these may well be "specialty" channels, much like cable television channels.

### Key people

The key people in radio are:

- **News director:** Determines the news items for a particular day, schedules interviews and sometimes conducts them
- **Public service director:** Decides which public service announcements will be aired
- **Producer:** Schedules interviews for talk show hosts
- **Researcher:** Develops background information on a story for the producer and host

## Magazines

Print media — once dominant in mass communication — have been largely superseded by the broadcast media. Although readership of national newspapers and magazines has declined, the appearance of local and even neighbourhood newspapers provides a valuable tool to community-based health organizations. There has also been a growth in the number of specialty and professional magazines, usually published monthly or quarterly.

Fact

Health-related stories can appear in a number of forms:

- **News stories:** These are topical and dramatic. National papers may also include your local story in its national edition
- **Background articles and profiles:** Many newspapers have a reporter or editor who looks after health-related stories. As with television and radio, these articles will tend to be based on interviews. The articles may have to wait until there is a "soft" news day and there is space in the publication. A rapidly emerging news story will often bump a background article

### Key people

The key people in magazines include:

- **Managing editor:** In charge of all editorial activities of a publication. You may send news releases and information kits to the managing editor of a small community newspaper or small magazine, but it will not be useful when you're dealing with larger publications
- **Editor:** Assigns and edits others' stories. Trade magazines tend to have one editor who oversees all topics covered in the publication. Newspapers, consumer and business magazines often have editors with responsibility for specific kinds of stories and specific topics, such as features, departments and health and medicine
- **Writer, reporter, columnist:** Research and write stories. Columnists generally have a specific area of coverage; on larger publications, writers and reporters generally do as well. Their stories may be assigned by an editor or self-generated

## Media relations: The process

### Develop a calendar

Develop a calendar of the Society's activities and events that merit media attention. The most important date will be ALS Month in June. In fact, the whole year's media planning will probably focus primarily on this period. Include any fundraising events and activities that involve partnerships on this calendar.

Add the media deadlines that lead up to an event or project. This process will help to schedule the work and facilitate assigning tasks to staff and volunteers. Don't underes-

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timate the lead time you will need to encourage or place a larger article in a newspaper or arrange for an interview with a radio or television station.

## Build your media list

Each ALS Society will want to research its own media environment. Use this data to produce a list of all the media available to your organization. In many cases, you may have personal links between your members and the media. Make sure that contact information is noted on the list. Update your lists annually. Networking is a one-to-one business that may require a personal phone call. The national office can provide you with a provincial media list. Help is only a phone call away!

**Establish your local area:**

A good rule of thumb would be to draw a 100 km circle on a map and consider that your local area. Identify where government offices are located. They may have media lists.

**List the television stations:**

Use the yellow pages and Internet searches to list all the television stations. Identify local programs that feature health-related stories; include the names of producers, reporters and hosts who have worked on them. Call the stations and ask for the telephone, fax and e-mail addresses of the people on your list. Also ask for the names and numbers of people who have worked on medical and science stories.

**List the radio stations:**

Most radio and television stations have their broadcast schedules posted on their web sites. Identify the names and times of programs that might feature health-related features. Note “lifestyle” programs in particular. Call the stations and ask for the contact information.

**List the newspapers and magazines:**

As you compile your list of print materials, you might want to research the way in which health articles have been written in the past and get a copy of these articles. Most libraries will have issues from the past year or have them on microfiche. Increasingly, past issues will be accessible through the publication’s web site. Remember to include the smaller community, neighbourhood and consumer newspapers. They are often open to carrying an article that you have written. Call the publications and ask for the contact information.

**Search the Internet:**

Search under such key words as “ALS” and “health issues” to see where ALS is being discussed. There is an explosion of information on the Internet, usually in the form of web sites dedicated to specific issues. People faced with health questions are increasingly turning to the Internet to find information about research and available resources. Always follow the links at an interesting web site to see if there are other sites that might provide informational and promotional opportunities. Keep a list of the URL addresses of these sites. Remember that most word-processing programs automatically turn an e-mail address into an immediate link button.

## Update the list

Media contact lists need constant updating. An old list of contacts is not useful. At a minimum, check the entire media list annually and update it accordingly. Encourage your members to watch for new media opportunities in the area: a change of reporters at a television station, a new neighbourhood newspaper, or a new lifestyle magazine. Note these changes on your list.

## Sample categories for database or template

**Print media: Newspapers and magazines**
*Name:* Newspaper, magazine, etc.
*Ridings:* Federal, provincial
*Other Districts:* Regional, municipal
*Frequency:* When is it published?
*Address:* Address, City, Postal Code
*Phone:*
*Fax:*
*Email:*
*Contact:* Name and title of contact person
*Web site:* URL address
*Published:* Specific days & dates
*Deadlines:* Days & times
*Circulation:* Area
*Notes:* History of contacts and past stories

**Electronic Media: TV and radio**
*Name:* Newspaper, magazine, etc
*Ridings:* Federal, provincial
*Other Districts:* Regional, municipal
*Frequency:* Times of broadcast
*Address:* Address, city, postal code
*Phone:*
*Fax:*
*Email:*

*Contact:* Name and title of contact person
*Web site:* URL address
*Local programs:* Names, days & times of programs
*Deadlines:* Suggested lead times
*Newsroom:* Contacts
*Notes:* History of contacts and past stories

# Giving interviews

## Media tips

### Checklist

- When a reporter calls, drop everything and look after his/her request
- Ensure that your media spokespeople go through media training
- Do mock interviews with your key spokespeople
- Develop your key messages and ensure that your spokespeople are familiar with them
- Always ask the reporter what the article is about, to ensure that you give the best spokesperson possible
- Check with your volunteers to see who has media experience and keep a roster
- Track your media calls and issue reports to your management team and board
- And most importantly, make sure when you issue a news release that you actually have news — is it an opening of a new office, your annual conference and you have high-profile speakers, or is it a human interest story (e.g., one of your members is organizing a fundraising concert with the proceeds going to your local society and the invited guests include some of the top Canadian musicians)

## Why is the media so integral to your Unit?

Why co-operate with the media? Why is it to your organization's benefit?

- Third-party endorsement
- Stories about your Unit's accomplishments help to increase awareness of what you are doing in the community; increase donations; increase government funding
- Public opinion is so important — and one of the most effective ways to influence public opinion is through the media

- A single appearance on TV, for example, gets your message across to thousands of people

## Choosing spokespeople

Interviews are challenging events that need careful preparation. Compile a list of people who are willing and capable of being interviewed effectively about ALS. Check with these people to ensure they are willing to be "on-call" to speak on behalf of the local ALS Society. They will be your front-line troops for the Society so they need to be carefully selected.

Your spokespeople might include:

- President/Executive Director of your Unit
- Person living with ALS who is comfortable talking about his/her personal experience
- Family member/colleague who has experienced ALS in the family/community
- Doctor who has experience with ALS and can speak knowledgeably about it
- Nurse/palliative care professional who knows the needs of the person with ALS
- Celebrity/well-known person who can speak with personal conviction
- Volunteer who speaks enthusiastically about the work of the local ALS Society
- Unit President of the local Unit
- President & CEO of ALS Canada

Refer to the Privacy Policy in Section 10, Resources.

ALS is a disease that crosses all categories of people. Aim to ask people who, in addition to their expertise and experience, reflect the diversity of Canadian society — in age, gender, ethnic and racial background, economic and educational background. As you orient these people, make it clear that public comments about ALS need to be factual. In many cases, the person will be speaking as an individual and their opinions will not necessarily represent the ALS Society's policies or positions.

These people need to know well in advance that they could be called at short notice to speak on behalf of the Society. Don't assume that you will be the first contact of the media. If your spokespeople have been interviewed previously, the media often will call them first.

If your spokespeople are conscientious, they will anticipate what they might say when interviewed. Connect regularly to keep them briefed about ALS and the local Society.

Give each spokesperson a file that includes:

**Checklist**

- Name and phone number of an ALS Society contact person who will work with them through the interview, e.g., the person who made the initial contact
- Articles and news stories that have appeared recently in the national or local media
- List of other ALS spokespeople, with phone and cell numbers
- News releases or kits prepared recently
- Key events that are taking place in the year
- *10 Facts About ALS*
- ALS Fact Sheets
- Briefing notes about current medical research and the issue of the moment
- ALS research newsletters
- ALS Researcher Profiles (Research Updates)
- Research synopsis
- *Northern Neuron*

Much of this material can be sent through regular e-mail distribution or mailed to your spokespeople. These people may want to keep informal contact with each other so that they can support one another. A social event during ALS Month is a good way of supporting and thanking your spokespeople for their work.

## Media training

This manual contains a number of tips that will assist you to be interviewed or to provide background information to reporters. However, it is worth considering having some media training for you, your experts and your spokespeople before embarking on a media relations campaign. It is important for everyone involved to review the resource material and consider how to respond to a variety of types of questions. In addition, provide spokespeople with a copy of the Media Relations section of this Communications Manual for reference.

### Preparing for an interview

Encourage the spokesperson to prepare for the interview with an ALS contact person. However, they may have to fly solo if a journalist phones unexpectedly. When a journalist calls, drop everything and make it a top priority to discuss the media opportunity with him/her. If it is not a convenient time, set up a mutually convenient time for both of you.

Be prepared for various interview formats:

- Telephone
- Face-to-face at home, office or a studio
- E-mail

Telephone interviews may be taped and edited for radio or may even be "live" calls. Broadcast interviews will be taped or filmed. A researcher may call in advance to brief the spokesperson on protocol, discuss what to wear, and prepare them by running through some of the questions and answers.

If a person with ALS or family member has agreed to give an interview, ask the journalist to keep it brief. You may also wish to help the person living with ALS or family member anticipate and prepare for the kinds of personal questions about the physical and psychological aspects of the disease that a journalist is likely to ask. The person living with ALS or family member should know that it is perfectly fair to ask for a "time out" if they become tired or overwhelmed by emotions during the interview. The ALS contact may want to attend the interview to give moral support.

We suggest that the spokesperson aim to focus on no more than three messages to convey to the media. Some sample issues are:

- What is the nature of the disease?
- What is the purpose of the ALS Society?
- What funds are needed for research and services for those affected by ALS?
- What is the need for volunteer assistance?
- What is the latest research news?

These issues will help to clarify and focus what the spokesperson might like to say. Be prepared to answer probing questions journalists may ask, for instance:

- I've never heard of ALS. What is it?
- What is the typical progression of the disease?
- What kinds of immediate relief are there for the person with ALS?
- How many people die each year from ALS?
- How many Canadians have ALS?
- What is the ALS Society position on assisted suicide? Have you ever considered assisted suicide?
- Who was Lou Gehrig?
- What did the Sue Rodriguez story tell us about ALS?
- What is the government doing to help people with ALS?

Not all interviews will be conducted in such depth. An interview about a social or community event may be much lighter in tone:

- What does the cornflower symbolize?
- How many people will be attending the event?
- Is this the first year that the event is being held? If so, why are you holding this event?
- Where will the funds go? (Research, client services)
- How long has the ALS Society been active in this community?
- What's happening at this event?
- Who will be there?
- How can people learn more about ALS?

# Writing for the media

## Working with the formats

The most important media documents are the *news release*, *media advisory* and the *fact sheet*. The following sections outline the main features of the news release with suggestions and examples. Refer to samples in the Resources section.

### Writing news releases for print and broadcast media

A news release is a communication from ALS Canada to the wider community through the media. News releases tell the media that the Society is newsworthy and should be part of their lineup of stories. ALS Canada has to compete in the information market not only with its partner organizations but with the whole range of political and entertainment stories.

Media divide items into "hot" topical stories and "cool" background stories.

### Getting the media's attention

Most days, editors are inundated with more "story opportunities" than they can possibly report on. Fax machines and e-mails constantly spit out all manner of press releases. Editors scan potential "stories" and quickly decide which ones are most interesting and most important to their readers, viewers, and listeners.

"Important" is a relative term, depending on whether we're talking about the local weekly newspaper or Peter Mansbridge and *The National*. Regardless, keep the key criteria in mind when seeking media coverage. Be concise, and focus on what aspect of your organization is of pressing interest to the outside world? Why should my issue matter to others? How can/will it affect lives in the community?

## News/Press releases

These are the most common and direct way of getting information in front of an editor. They are particularly useful for flagging the media to a significant announcement or upcoming event, or offering your organization's "local angle" response to a broader development or government announcement.

The media is always after a good story. Achieve third party endorsement from the media and you've landed a goldmine.

But before you approach the media, ask yourself, have you got a STORY to tell? If you think you do, answer the 5Ws of journalism — the Who, What, Where, When, Why, and How — then write a news release.

Writing a news release involves an awareness of the basic news release format. Start with an attention-grabbing headline. Answer as many of the 5Ws as you can in the first paragraph. Answer the remainder in the next. Find someone in senior management to provide a quote that supports your story. The balance of your news release should be background information or information that backs up the 5Ws you introduced at the beginning of your release. Finally, provide a short history of your organization. Include contact names and phone numbers so that interested media people can talk to someone from your organization.

Marshal McLuhan, the world-renowned authority on Communications stated that, "the Medium is the Message." Today, I ask you to consider the Message as the Medium — for success! Planning what you say, who you say it to, and when and how to say it, is what makes the difference between a good marketing campaign and a great one.

A *topical story* will be event and people-driven. If, during ALS Month, you have a prominent celebrity or an unusual visual aspect (e.g., a fundraising run for seniors), it will be attractive as a lead story. In print that will mean a story, perhaps with a longer article farther back in the newspaper or magazine. Broadcast media might use it as their local lead story or as a "hook" to keep viewers after the commercial.

A *background article* will often appear on a "soft" news day when there is not much competition from topical news stories and there is space available. Background articles may sit in a file for a while until time and space permit publication. Background articles will place ALS Canada in direct competition with other health organizations. In general, the media will spread their background articles in a pattern across the year: the spring is a high-demand time for health stories.

### Structuring the news release

Write your news release as if it is going to be shortened by an editor. The media will never use all of your material. They will cut from the bottom up, so structure

notes

your release in three main sections:

- **Lead:** The first sentence will capture the interest of the reader, listener or viewer with strong visual images and a focus on people. Imagine that your first sentence is the only part of your release that will be used. Make sure the lead covers the five Ws and the How. Provide the lead with a headline of three to five words — you want to control the focus. Put a maximum of three sentences in the lead paragraph. If you have photographs or video footage, write your lead to those images. A photo will increase the likelihood of your story being covered
- **Details:** If the reader's or viewer's interest is piqued by the headline and lead, he/she will want to know more details about the story. Expand the 5Ws above, always putting the most interesting information first. These details may be explanatory material about ALS or more details about the news story. Quotations from participants are frequently used. Break this material down into three sentence paragraphs
- **Background information:** The final section will be material that provides factual information about ALS and the Society, locally, nationally and internationally. This material can be repeated in other news releases, but should be updated annually

## Outline of a news release

**Write a lead:**

Write a lead headline of three to five words that grabs the attention of the reader or viewer.

If you have photos, write short captions so that they can run beside the headline. Many people only read headlines and captions, so make sure your story is told in summary by the bold face titles.

Some style suggestions for the lead:

- Keep the language direct, concise and simple
- Read the lead out loud and see if it makes a listener want to ask questions
- Avoid technical language
- Avoid using adjectives, the facts speak for themselves
- Make sure that ALS is mentioned in the lead. Explaining exactly what it is — rapidly progressive neuromuscular disease — can be left to a later paragraph

**Expand the details of the lead:**

Write five to ten sentences that expand the details of the lead.

Rank the five Ws in order of interest and provide more information on each. Always focus on the visual and the people aspects of the details.

Use quotations.

Describe activities as short visual narratives:

- Capture the "personality" or mood of the participants
- Briefly tell what ALS is
- Briefly describe the work of the local ALS Society

Write three to five sentences that make the story news.

### Checklist

- **Who** will make the event newsworthy?
  - A celebrity
  - A politician
  - Local personalities
  - A high-profile person living with ALS
  - A particular group from the community
- **What** will make the event newsworthy?
  - A new type of event or activity
  - An entertaining or moving atmosphere
  - A regular community event
  - Issues that have potential public or community impact
  - Results of a study, research, or program
  - An important human interest story that sheds light on your issues
- **When** will the event occur?
  - As part of ALS Month
  - As part of a regular community event
  - WALK for ALS
  - Hike 4 ALS
  - During a holiday
- **Where** will the event occur?
  - In a new and interesting location
  - In a regularly used venue
  - Will the location look different
- **Why** will the event occur?
  - Fundraiser
  - Awareness event
  - Volunteer appreciation event
  - Memorial or thanksgiving
  - Advocacy event

Some style suggestions for the details:

- Sentences can be slightly longer than in the lead, but should still sound conversational in tone
- Break the details section into short paragraphs, each with a subheading
- Always write with the general public in mind. The reader or viewer wants to be informed or entertained by stories that relate to them personally. They are not particularly interested in the internal operations of the local Society
- Make sure that the abbreviation ALS appears two or three times in the detail section

**Give general background information:**

Write five to 10 sentences that give general background information about ALS and the local Society.

Provide further information to answer questions about the disease and the local Society. This material might be developed as a series of bullets that could stay in a master file and be used selectively for various news releases.

Provide contact people with phone/cell numbers and e-mail addresses. Give the ALS Canada web site address (www.als.ca).

Some style suggestions for the background:

- This is the place for technical and medical terminology. Make sure that unfamiliar terms are explained briefly
- Keep this section factual
- Keep the paragraphs independent so that they can be cut without the editor having to rewrite the piece

### Editing and approvals

A news release is a communication of the whole organization. Make sure that you have a procedure for obtaining approvals and "signing off" on each release that is sent to the media. For instance, you will want to have another ALS Society person check the release for accuracy of dates and names. Be sure to check your quotations by contacting the person being quoted.

## Fact sheets

ALS Canada has developed a selection of fact sheets that provide an overview of information about the disease, statistics and issues. Units may also want to develop fact sheets that outline the people, programs, and activities specific to that location.

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Fact Sheets are available on our web site, www.als.ca.

There are fact sheets covering frequently asked questions, issues, research, how ALS, MS & MD differ, alternative/complementary treatments, statistics and information about the Society.

## Media/News kits

A media kit is often prepared for major events such as ALS Month and for a particular fundraising activity. A media kit is a package of information designed specifically for the media. It could include:

Checklist

- News release
- Fact sheet on the issue
- History of the issue or background about the event
- Quotes or comments by experts and contact details
- Charts, visuals or photographs
- Brief biography on your spokesperson/s
- One-page description about the organization

It provides detailed issue information to the editors, producers and reporters of the media. It gives you an opportunity to educate the media about your issue. Distribute news kits to all the media who attend a news conference; provide kits to individuals who attend an editorial board meeting; send kits to reporters who express interest when you make your media follow-up phone calls; or send them to media contacts before a major event such as ALS Month or a fundraising campaign.

### Producing the news release and media kit

Rules for hard copy:

Checklist

- Use 8.5" x 11", good quality, white paper
- Use ALS Society letterhead
- On the last page provide the name and numbers of the contact person
- Type the ALS Society name and web site at the top of each page (if not on letterhead)

- Issue news releases FOR IMMEDIATE RELEASE which means that the material can be used on receipt or, if there is a specific day for the release. Fact sheets do not need this notation
- If your copy runs more than one page, type "more" after the last line of each page
- Put the page number at the top of each page after the first
- At the end of the release, type "-30-" under the last line (an old telegraph signal that meant the message was completed)
- Follow local media guidelines for abbreviations and capitalization. Some newspapers have a style sheet for reference. We use the CP Stylebook
- Keep copies of all releases and attachments

### Using pictures

- Check with the editor for special requirements for pictures
- Don't write on the photograph
- Attach a caption to each photo with information and identification details

### Distribution

Fax, e-mail, hand-deliver or courier the news releases.

### Follow-up

Always track the progress of your release through the media. If the material is used, follow-up with the publication or broadcast with a letter of thanks.

## Media advisories

A media advisory is a one-page communication used to advise the media that you have an upcoming event you that would like them to cover.

An advisory provides enough information to get a reporter interested in reporting on your event, or speaking to your spokesperson. Unlike a media release, an advisory does not reveal the whole story, so reporters still feel the need to attend the event. Provide just a nugget of information to pique the reporter's curiosity.

You can also use an advisory to alert editors and producers that your organization's spokespeople are prepared to respond to a particular issue in the news. For instance, if there is a provincial ministry budget cut that affects your client base, send an advisory with a brief sentence on your organization's position on the funding situation and offer your spokesperson for comment via live interviews on radio and television. This is also known as “piggybacking” and is an effective and relatively easy way to ensure that your voice is heard in a public debate.

Send your media advisory one week before your event so reporters can put it on their calendars ahead of time. Or send it out immediately after (same day or day after) an announcement, event or media story alerting the media to your preparedness to comment on a particular issue. Include the times, dates, contact numbers, and brief biographies of spokespeople on your advisory.

Always think about the people who will cover the type of event you are holding and direct your advisory to them. Read your local paper to identify the specific reporters who are covering your issue. If you still are uncertain, call the newspapers, TV and radio stations to find out who the news and/or assignment editors are. Those people are responsible for assigning all news stories.

The best way to deliver a media advisory is by fax, e-mail or hand delivery. Do not send lengthy attachments to reporters; send your advisory in the body of a message.

Keep the advisory short, i.e., one page maximum. Include a catchy headline, a contact name and a phone and cell numbers at the bottom of the page. Print your advisory on letterhead. Use the notation “-30-” to indicate the end.

Special TV tip: Broadcasters need to know if there will be a good “visual” at your event. If you are publicizing a field trip or other hands-on activity, make this clear in your release in a note near the bottom of the page.

## Other media opportunities

Although news releases and media kits are the bread and butter of media communication, your Working Group might try to develop other opportunities.

### Media calls

A media call is a phone call to a reporter, editor or producer to pitch a story idea or to follow-up on a news release.

There are a number of strategies to use when making media calls. Some organizations call reporters, columnists and editors from time to time to update them on relevant changes in the issues the organization addresses. Others only call when they are actively promoting a story.

Even if you don’t have a story to pitch, reporters who are interested in your issue will appreciate being kept up-to-date on changes. This contact will help you build your credibility as an information source.

At the very least, every time you send a news release, follow-up with a quick call to the editor to see if he/she is interested in the story, if you can add any more details, or to arrange an interview for a reporter. This can turn a “story idea” into a story. Be sure to find out if the timing of your call is good or determine what time would be better.

## Editorial boards

Most daily newspapers hold editorial board meetings in which their opinion writers and senior editors have topical discussions with politicians, community groups, or other organizations whose message is relevant to the community.

Newspapers are selective about who gets an editorial board meeting. It comes down to whether the topic is relevant to the public, as opposed to just the party requesting an editorial board meeting, i.e., no commercial interests, and they’re not “instant publicity” sessions where a news story appears in the paper the next day.

## Letter to the editor

This allows you to present your position and to respond to issues that have appeared in a print publication or issues that should have been covered by the media. The advantage of this form of communication is that you control the content and so control the messages it delivers. (As well, editors often scan letters to the editor in their own papers and sometimes have reporters contact the writers for a follow-up story.) Your arguments should be reasoned and supported by facts. To ensure your letter is not abbreviated it should be kept short, less than 300 words.

## Op-ed articles

A guest opinion piece that appears opposite the editorial pages of newspapers. Intended to let knowledgeable, outside voices address political or public policy issues in the news. If you have a topic for discussion that might interest the editor of your local paper, here is the process that you would follow:

- Send an outline of your idea to the editorial page editor via mail/fax
- Follow-up with a phone call
- Your “pitch”’ should illustrate that:
    - you are addressing an issue currently in the news
    - your article will add to the debate and be interesting to their readers
    - you or your organization is a credible source of opinion on the topic

A good resource on “How to Write an Op-Ed,” (English only) is available at http://aboutpublic relations.net/ucmelaina.htm

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## Gimmicks and non-news items

A gimmick is a “creative hook” or “angle” that provides a visual, funny and or/provocative element. This might include outlandish costumes or props, a stunt of some kind, or a “teaser” campaign that arouses curiosity.

It can sometimes draw attention to a story that you have had difficulty getting the media interested in, or it might make up for a lack of hard news content, generating coverage by virtue of its quirkiness. Television news producers, in particular, often like to balance hard, serious stories with softer, more colourful ones. If your timing is right and your hook original enough, you could benefit.

You can use this approach when you can come up with an idea that is both relevant to your issue and innovative or crazy enough to attract media attention. Or use it when you’ll be happy with superficial or spot coverage, as opposed to an in-depth discussion of complex issues.

How you use it depends on the gimmick. If it is humorous and not visual, but lends itself to disc jockey patter, you might make the rounds of the morning or afternoon drive shows on local radio stations. If it is a once-only stunt that you want the TV cameras to come out for, pick a time when they are least likely to be occupied and send a teaser or two in advance that gives enough away to persuade them it will be worthwhile.

Don’t send gimmicks to news reporters. The best targets for gimmicks are the soft news sections of the paper (food, fashion and new homes) and the morning and drive shows on radio.

# Media matters

## Working with the media

### Why work with the media?

- Show your Unit in a positive light
- Increase donations
- Increase awareness
- Get your Unit’s message out. Through the media we reach not only the general public, but also government, community leaders and other key influencers as well

**Develop your media strategy:**

- What do you hope to achieve by publicizing this information?
- Which audience are you trying to reach?
- Which media are you going after — local or provincial
- Have an up-to-date media contact list
- What is your message? Explain the who, what, why, where, when and how of your issue. Include details such as funding issues, stats, background information in your series of messages
- Determine how you will deliver the messages — news conference, editorial board meeting, news release, op-ed page offering, talk show, etc.
- Afterward, evaluate your results. Did your message get covered? Do you have a media monitoring service? Was the story to your liking? Why/not? What could you have done differently?

**Why develop key messages?**

- To identify phrases/words that best represent the message an organization wants to project
- To improve your ability to reach your target audience
- To help you focus on what's really important

**Developing key messages:**

- You need a core message supported by clear major points
- To determine key points about your topic, write down as many as you can think of, then combine and condense until you have three or four concise bullet points that capture the information your audience needs to know
- Think like your audience: What would your audience want/need to know about your organization/issue?
- Get to the point. Don't blur your key messages or crucial information by going on and on about unnecessary details

## Interview tips

### The media comes to you

When you are asked to do an interview:

- Know who the reporter is, and what "beat" they cover
- Find out the angle of the story
- Do your homework on the issue
- Ask the reporter who else he/she has spoken to about the subject. A poorly informed reporter could hurt your ability to do a good interview. If the reporter is misinformed, provide adequate background

- To accept/decline an interview, set a date and time for a call back
- Be prepared. Have backgrounders about your organization available, its senior management team, and all of its spokespeople ready with photos
- If you decline, provide a reason and alternate people to talk to. Leave the door open

## Before the interview

- Tape yourself… practise. Our first few words are critical
- Don’t answer off the top of your head
- List possible benefits/risks of doing the interview
- Are there consequences to not doing the interview?

## During the interview

Important tips:

- Be concise. When responding to questions, stick to the notes and main messages you have decided you wanted to convey
- Simplicity, brevity and clarity
- For broadcast media, talk in sound bites. Eight seconds is the average length of time for a newscaster/journalist on TV re: your association
- Avoid jargon and big words; you’ll sound pompous or insincere
- Be poised/focused and confident — or act it
- If you are interrupted before you adequately answer a question, ask the journalist to please let you finish. Do not answer any other question until you have completed your answer
- If you are asked a controversial or unfair question, divert the journalist’s attention back to your position by restating one of your three main messages
- Speak to journalists by name when you respond. Develop a rapport. Personal touch does not hurt and helps to establish a relationship of trust
- Cut to the chase. Journalists use the “inverted pyramid” style: the most important fact first, then the second point and so on, as opposed to business people who often close with the most important fact. Model your messages accordingly
- If you feel you have failed to get the message out, repeat it at the end of the interview (i.e., “I think we’ve missed the real, critical issue here, which is…”)
- Remember, you are never off the record. Avoid casual asides, off-hand remarks and jokes

Use phrases such as:

- Let me tell you about…
- That’s why we’re…
- Let me bring you up to date…

Questions you may be asked:

- What's your main concern?
- Can you describe the situation at hand?

How to start an answer:

- Start with a fact. "Our research shows that…"

What if you don't know what to say?

- If you don't know the answer, say so and promise to get back to the reporter (within a specific time period) with the information
- Correct any inaccurate information as quickly and diplomatically as possible. But position it as a "clarification" rather than putting reporters on the defensive with words like "mistake" or "error." You may win a battle, but you will most certainly lose the war
- When things have gone wrong in your association, explain what you are doing to fix things in hopes of minimizing damage

**These are message opportunities:**

View interviews, editorial board meetings and other media encounters as opportunities to get your message out through the media. But accept that you have no control over the final product. If you want control, purchase an ad.

**Top interview NO NOs:**

- Don't try to stop a story. If you're concerned about what may be written, offer clarification and perspective, and appeal to reason in an unemotional, factual way
- Never lie. Tell the truth even if it hurts. If you don't, it will come back to haunt you
- Answer the questions asked
- Never make a statement you can't back up. There's nothing worse than to have an interviewer say, "We checked and found just the opposite is true."
- Make your own statement, don't let anyone influence your agenda
- Avoid any statement that cannot be substantiated
- Don't tell reporters how to write their stories
- Facts, numbers and case studies strengthen your message and make you look aware and informed
- Closing slogan — close with a motto or slogan that sums up why you do what you do, or why it's important
- Don't delay in clarifying or correcting inaccurate stories

| Instead of saying... | Say... |
|---|---|
| "No comment." | "I'd be pleased to answer questions about…" |
| "Don't blame us for this mess." | "We're working with…whose job it is to repair x/y/z." |
| "It wasn't all that bad." | "This was a serious situation and that's why we're working to do x/y/z." |
| "We're not ignoring anyone." | "We realize that there are some people who still are not satisfied. We ask them to keep in mind concerns such as x/y/z." |
| "I can't help you with that." | "I can help you with…" |
| "It's not our fault." | "We're anxious to find out what happened." |
| "We didn't do it." | "The situation resulted from this, this and this..." to explain your case |
| "I can't guarantee." | "We're working to improve such and such. I can guarantee that there is a plan." |
| "I can't talk to you right now." | "I'd be glad to talk you just as soon as I can." |

**Bridging:**

- Take control of the interview. Following a reporter's question, bridge to what you want to talk about, i.e., "Before I answer that question, let me explain our concerns/plans/situation etc…. Let me give you an example."

**Dealing with hostile questions:**

- Listen carefully, look directly at the reporter, and pause before answering
- Create time to think, ask person to restate the question to define or clarify a point that is unclear
- Do not bluff or lie
- Don't sound defensive. Explain what your organization has done, rather than defend what it has done
- Redefine the wording in "negative trap" questions, i.e., "Why have you failed?" In your answer don't repeat a word like "failed." Use another approach
- If you don't know the answer, say so. Offer to get back to the reporter with the information at a mutually agreed upon time
- Offer assistance. If you can't help, refer reporter to someone who can
- If you don't want to answer a question, decline graciously, giving your reasons
- Prepare answers for best and worst questions you may be asked
- Don't let the reporter put words in your mouth or lead you into agreeing with his/her statements

**When you’re asked negative questions:**

- Don’t become emotional, or angry, or defensive. Stay calm.
- Remember, you are in control. If you don’t say something, it can’t be used. If you are asked a question about something irrelevant to the issue, answer politely that was not what you understood the interview was about and indicate the subject matter you were told you would be discussing.
- Never repeat a negative sentence used by a reporter when you respond. You might be quoted as saying this negative phrase if the reporter is trying to support his/her angle.
- If a reporter asks you for your response to an exaggerated situation or position, be sure to say, “NO, that is not correct.” Continue then with what you know as the truth.
- Never guess or speculate if you don’t know the facts. You risk your credibility and that of your association if you make wrong, hypothetical assertions.
- Watch to see if the reporter paraphrases your opinion inaccurately. Correct the inaccuracy immediately.
- Tell a reporter you would like to answer a question again if you were not pleased with your comments. Ask the reporter to read your quote back.
- Explain why you can’t answer a question (i.e., “it’s a personnel issue”). Otherwise, “no comment” implies guilt, secrecy, or underhandness.
- Journalists will often stay silent so you can nervously babble on. Answer the question succinctly and end your response. Let the reporter worry about the silence.

## Getting prepared

**Looking good on TV**

- Wear professional business attire
- Hair neatly combed (go to the hairdresser)
- Avoid narrow stripes, bold prints, plaids or busy clothing around your shoulders and neckline. Viewers will be distracted from your comments by your clothing
- White shirts cause a glare on TV. Off-white is better
- Good choice: navy, black, or brown jackets with a solid coloured shirt
- Wear minimal jewellery
- Wear clothes that hide or flatter your shape
- Clean up your desk/office

**Body image:**

- Maintain eye contact with the interviewer
- Don’t look at camera
- Smile
- Don’t shift around

- Sit on your suit jacket so it doesn't ride up
- Watch hand movements or placement
- Nothing in your hands
- Don't jangle change in your pockets

# Exercises

## Media preparation exercise

- Create a trap question containing a negative word. Redefine the issue in your own words
- Express your main concern, action or vision
- Write three fact-filled statements that show you are aware of the issue
- Write down questions you think a reporter may ask
- Identify your main points, your facts, your summary
- Rehearse out loud and in front of a mirror three or four messages to deliver and repeat them

## Editorial board exercise

Write a letter to the editor:

- Why should the editor meet with you?
- Identify your concerns

# Blooper brigade

Use the words on the right-hand side vs. the left-hand side. Your writing and speaking abilities will be much clearer.

| Instead of saying... | Say... |
|---|---|
| "In order to facilitate a solution..." | "To solve the problem, I suggest..." |
| "For the purpose of..." | "For..." |
| "In connection with..." | "About..." |
| "In reference to..." | "About..." |
| "Notwithstanding the fact that..." | "Although..." |
| "Pursuant to our agreement..." | "As we agreed..." |
| "We are not in a position to..." | "We are unable to..." |
| "In the month of June..." | "In June..." |
| "In the event that..." | "If..." |
| "Anyways..." | "Anyway..." |
| "Firstly, secondly," | "First, second," |

| | |
|---|---|
| "At the present time…" | "Now…" |
| "On condition that…" | "If…" |
| "In regard to…" | "About…" |
| "In accordance with…" | "By…" |
| "A lot of…" | "Many…" |
| "Very" | Do not use — it's overused |
| "Irregardless…" | Do not use — it's a pretentious lengthening of "regardless" |
| "The reason is because…" | "The reason is that…" or, "Because…" |
| "Everywhere" | Do not use — widespread |
| "With the exception of…" | "Except…" |

# ALS Awareness Month

**ALS Month in June is a focus for many ALS Society events that enable us to increase our visibility so that our target audiences become increasingly aware of the disease and the Society's activities and programs designed to help people with ALS, their families and friends.**

In this section

- Awareness activities
  - Focusing on the cornflower
  - Other events to raise visibility
  - Event in a box
  - Publicizing the event

## Awareness activities

Raising public awareness is tied to the goals and objectives of the ALS Society. Events and activities must contain a clear message that we want to send to our target audiences. (Refer to key messages in the Section 1, Introduction.)

Even something as simple as wearing the cornflower provides an opportunity to increase visibility because it causes people to ask a question; the answer promotes the ALS message. Plan to stage events that maximize its visual and community potential.

Activities will be aimed at small and large groups of people. They will reach out to groups directly or through the media.

The media likes events that have a strong visual impact, events that tell community stories. You are more likely to attract a local television reporter looking for a camera shot for the evening news, or a newspaper photographer looking for a front-page photo if you plan to make your event interesting.

### Focusing on the cornflower

The cornflower is an international emblem which is particularly appropriate for the ALS Society of Canada because despite its fragile appearance it is a hardy wild-

notes

flower found throughout Canada. Like the cornflower, people with ALS show remarkable strength in coping with a devastating disease. Like the cornflower, awareness of ALS and funding for care and a cure is growing across Canada.

An event doesn't have to be a Hollywood production, but plan to make it as attractive as possible to the media.

Some factors to consider:

- What is happening?
  - A truck pulling up with hundreds of flowers?
  - Children making boutonnieres?
  - Volunteers on the streets?

Make the event as dramatic and visual as possible. Even if the event lasts all day, try to find a visual moment that might attract media attention.

- Who is there?
  - A celebrity kicking off the flower distribution
  - Someone living with ALS, a caregiver or health-care worker with a story to tell

Will a large number of people be attracted to this event? Media prefer to tell personal stories rather than outline background fact sheets.

- When is it happening?
  - Is the event being held during business hours when the media might have time to attend?
  - Is the event being held on a weekend where a large number of participants might attract the media?

A "soft news" item like a health organization's flower day is more likely to be featured in a weekend edition or broadcast.

- Where is it happening?
  - A recognizable public space like a park or municipal office
  - A more personal space like a hospital room

Choose a location that provides an interesting backdrop to the activity.

## Other events to raise visibility

Our volunteers develop a variety of ways to increase the Society's visibility during ALS Month. They include:

- Open forum — a panel of healthcare specialties and people with ALS discussing issues facing those with the disease
- Exhibits in local malls
- Displays and health fairs
- Special events such as silent auctions, galas, concerts, golf tournaments
- Tag days, garage sales, bake sales

Special events present opportunities to reach target audiences, increase visibility, involve the community, handout information and raise awareness and funds.

Be ready for special events. Our “Event in a Box” checklist gives you an outline to have at your fingertips for whenever you are planning your special event.

## Event in a box

Participating in displays and health fairs allows us to reach our target audiences in person. With some display material, pamphlets and flyers and trained volunteers, you can present the ALS message face to face, allowing time for personal discussion and interaction. Your focus will be to increase visibility of the organization and the disease and to recruit volunteers.

When planning for a display, consider the following. This checklist covers details for a large event; just select the points that relate to your needs.

### Checklist

- Date, time, location, and theme
- Amount of space and set-up
- Table, chairs, table covering
- Restrictions re fundraising, selling items
- Storage space
- Location of washrooms
- Car parking facilities
- Public transit
- Medical services
- Security arrangements
- Access to telephone
- Signage
- Adjacent attractions
- Display materials, i.e., display boards, graphics
- Availability of electrical outlets
- Rent TV-VCR/DVD player
- Handout materials: flyers, bookmarks, etc.
- Schedule of volunteers to co-ordinate the booth
- Set up and dismantling arrangements

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- Photography
- Media invitations
- Draw to enable obtaining names and addresses for subsequent fundraising activity

General supplies include:

- Tape (Scotch, masking, duct)
- String
- Scissors
- Extension cord (indoor and outdoor)
- Rubber bands
- Thumb tacks
- Pens and pencils
- Stapler
- Ruler
- Phone numbers

ALS specific supplies include:

- Displays (ALS Society sign, March of Faces banner)
- PowerPoint presentation (*10 Facts about ALS*)
- PSAs ("What would you do, while you still could?")
- Giveaways
    - cornflowers
    - information cards
    - business cards
    - ALS publications (Fact Sheets, *Research News*, research updates, *Northern Neuron*)

Technical details:

- TV/VCR/DVD player
- Computer and LCD projector

Other suggestions:

- Wear colours that complement the ALS purple or wear ALS t-shirt, cap etc.
- ALS pin

Check out Section 5, Making Presentations, for other tips.

# Publicizing the event

notes

## Recruit people to publicize the event

Personalities are invaluable components of publicity. Although people such as **doctors** or **politicians** may not be high-profile, recognizable faces, their positions and knowledge can attract attention. A doctor can outline the latest medical research or treatment options; the politician can talk about public health policy and issues related to care. If you invite people such as these to open an event or speak. Use their presence as a media lure.

**Celebrities** can use their media recognition as a way of drawing attention to ALS. Most of them will not have a personal connection with ALS, but will be willing to take on a promotional role. However, a connection with ALS will have a greater impact — they can speak with passion and authority. The social network of the local Society needs to be working full-time to make celebrity contacts. The most desirable is the celebrity such as an actor, musician or sports figure who has a national or international reputation. He/she is unlikely to attend, but might record a public service announcement for you over the phone. If there is a local connection, contact the celebrity through his/her agent.

Local personalities can, for example, include politicians, **radio and TV hosts**, **musicians**, **athletes**, **writers**, **religious leaders**… just about anyone who is interesting. A winning hockey team at the local high school may be willing to shoot a goal for ALS.

Most celebrities will want a limited time slot to do their pitch. It will be easier to find someone willing to pin on the first cornflower than to come to a dinner that lasts all evening. Whoever makes the contact should confirm the celebrity's attendance, be there to meet and guide the person through the event, and follow up with a call or letter of thanks.

People in the public eye have crowded schedules: recruit celebrities as early as possible. And plan for back-up.

People with ALS have circles of friends and colleagues who may want to contribute their time and expertise: friends, family, professional colleagues, community groups, churches, synagogues, mosques, temples, athletic and recreational groups. Approaching these people requires sensitivity: a relative or friend of the ALS patient may be able to help.

## Develop a public service announcement (PSA)

Prepare a short summary of the event of no more than 100 words. Write it in short full sentences so that it can be read on air, used on a cable broadcast, or be a small

notes

print announcement. Fax or e-mail the PSA. E-mail is increasingly popular because the text can be downloaded into word-processing systems.

Include all the deadlines on your planning calendar. Some monthly magazines have up to a three-month lead time for submissions. Try to send the PSA to a specific person in the organization: your announcement has more chance of appearing if it has a personal advocate. Include the name, phone, fax and e-mail address of the ALS contact person.

If your local Society has the resources, consider producing your own audio PSA. On a recorded PSA you can include music and more production values that merely having it read by an announcer.

Refer to Section 6, Public Service Announcements and Print Ads, for suggested format and sample PSAs.

## Prepare a news release

Use a news release to provide information to generate an article or interview. It will be about a 250-word description of the event or issue. This content is information that could be used as the body of an article with a topical introduction or conclusion. In addition, include background material about ALS and the Society.

For newspapers, consider including photographs, especially if a celebrity is involved. Have generic photos of past flower days available. Include the ALS logo in reproducible form; it is available on the web site, www.als.ca.

Refer to Section 3, Media Relations, for more information. Refer to the Resources section for sample news releases.

## Promote the event as a community event

Every community, big or small, has organizations that can help to promote ALS. The flower distribution, for instance, could be positioned as a community effort. Ask the mayor to proclaim June as ALS Month and ask your MPs and MPPs to raise the event in the House of Commons as part of their concern for a major health issue. Members of Parliament also have regular mailings to constituents called “10 percenters,” i.e., they can mail to 10 per cent of their constituents with costs covered. Providing local focus and ALS facts could become 10-percenter material. Inquire at the constituency office for the preferred way to provide such information.

### Local groups

Involve local service organizations such as the Boy Scouts, the Chamber of Commerce and the Kiwanis in the event. These groups usually have quarterly newsletters and web sites that can carry material. The involvement of service associations will often draw media interest. If contacted early in the academic year, high school students might make ALS a community outreach project.

Ask community and religious groups to designate the first Sunday or another day in June as ALS Day. Many will include material in their newsletters, web sites and service leaflets, and may become involved with the flower drive. The membership of the local Society will provide ready-made contacts. Ask to speak to the local ministerial group — a gathering of clergy from many denominations — and in some communities are an interfaith group. ALS Canada provides a generic church bulletin form that can be used by churches during ALS Month and to promote ALS Society events.

Offer speakers who can make presentation about ALS in schools and to service groups. Speaker resources — *10 Facts About ALS* — are included in the Communications Manual.

**Look for corporate support**

Business and health organizations both need publicity to get their messages to the public. Business sponsorships can range from funding for the event to employee participation in the activity. A promotional partnership with a business — the printing and distribution of a poster, for example — can produce high-visibility and public awareness. The person with ALS and/or family members may suggest a corporate connection.

Unit and National offices will likely have organized corporate sponsorships. Keep in touch with them so that you can be part of the relationship. Most business sponsorship will have guidelines to follow.

Developing contacts in business is an ongoing project for the local Society. Most corporate sponsorship or partnerships will result from a personal contact with someone who is in the business. Competition for corporate involvement in the community is stiff.

## ALS Communications Manual for ALS Month

A copy is included in the Resources section. Please refer to it. There are many practical tips that you can use during ALS Awareness Month. This Manual contains a variety of resources and suggestions to help volunteers and staff tell the ALS story. If there is information that you have to share, let us know. And if you have questions or need additional information, call the Communications Department at ALS Canada.

# Making Presentations

In this section

## Preparing a presentation about ALS

### Your story

As a local representative of the ALS Society you bring your own experience of ALS. Bring your passion, concern and expertise to your audience — that is probably why you were invited. It is also essential to be accurate.

ALS Canada has developed a series of 10 slides that can be used for either an overhead projector or PowerPoint presentation. These points cover the key facts that we have identified as our key messages, i.e., the messages that we want our target audiences to know about the disease and its impact on those living with ALS and their families. You may want to make notes about what else you would like to add about your experience of each fact.

### Be prepared to answer difficult questions

It is quite possible to be asked questions that either you feel unable to answer or are just uncomfortable answering. It is reasonable to say you don't know the answer and will take a name and number and get back to the caller with an answer after consulting with your ALS Society Unit or ALS Society of Canada staff.

People connected with ALS are often asked about the issue of Sue Rodriguez and assisted suicide. The ALS Society neither opposes nor supports any attempt to change the law regarding assisted suicide. If you are giving an opinion make sure people understand that it is your own view. Before attending any engagement it is wise to work out your response in advance.

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# Some tips on making presentations

Making a presentation to one of our target audiences is a significant communications opportunity. Many groups look for speakers to inform their members. For instance, there are community groups, service clubs, business networks and audiences of seniors. Given that we have limited resources (i.e., speakers) it is important that we identify what target audience we are aiming to reach with our speakers' program.

Your audience could be:

- Potential donors
- Potential volunteers
- Opinion leaders

## Planning the presentation

The first step in planning your presentation is to determine your main objective. You will want to remember this objective during your preparation and presentation. It will be reflected in your focus and your style. It becomes the pulse of your presentation. You will place emphasis on remarks related to this goal.

Your objectives could be to:

- Inform
- Convince
- Get action

## Captivating your audience

- Enthusiasm
- Sincerity
- Conviction

In public speaking, the three most important points of focus are the audience, the audience and the audience. To be able to keep your audience's attention and interest, you must first be aware of their needs, their level of knowledge and interest. Prepare your presentation accordingly. Be sensitive to their reactions and show your desire to communicate with them.

Energize the audience. Think of effective communications as a form of energy-sharing. Words are only a part of the total event. You communicate with your eyes, your gestures and your movements. Words communicate meaning and delivery communicates how you feel about your material. Your audience will respond as much to your feelings as they will to your words. If you appear enthusiastic, the audience will be enthusiastic. If you are tentative, they will be too.

Also, an important quality of a successful speaker is sincerity. Indeed, if you do not speak with sincerity, everything else is useless. To grab your audience, be sincere and convinced.

## How to captivate your audience

### Checklist

- Develop an effective introduction
- Use personal experiences
- Use interesting and active language
- Maintain eye contact
- Avoid wearing jewellery that jangles
- Keep loose change out of your pockets — it will jangle as you speak
- Move around
- Include humour where appropriate

An attention-getting introduction is very important: it is the first couple of minutes that will convince the audience to listen and will establish the speaker's credibility.

To arouse curiosity, use examples, anecdotes, personal experience, and dramatic facts.

If you have enough room, move around. This allows you to establish a better contact with the audience and to project energy and authority. With experience you will be able to avoid reading your speech. Do not read from your notes. Rehearse in front of a mirror before your presentation.

## Encourage participation

You can considerably increase the attention by associating the audience to your speech. Ask open-ended questions, i.e., questions that can't be answered with a "yes" or "no." For instance:  "Does anyone here know someone with ALS?" or "How could you help the ALS Society?"

According to professional motivational speaker Dale Carnegie, "In your audience, everyone feels concerned when one of them participates in the presentation. If a wall seems to separate the animator from the group in the room, encouraging participation is an excellent way to knock down that wall."

## Use visual aids

Visual aids help the presenter prepare his presentation and facilitate his task during the event. The benefits of visual aids are:

- Requires selection of key points
- Forces order and sequence
- Prevents omission of key points
- Gets the attention and keeps interest
- Saves time
- Instills confidence

The PowerPoint presentation and video cover major points and will assist speakers as they prepare for their presentations. You will want to:

- Become familiar with these resources by reading each slide and watching the video
- Decide which resources you will use. You will want to know your audience's interests. For instance:
    - Is this an opportunity to raise awareness?
    - Who is your audience: healthcare professionals, a community group, a church or service club?
    - Are there caregivers in the audience?
    - Is this an opportunity to raise funds?
    - Is this an opportunity to recruit volunteers?

Let the organizers know your equipment needs — overhead projects, TV/VCR/DVD player, etc.

Some other details to consider: how many people will attend? Be sure to have handouts available. How long have you been given for your presentation?

# ALS speaker's resource list

The resources gathered here are designed to help you make a presentation on ALS to a variety of different audiences.

## Resources

**Fact Sheets**

Use as handouts at a presentation or develop custom packages for volunteers, potential donors or community groups.

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You may access the Fact Sheets through the ALS Society web site, www.als.ca. (See Section 10, Resources, for a list of available Fact Sheets.)

# Public Service Announcements and Print Ads

In this section

- ALS print ads
    - ALS Society ad campaign asks: "What would you do, while you still could?"
- Public service announcements
    - Local PSAs
    - Recorded radio PSAs
    - Sample PSAs

## ALS print ads

BBDO Canada, the advertising agency that created our PSA campaign, "What would you do, while you still could?" has also designed two print ads which appeared in newspapers, subway stations and buses across the country in June for ALS Awareness Month. The print ads worked as the educational piece of the campaign, allowing more information to be shared about what ALS is and what it does.

Quote

Keeping with the "What would you do, while you still could?" theme, the ads read: "People with ALS often lose the use of their arms. Which is why we're asking you to write the cheques." The second ad states: "It's ironic that a disease that makes you want to pound your fists in anger leaves you unable to do so."

The two ads capture the tremendous effects of the disease with bold letters and photos of the hands of people who are living with ALS, reflecting the urgency to find a possible treatment or cure. They were created to build awareness of ALS and the ALS Society's efforts to support research towards a cure for this devastating disease.

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## ALS Society ad campaign asks: "What would you do, while you still could?"

The ALS Society of Canada launched a new public service advertising campaign in January of 2005 created by BBDO Canada to raise awareness about ALS and the ALS Society's efforts to support research towards a cure for the disease.

"The nature and progression of ALS lead many of those living with the disease to consider how they will use the time they have left. This campaign asks consumers to consider a similar scenario with the question — 'What would you do, while you still could?' We're very excited about it because we think it will help the public better understand what ALS is all about," explains David S. Cameron, President & CEO, ALS Society of Canada. "We're very appreciative of BBDO's dedication to this project and of those who donated their time and services during the production process."

Created by BBDO Canada on a pro-bono basis, the campaign includes two 30-second and one 60-second television public service announcements (PSAs), *Running* and *Hugging*.

"We wanted to help people understand how ALS changes the lives of people living with the disease and those around them," says Stephanie Nerlich, Senior Vice President, Group Account Director, BBDO Canada. "That led us to think about simple tasks that we take for granted, tasks that people living with ALS are forced to consider every day."

### Excerpt

In *Hugging,* viewers watch as a man hugs all that he comes in contact with — a police officer handing him a ticket, his disinterested horse and the waitress pouring his coffee. As he hugs a tree, the line "Most people with ALS lose the use of their arms in the first two years of the disease," appears on the screen. As he hugs his sleeping wife, the campaign tagline "What would you do, while you still could? ALS kills the body first. Please donate, www.als.ca." appears.

*Running* features a man on what appears to be an endless jog. As he stops to catch his breath, the line "Most people with ALS lose the use of their legs in the first two years of the disease," appears on screen. The man then turns around and continues his run as the campaign tagline appears.

Both ads are available in French and English for airing as public service announcements and can be viewed online at www.als.ca. Television stations interested in obtaining a copy of the ad should contact Bobbi Greenberg at the ALS Society of Canada.

BBDO Canada is responsible for managing the communication needs of some of Canada's largest and best known brands. BBDO Canada was established in 1992 and has offices in Toronto and Montreal. BBDO Canada is a subsidiary of BBDO Worldwide, in turn owned by Omnicom, a public company traded on the New York Stock Exchange.

BBDO Canada has received numerous awards for the *Running* and *Hugging* PSAs. They were recognized with the following awards:

### Cannes International Advertising Festival

The PSA *Hugging* has been awarded a Bronze Lion from the Cannes International Advertising Festival. This prestigious event, also known as the "Olympics" of advertising, was held from June 19-25, 2005, in Cannes, France and drew an audience of 8,000 people from more than 75 countries around the world. Ten Canadian agencies were among those honored at 52nd annual festival with awards presented in 10 advertising categories, including film, press, outdoor and cyber. Entries are judged by an international jury and the shortlist of approximately 450 films is decided by the first voting. A computerized voting system selects the highest marks given in each category and further voting establishes the ranking in each category which is the basis for the Juries discussions and the awarding of Gold, Silver and Bronze Lions. The film Grand Prix is then selected from all the Gold Lion Entries. Charities and public service categories are excluded from winning the Grand Prix.

### The Bessies

*Hugging* received a finalist recognition (single) on June 9, 2005, at the Bessies. In 2004, the Bessies celebrated 41 years of recognizing the finest in Canadian television advertising. The Bessies is an annual TV commercial competition organized by the Television Bureau of Canada in conjunction with the Broadcast Executive Society.

### Marketing Awards

*Hugging* and *Running* received a bronze award at the 2005 Marketing Awards. The Category was Public Service TV and Radio campaign. The Marketing Awards, which trace back 83 years, are Canada's leading national awards recognizing excellence in advertising creative. The 150-member jury examined 2,033 entries and gave out 158 gold, silver, bronze and certificate prizes.

### Canadian Marketing Awards

BBDO Canada received a Silver Award at the 2005 Canadian Marketing Awards on November 25, 2005. The agency received the award in the Charity/Pro Bono Category. A total of 696 submissions were received in the 2005 competition.

**Agency of the Year Award**

BBDO competed against nine advertising agencies to take third place (bronze award) in *Strategy Magazine*'s 16th annual "Agency of the Year" award. Among the five campaigns entered by the agency was the PSA campaign they created for ALS Canada "What would you do, while you still could?"

# Public service announcements

Public service announcements (PSAs) include:

- Calendar listings to promote events
- Scripts — radio
- Recordings — radio and TV
- Messages for cable TV

A public service announcement is a free announcement given to a community service organization to announce an event. PSAs are broadcast when advertising time has not been sold, so it is a considerable donation of free public exposure to the organization. Since they are free, you have little or no control over how often they are printed or broadcast, or at what times.

PSAs can be provided as:

- Scripts to be read by the announcer
- Notices to be printed in calendars and community listings
- Pre-recorded tapes for airing on radio or television

## Local PSAs

Find out various media outlet policies, lengths and timing by calling their public service director/co-ordinator. For broadcast, a general rule is to write 15- and 30-second scripts. Contact your local community television station to see if they could assist in producing a TV PSA. Many radio stations will produce PSAs free of charge, since they are obliged by their CRTC licence to broadcast a minimum number of PSAs each month.

Some suggestions:

Checklist

- Open with the most interesting fact: the appearance of a celebrity, a community-wide event, a rhetorical question. Your first sentence may move your PSA up to the front of the line
- Mention the essential facts of the event: who, what, when, where, why
- Use the name ALS a couple of times throughout the PSA
- Avoid asking for money: you may ask for volunteer help
- Include a short explanation of what ALS is near the end of the copy. Refer to Lou Gehrig’s disease
- Repeat the facts again near the end. If you have a local web site, give the URL
- Provide contact information

Some style tips:

- Use short direct sentences
- Be conversational — remember, this will be read informally over the air, e.g., “It’s spring, time to think about cornflowers.”
- Address the listener directly — make it personal, e.g., “Do you want to have some fun and help out our community?”
- Simplify numbers, e.g., “Two to three Canadians a day die of ALS.”
- Simplify technical language. Don’t use medical/technical jargon, e.g., “ALS is a disease that affects the nervous system.”

## Recorded radio PSAs

If you have the resources, record the PSA using a good voice and music. Check which format the radio station wants to use.

Always read your PSA out loud to see if you have achieved an easy conversational tone.

## Sample PSAs

### Copy for WALK for ALS PSAs

We wrote this copy for a 60-second walk PSA:

> We are taking to the streets, sidewalks, paths and parks across Canada in support of ALS research and to raise money to provide quality care for the thousands of Canadians living with ALS and their families. Please join us. WALK for ALS is a fun, family-friendly event occurring in more than 60 communities across Canada.

> We are walking because ALS is a devastating disease. The average life expectancy is only two to five years.
>
> We are walking because every day, two to three Canadians die from ALS.
>
> We are walking to provide hope.
>
> We are walking for those who can’t.
>
> Most people with ALS will lose the use of their legs in the first two years of the disease. What would you do, while you still could?
>
> For more information or to register for WALK for ALS please visit www.als.ca/walkforals

A 30-second walk PSA:

> Join us as we take to the streets, sidewalks, paths, and parks across Canada in support of ALS research and to raise money to provide quality care for the thousands of Canadians living with ALS and their families.
>
> We are walking because ALS is a fatal disease.
>
> We are walking because every day two to three Canadians die from ALS.
>
> We are walking for those who can’t.
>
> Most people with ALS will lose the use of their legs in the first two years of the disease. What would you do, while you still could?
>
> For more information visit: www.als.ca/walkforals

## Sample radio PSAs

| | | | |
|---|---|---|---|
| **610/CKTB** | | **CREATIVE** | |
| Client | Jim Hughes Golf Classic #1 | Length | 30 |
| Writer | lh | Sales Rep | House |
| Date | May 14 – June 7 | Cart # | |

**PRODUCTION:**

**Music: upbeat** How do you help a worthy cause and have fun at the same time? Come out and golf in the JIM HUGHES & FRIENDS

GOLF CLASSIC! We're raising awareness and funds for ALS (sometimes called Lou Gehrig's disease). Support the cause by golfing in the classic, or by making a donation. It's a great way to enjoy a game of golf and all the while supporting ALS. The JIM HUGHES & FRIENDS GOLF CLASSIC, Friday June 8th (THIS FRIDAY) on the Links of the Niagara at Willo-Dell. For details, call 905-688-44-83. Sponsored in part by 610 CKTB.

Sfx: golf swing

| | | | |
|---|---|---|---|
| **610/CKTB** | | **CREATIVE** | |
| Client | Jim Hughes Golf Classic #2 | Length | 30 |
| Writer | lh | Sales Rep | House |
| Date | May 14 – June 7 | Cart # | |

PRODUCTION:

**Music: upbeat** On Friday June 8th (THIS FRIDAY), tee up in support of ALS in the JIM HUGHES & FRIENDS GOLF CLASSIC! We're raising awareness and funds greatly needed for ALS (sometimes called Lou Gehrig's disease). Come out and golf in the classic, or make a donation. Either way, we need your help. So plan on spending the day on the greens and help support ALS. The JIM HUGHES & FRIENDS GOLF CLASSIC, June 8th (THIS FRIDAY) on the Links of the Niagara at Willo-Dell. For details, call 905-688-44-83. Sponsored in part by 610 CKTB.

**Sfx: putt into hole/clapping**

# Using the Internet

In this section

## ALS and electronic resources

The Internet is an invaluable research tool for individuals and organizations, as well as the media. The ALS Society of Canada web site — www.als.ca — is visited by thousands of people each month and is recognized internationally as a timely and accurate source of news and information for people living with ALS. It provides user-friendly information that is regularly updated with current content as well as offering a convenient method of donating online. We have seen more than a 500 per cent growth in visits from June 2004 to June 2005. The web site growth has grown both in popularity and in size; much of the visitor growth is due to our focused efforts to ensure new and updated materials, which are being added to the site regularly. The ALS Society of Canada appears among the first three sites on Google when you type in the letters ALS.

**A caution:**

Not all web sites provide reliable information. Here are several hints:

### ALS Local and Internet resources

The Internet gives your local group access to the most up-to-date information available. Access is easy and available to anyone anywhere. Even small rural communities are part of a global information network. Make sure that your volunteer teams can draw on the expertise of a computer-literate volunteer who can research the Internet and record web sites which are of interest to ALS. Make Internet skills a priority for your local group.

## The media and Internet resources

Many media organizations do their primary research on the Internet. Providing them with a list of links will broaden their research to the whole ALS community and perhaps even give them the news “hook” that they need to write an article or produce a television story.

Always e-mail your list of links to the media. E-mail and word-processing programs now routinely turn the typed address into a “button” which, when clicked, takes the reader automatically to the web site.

## Web site tips

### Checklist

- Quick and easy access to information
- Who is your target market? Who will use your site? Keep that in mind when adding new copy
- Present information clearly and logically, making it easy for users to find what they want. Label pages and buttons accurately
- Remember the golden rule of web sites — allow people to access information with as few mouse clicks as possible
- Update your site regularly. Remove out-of-date material
- Accessibility — your contact info or link to it on the top/bottom of every page
- Include a way to return to the home page on every page
- Test your links
- Remove dead links
- Readability — ensure that your text is easy to read; it’s difficult to read light text on a light background, similarly, dark text on a dark background
- Ensure text is large enough to read

What to avoid:

- Distractions such as too many graphics, blinking text, scrolling text, animation and music that takes time to download
- Pop-up windows (they’ll annoy your visitors)
- Clutter
- Frames that hinder reading or printing

Three articles that may be of interest are:

- Web site design tips (http://michael bluejay.com/webdesign/)
- How Users Read on the Web (http://ww.useit.com/altertbox/9710.ahtml)

- Is your web site communicating what you want? (www.compad.com.au/cms/prinfluences/articles/239)

# Communications

In this section

## Building an effective communications plan

### What is public relations (PR)?

PR practitioners sometimes use the circus analogy to explain their craft:

When the circus comes to town and you paint a sign to announce it — that's advertising. Put a sign on the back of an elephant and march him through town — that's promotion. If the elephant walks through the mayor's flowerbed — that's publicity. Get the mayor to comment about it — that's public relations!

Public relations is considered by some to be the most misunderstood of all business functions. PR is often thought of as nothing more than a few press releases, hosting special events, and a few special events thrown in to attract attention. What many people fail to see is that public relations is much, much more.

At its roots, public relations is about communicating an organization's messages to a specific group of people. Through this communication process, organizations build public consent or approval for their business, its goals and objectives. PR is an innovative and cost-effective way to get results.

Public relations is multi-faceted and includes numerous activities and disciplines.

"PR is everything… everything you do communicates something about your brand… it all influences whether anyone will buy what you are selling," says Sergio Zyman in *The End of Advertising as We Know It*.

According to a study by Inquiry Handling Services of San Fernando, California, PR generates 28 per cent of sales inquires. Bottom line: PR, compared to paid advertising, is relatively free.

notes

Fact

PR provides four essential services — all created and validated through the third party endorsement of the media:

- PR protects, promotes, and enhances your organization's image and reputation
- PR builds personal relationships with the people your organization depends upon the most
- PR influences decision makers and opinion leaders
- PR creates awareness and excitement

### Integrated communications

- An advertisement, no matter how good it is, is only seen by viewers for 30 to 60 seconds. Adding PR allows you to target specific audiences
- PR allows your story to be told in-depth, through the media. This ultimately increases the impact the message has on viewers
- PR can add credibility when the message is endorsed by a third-party or seen in the newspaper/news clip on the radio or TV

### What can PR do for your organization?

- Build, maintain and protect brands
- Increase understanding of a business/organization/product
- Build buzz
- Provide third-party endorsements
- Change attitudes
- Inspire action and participation
- Help manage issues and or crises quickly and effectively
- Grassroots, community image building

## The communications plan

Think of your communications plan as a blueprint for your organization's goals and objectives.

An important first step in mounting a communications program is to develop a communications plan. This section will provide you with some guidance for this important beginning phase of your activities.

One of the advantages of developing a communications plan is that it allows you to assess your situation, establish your objectives, and maintain greater control over your communications program and, in turn, the image you project for your Unit or Chapter. In addition, by outlining the various activities you may want to pursue, you will be able to set priorities for those that can be supported within your budget or time constraints.

Checklist

Following are key steps in establishing a communications plan:

- Step 1: Business plan assessment
- Step 2: Research — situational analysis
- Step 3: Target messages/the media list
- Step 4: The strategy
- Step 5: The campaign
- Step 6: Budget
- Step 7: Action plan
- Step 8: Evaluation

## Step 1: Business plan assessment

The first step in developing your plan begins with approval from your board. To build a cohesive and effective communications plan, one that everyone can follow, it's important to make sure your Unit President is on board from day one.

The next step is to analyze your Unit's current business plan, which includes your Unit's vision or mission for the future. Take the time to record your Unit's goals, objectives, policies, and procedures. Have them on hand as a guiding source for structuring the balance of your plan.

## Step 2: Research — situational analysis

Before you proceed in any direction, it is important to know where you are. What are the strengths and weaknesses of your organization? What does your organization offer people living with ALS? What is the Unit's purpose? What is the current profile of ALS and the ALS Society in your community?

To assess this, you could engage in some informal research. Ask people outside your organization informally what they know about ALS and the ALS Society. A brief questionnaire will help you ask organized questions and provide comparable information. This data will give you a new perspective in analyzing your situation and determining your future course of action.

In PR jargon, we refer to communications research as the situational analysis, broken down further, the situational analysis is divided into three parts:

- Scanning the environment
- Segmenting the publics
- SWOT

### Scanning the environment

Scanning the environment sounds ominous but all it involves is conducting a detailed background search on your product or service, your competition, your regulatory situation, current market trends, and public perceptions (this is very important). In effect, you are drawing an internal and external picture of your organization. Libraries and the internet are excellent sources. Review past clippings — how was your Unit portrayed in the media? Conduct an analysis of the media coverage — was it positive/negative?

### Segmenting the publics

"Publics" is a PR word, loosely defined as specific groups of people or key organizational stakeholders. It's important to define your key publics (see Section 1, Introduction) because each one has a unique set of needs. Address their needs and you begin to develop a very special relationship. With enough effort on your part, this relationship blossoms into a partnership.

The importance of segmenting, or breaking down, your stakeholders into individually identifiable groups, becomes apparent in step three of our communications plan, "targeting key messages."

### SWOT Analysis

The third step in our situational analysis is the SWOT analysis. SWOT is an acronym for Strengths, Weaknesses, Opportunities, and Threats. If scanning the environment is the foundation of a situational analysis, and segmenting the publics is the cement, SWOT is the "heart and soul" of the research process.

SWOT analyses vary depending on your organization's goals and objectives. In our case, our SWOT will be focused on developing an effective communications plan.

| | |
|---|---|
| Strengths/Weaknesses: | When you analyze the strengths of your Unit, you are documenting the strong points your Unit already has in place. Weaknesses, conversely, are areas in which your organization is limited or restricted. |
| Opportunities/Threats: | When scanning the environment, you may have missed opportunities and possible threats to the future success of your Unit. At this point in the situational analysis, we attempt to document these observations. Once the situational analysis is complete, its time to attack step three in our plan. Targeting your key communication messages to your publics. |

## Step 3: Target messages and the media list

Step 3 may be the most interesting of the six steps. Real Estate Agents tell us that the three most important factors in choosing a home are Location, Location, Location. In marketing and communications, we say: Target, Target, Target.

*News releases (see Section 3, Media Relations, pages 25 to 28)*

### Shape your message

Once you have learned what your audiences think of the ALS Society in your community, you can begin to mould your desired image. You can use communications opportunities to shape your image. If you want the public to see your Unit as progressive, professional or community-minded, look for opportunities to display those qualities. Then be sure your target audiences are made aware of what you have accomplished.

Programs for reaching your target audience:

- Having an effective media relations program
- Offering a speakers' program
- Holding displays at health fairs and in malls
- Developing a newsletter

Tools provided by ALS Society of Canada to assist:

- Communications Manual
- Web site, www.als.ca
- *Coast to Coast*, the national newsletter
- Alerts re: issues in the news
- Briefing notes about issues
- Fact Sheets
- *Research News*
- Communications Manual re: ALS Month

## Step 4: The strategy

This is where you begin to lay the groundwork for your communications plan. During this stage you establish the following:

- Plan objectives
- Programs
- Strategy
- Tactics

### Establish objectives

Record all of the outcomes you want your plan to achieve. More specifically, do you want to:

- Increase government awareness?
- Increase public awareness?
- Raise funds for much-needed services?

Decide what your desired objectives are and rank them in terms of priority or importance. What do you want to achieve first? What can wait until later?

Once you know where you stand, you can determine where you want to go and how to get there. When establishing objectives, remember they should:

- Be improvement oriented
- Be clearly defined
- Be measurable
- Be attainable
- Be tied to specific expectations
- Identify your audience

First, consider a broad audience to include those who affect the organization and those who are affected by it. You may cite groups such as those with ALS, family members, health-care professionals, media, volunteers, donors and community groups.

The next step is to divide these larger groups into smaller, reachable target audiences and prioritize them so your communications effort is directed toward the most important among them. In this way you can direct your primary effort toward those groups on whom you are likely to have the greatest impact.

### The program

Units have a number of different programs which are natural extensions of your objectives. For example, the WALK for ALS and Hike 4 ALS programs increase public awareness about ALS.

### The strategy

A strategy is a general plan aimed at obtaining long or short-term results.

### The tactic

Your tactic is the specific tool you use to implement your strategy. The ALS Society has a number of tactics in place to gain public awareness. For example, we have print ads and PSAs, a presentation about ALS and other resource material to increase awareness about ALS.

## Step 5: The campaign

Now that the fundamentals are in place, it's time to assess your available resources. Develop a list of in-house and off-site services you need to have in place. Your checklist should address all of the following:

- Advertising
- Media relations
- Community relations

### The tools

Keep in mind that your tools are your communications vehicles. They are the tools you'll use to express your key messages. Choose tools that best meet your communications' goals. The following are some examples:

- Community service billboards
- News releases
- Newsletters
- Flyers in local shopping centres
- Your web site

## Step 6: Budget

Once you've reached the budget stage you should have a well-thought out plan in place. It's at this point that you have to decide what kind of campaign you can afford. Instead of one budget, you really need two. First, how much is it going to cost to create the program — the creative process? Second, how much is it going to cost to deliver the program?

## Step 7: Action plan

Establish a critical path or timeline for your campaign. Develop a critical path, starting with who is responsible for an action and when it's due. Create deadlines that include the start times of programs, campaign resources, and the tactics you've set in place to meet your goal. Once you develop your action plan, encourage your committee members to stick to the deadlines as much as possible.

## Step 8: Evaluation

Finally, the last step, the plan evaluation. Think of your evaluation as a constantly changing and fluid process. Strategies aren't written in stone. Some tools prove to be ineffective, while others seem to appear out of the blue halfway though the campaign.

Evaluate every step of your plan, every step of the way. Ask yourself the following:

- Is your plan working?
- Are your tools working?
- Has anything gone wrong?
- Why?
- How can I fix it?

**Evaluation methods**

Before you began your campaign, you had a general understanding of where your organization stood and where it wanted to go. You had a benchmark or starting point from which to gage your future success. The following can help you measure the success of your campaign:

- Media clippings
- Discussion groups
- Surveys (in your newsletter or on your web site)

# Communications Tools

In this section

- Our logo
- Writing a Unit/Chapter newsletter
  - Why publish a newsletter?
  - Newsletter content

The ALS Society of Canada produces a series of resources to assist local volunteers with their communications activities. They include:

Checklist

- Fact Sheets (French and English)
- *Research News* (French and English)
- *Research Update* (French and English)
- *Research Synopsis* (French and English)
- *Northern Neuron* (French and English)
- *Coast to Coast* (French and English)
- *10 Facts About ALS* – presentation (French and English)
- *Elizabeth's Hope; Making Hard Decisions* (for health-care providers); *Making Hard Decisions* (for the general public) – Videos (English only); available from LM Media Marketing
- Public Service Announcements (*Hugging* and *Running*) are available from the national office
- Radio PSAs promoting WALK for ALS
- Logo
- Web site

## Our logo

Our logo was designed to express the nature and goals of the ALS Society community.

- What does the logo say about the nature of the disease?
- What does the logo say about the work of the ALS Society?

The ALS Society of Canada logo, in wide use since 1996, was designed by Trevor Pedler of Portofino Studios and a former board member. The bilingual logo incorporates an element of humanity and an element of fluidity that helps explain ALS — the physical degeneration, mental alertness, or weak body and a strong mind. The colour was selected for its distinctiveness and for its authority. The strong image has assisted in the wider recognition of ALS, the disease and the work of the ALS Society. It is registered with the Government of Canada.

The national identity is composed of the symbol, ALS/SLA monogram, English and French names. The ALS Society logo may be used in two ways:

- With the full name of the organization in French and English below the image and acronyms ALS SLA
- Without the full name of the organization below the image but with the acronyms ALS SLA

When the full names are used, they describe the monograms used. Never use the English monogram with bilingual names, never use English and French monograms with the name in just one language. Never distort or curve the identity elements.

Our logo is an important symbol for our organization. For information about logo usage please contact bg@als.ca.

## Incorrect logo usage

### Checklist

- Never use colours other than Pantone 2627C/2613U or black for the logo. The graphic and word mark must be in the same colour
- Never reverse the logo (i.e., white logo on a black or purple background)
- Do not stretch, skew or reshape the logo
- Do not place text or additional graphics over the logo
- The logo should always appear large enough to read
- The logo should never be framed in a box
- Never position the logo over a patterned or graphic background
- Never position the logo over a complex photographic background. It should always appear on solid tones. Every letter in the word marks should be clear and easy to read

## Colour specifications

The ALS logo colours are Pantone 2627C (for coated stock) or black. For uncoated stock use 2613U. In four-colour printing, pantone 2627 should be substituted with 78% cyan, 100% magenta, 0% yellow and 23% black. No other colours may be substituted. The logo may not be reversed.

## Approved type fonts

Minion Display Regular SC
abcdefghijklmnopqrstuvwxyz
ABCDEFGHIJKLMNOPQRSTUVWXYZ
123456789 ?!%&“”

Gill Sans Light
abcdefghijklmnopqrstuvwxyz
ABCDEFGHIJKLMNOPQRSTUVWXYZ
123456789 ?!%&‘“’

## Protection zone

The ALS Society of Canada logo must maintain a protection zone around it, allowing it to stand without interference. Using the height of the letters in the acronym ALS as a unit of “X,” place the “X” around all sides. No type or graphic element may be within the protection zone.

## Minimum size

The ALS Society of Canada logo may appear in a variety of sizes, as long as it is always sized proportionately and not stretched, condensed or angled in any way. The minimum acceptable size of the logo is 1.5" wide.

ALS SLA

AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF CANADA
SOCIÉTÉ CANADIENNE DE LA SCLÉROSE LATÉRALE AMYOTROPHIQUE

265 YORKLAND BOULEVARD, SUITE 300, TORONTO, ONTARIO M2J 1S5 • TELEPHONE **416 362-0269** • FAX **416 362-0414** • TOLL FREE **1 800 267-4257** • WEBSITE **www.als.ca**
CHARITABLE REGISTRATION 10670 8977 RR0002 E-MAIL **alscanada@als.ca**

*Sample letterhead layout*

notes

# Writing a Unit/Chapter newsletter

## Why publish a newsletter?

Newsletters are an effective tool for communicating news and ideas; for keeping readers up to date on events taking place in your unit; and, for creating a sense of community.

Some important questions need to be answered before you invest the time and money to publish a newsletter:

- What's the overall purpose of the newsletter?
- Who is your audience?
- What does your audience need and want to know?
- What is relevant and important to them?
- What are your goals and objectives in producing a unit newsletter?
- How many issues will you be publishing this year?

## Newsletter content

### A newsletter consists of the following:

Checklist

- The banner — includes the name of the publication and issue information
- Masthead — lists the publisher, editor, credits, and contact information — usually appears in the same place in each issue
- Headlines and sub-heads — introduces the story
- Body copy
- Graphics and photographs — enhances the copy
- Advertising (optional)

Most newsletters are published monthly, bimonthly, or quarterly.

What to include:

Checklist

- Message from the Chair/President
- Message from the Executive Director (you could combine these two)
- Upcoming events/event listings
- People in the news

- Profiles of people living with ALS and their caregivers (stories of hope and inspiration)
- News from the national office (new publications, fact sheets, etc.)
- Unit news and stories
- Research news

## Design and layout

- Become familiar with good principles of layout and design
- Re-evaluate the layout annually to keep updating the look
- Always include the source of the material used in case people want to learn more about the topic
- Divide your page into columns (two, three, or four)
- Select a type face that is easy to read (we use Garamond)
- Create emphasis with colour
- Design with white space
- Think visually – how might a story be illustrated?

Sources for clip art: www.clipart.com (subscription-based) and www.clipartconnection.com (royalty-free).

## Tips

- Adhere to a style guide; we use *The Canadian Press Stylebook* as our official style guide. For example, MD (with no periods)
- Less is more in writing
- Be sure to proofread — use spellcheck, proof backwards
- Make sure that you have news — news they can use — for example, new developments in research and sources they can turn to for more information
- Keep stories short and to the point — invite readers to check your web site for more information
- Ensure all your facts are correct
- Adhere to deadlines
- Balance long and short articles for variety
- Most important article should go on the front page (if it is long continue it inside)
- News should be timely and interesting
- Develop a network of contacts to write articles, take photos, generate ideas and information
- Profile achievements or awards of clients
- Thank your volunteers – what have they done?
- Recognize individual achievements
- Use lots of direct quotes

## Photo tips

- Ensure photos are in focus, sharp, and clear
- Avoid photographing against a light background (into the sun)
- Try to take action photos
- Include captions with the photos

## Organize your work

Prepare an issue-by-issue checklist so that everything that needs to be included in each issue is. Collect filler material in between times so that you always have a store of good material to include when room is available.

## Circulation

Post your newsletter on the web (is it going to be a web-only publication — this will save time and money). And, make sure to prune and update your list regularly.

Whom do you want to include on your mailing list?

- Clients
- Members of Provincial Parliament
- Donors/funders (past and current)
- Media (local)
- Other units

## Writing tips

- The most important is the KISS rule — Keep it simple, sweetheart. Write with your reader in mind. If you have a story, tell it
- Use active verbs
- Vary the length and structure of your sentences
- Minimize the use of the passive voice
- Eliminate jargon
- Write interesting headlines to catch the readers' attention – you want them to read the articles
- Say what you mean in as few words as possible

## Typeface tips

- Avoid excessive use of caps
- Stick with one font (we use Garamond)
- In the body copy of your newsletter — go for larger rather than smaller — use 12-point type
- Don't overuse bold face

notes

- Headlines should be short and catchy – entice readers to read the body copy
- The most readable typeface is black on white

## Evaluation

How do you know if you are successful?

- Feedback from your readers
- Readers clip your articles and keep them

## Other tips

- Build in regular feedback features
- Run contests (this will help assess as to how many people are actually reading your newsletter)
- Take care of your mailing (email list). Prune it regularly

And, most important of all, ask for readers' feedback — do a formal readership survey on a regular basis.

# Resources

In this section

## ALS Society Resources

### Fact Sheets

### *10 Facts About ALS*

The *10 Facts About ALS* are:

- the key messages of the ALS Society of Canada
- the most up-to-date information of the Society
- key talking points about the disease
- answers to the frequently asked questions about ALS
- available for use in PowerPoint presentations and as overheads
- in this manual and on the web site for easy reference

### ALS Fact Sheets

There are a number of fact sheets that can be used to develop customized information kits for volunteers, potential donors, community groups and the media. These fact sheets are on the ALS web site and updated regularly. We are in the process of updating and adding new Fact Sheets.

### Checklist

| | |
|---|---|
| ■ Fact Sheet #1 | 10 Facts about ALS<br>10 Faits Relativement À La SLA |
| ■ Fact Sheet #2 | When Speaking About ALS<br>En Parlant De La SLA |
| ■ Fact Sheet #3 | Our Mission<br>Notre Mission |
| ■ Fact Sheet #4 | Caregiver Stress (for caregivers)<br>Le Stress Chez L’aidant |
| ■ Fact Sheet #5 | Reducing Stress (for caregivers)<br>Diminuer Le Stress |
| ■ Fact Sheet #6 | ALS-MS-MD<br>SLA, SP et DM |
| ■ Fact Sheet #7 | ALS First Step (for caregivers)<br>SLA Les Premiers Pas |
| ■ Fact Sheet #8 | ALS Ways to Help (for caregivers)<br>SLA Comment Aider |
| ■ Fact Sheet #9 | The Dangers of Unproven Therapies<br>Les Dangers Des Thérapies non Prouvées |
| ■ Fact Sheet #10 | Natural Health Products<br>Produits Naturels |
| ■ Fact Sheet #11 | Clinical Trials<br>Essais Cliniques |
| ■ Fact Sheet #12 | Genetic Testing for ALS<br>Tests génétiques pour la SLA |
| ■ Fact Sheet #13 | Primary Lateral Sclerosis<br>Sclérose latérale primitive |

## Research Updates

These research updates profile the research undertaken by some of the top ALS researchers in Canada.

### Checklist

| | |
|---|---|
| ■ Research Update #1 | Oxidative Stress Not the Whole Story<br>Bien Plus que le Stress Oxydatif |
| ■ Research Update #2 | Rapid Diagnosis for ALS<br>Un Diagnostic Rapide De La Sla À L’horizon |
| ■ Research Update #3 | ALS4 Gene Found<br>Découverte du Gène Als4 |
| ■ Research Update #4 | ALS Research Accelerates<br>Les Progrès Dans La Recherche Sur La Sla |

| | |
|---|---|
| Research Update #5 | Another step for stem cells<br>Autre Pas Dans La Recherche Sur Les Cellules Souches |
| Research Update #6 | Misadventure in the Motor Neuron<br>Incident Chez Le Motoneurone |
| Research Update #7 | Cognitive Deficits Provide Clues in ALS<br>Les Troubles Intellectuels Donnent Des Pistes Dans La Sla |
| Research Update #8 | Devoted Researcher Brings New ALS Lab to Canada<br>Chercheure Dévouée Ouvre Un Nouveau Laboratoire De Recherche Sur La Sla Au Canada |
| Research Update #9 | Help or Hindrance<br>Un Allié Ou Un Obstacle? |

## Web site

The ALS Society of Canada web site contains current information about the disease and the Society's various programs. Visit www.als.ca.

**Other ALS links:**

- The ALS Association (ALSA), http://www.alsa.org
- USA Newsletter, http://Als.mdausa.org
- http://www.alsmndalliance.org/
- http://www.alslinks.com/
- http://www.alsnetwork.com/
- http://www.geocities.com/sweekes99/ALStitle.html
- http://www.als.net
- http://www.lesturnerals.org/
- The WFN Research Group on Motor Neuron Diseases, http://www.wfnals.org/
- Neurology forum, http://www.neurologychannel.com/als/
- Les Turner ALS Foundation, http://www.lesturnerals.org
- ALS Therapy Development Foundation, http://www.als.net
- Johns Hopkins ALS Center, http://www.neuro.jhmi.edu/alscenter/
- The ALS Reporter, http://www.tapa.com/ALS/
- ALS Survival Guide (personal web site of someone living with ALS), www.lougehrigsdisease.net
- BrainTalkCommunities (online discussion), http://neuro-mancer.mgh.harvard.edu/cgi-bin/Ultimate.cgi/

# Policies

This section contains the policies that have been approved by the ALS Canada Board of Directors that affect communications, i.e.,

- Media Relations
- Crisis Communications
- Privacy
- Assisted suicide

## Policy on crisis communications

The ALS Society of Canada has a Policy to give direction to all staff and volunteers when a communications crisis surfaces.

ALS Canada will co-ordinate an organized response to issues which capture the attention of the media. ALS Canada will provide clear and trustworthy information to the media and provide assistance to the Units to support them in responding to regional media.

### Procedure

An ALS Unit will bring to the attention of the President & CEO any issue in any part of Canada which appears to have media potential beyond the boundaries of any one jurisdiction. Issues confined to the Unit's boundaries may also benefit from the utilization of this procedure, since expertise is available to support the Unit.

The President & CEO and the Director of Communications will immediately institute a crisis communications team to handle the crisis. Time will be of the essence.

With the help of the Unit involved, a preparatory paper will be e-mailed to the members of this team outlining the problem, and suggesting some possible responses.

A teleconference will occur to develop the response methodology, including the designation of the spokesperson, the key messages, and the target audiences for these messages.

All Units will keep the right to follow-up their own communications and will be responsible for it. ALS Canada may co-ordinate the process.

The team may be supplemented as the crisis unfolds.

When the crisis has subsided, an evaluation of what was learned will be conducted by the Director of Communications. The results will be used to improve these procedures in the future.

ALS Units will provide assistance to ALS Canada to support them in responding to media.

ALS Canada will co-ordinate an organized response to issues that capture the attention of the national media. ALS Canada will provide clear and trustworthy information to the media and provide assistance to the Units to support them in responding to regional media.

These events often begin with a call from the media and can develop very quickly. Each group needs to assess its ability to meet these communications situations. Having a Crisis Communications Protocol in place enables us to manage the event more effectively.

## Critical response statements

*Reprinted with permission of the ALS Society of Alberta*

Key messages if requested to comment on the relationship between ourselves and the Lou Gehrig Society of N-AB:

- The ALS Society of Alberta is a completely separate legal entity from The Lou Gehrig's Society of Alberta though we both provide services to those with ALS
- The ALS Society of Canada, in partnership with ALS Alberta, is the only national organization whose mission encompasses care for those with ALS and research for a cure
- The mission statement of the ALS Society of Alberta states: The Amyotrophic Lateral Sclerosis Society of Alberta is dedicated to making everyday the best possible day for people with ALS by providing support, facilitating the provision of care, promoting awareness, and helping find a cure
- Both organizations provide services to those with ALS, and the needs of those with ALS are of paramount importance to both organizations

**Remember:** Whenever possible, respond positively and keep on the theme. Only respond to questions that are asked, using one of the above statements. Do not offer any more information. If the interviewer asks more questions, repeat the same responses. Stay neutral in tone when referring to LGS of N-AB and have a positive tone when referring to ALS AB.

## Preparing for a crisis

Although most communications planning will focus on the positive aspects of promotion and raising public awareness, we recommend that each group develop a plan to cover the unexpected and be ready to respond quickly and consistently to unexpected events.

What can happen?

Events can be generally divided into external and internal events, i.e.,

**External Events**: do not involve the local group directly but may appear in the wider community and impact the ALS network, for instance:

- A dramatic breakthrough in ALS research
- An incident relating to "assisted suicide"
- An incident of possible criminal activity in another local society
- A celebrity announcing that s/he has ALS

**Internal events** include activities such as:

- Accidents in settings where there is interaction among ALS staff and/or volunteers and people with ALS and at ALS events
- Incidents involving ALS staff, volunteers or a person with ALS: abuse, harassment, fraud, theft, slander, violence

## Dealing with the media during a crisis

- The media want information: be prepared to give it to them
- Media investigations are directed toward producing a story with a focus on people. They will want to know the sequence of events and the players involved. They will be looking for the "human interest" side of the situation: every reporter will want quotations from people involved
- They will create their own photo opportunities
- Always respond truthfully and factually. If you don't have the information, say so — then promise to follow up on the question
- Don't speculate or editorialize about the situation
- Keep your responses simple and direct
- Have the capacity to identify and respond immediately to crisis situations
- Media contact lists need to be accurate and up-to-date
  - Identify and train your spokespeople
  - Have alert systems in place
- Have a distribution system for media, the public and other stakeholders
- Monitor the media

For a crisis communications plan to work — it needs to be simple, practiced and include checklists.

notes

Tips

Things to communicate in a crisis:

- What can be prepared in advance?
- Messages that build credibility and trust
- You don't need the entire story to start your communications
- Don't be defensive
- Show you are engaged and concerned
- Show your compassion, sympathy, empathy for the affected parties

Four things you must have to communicate effectively in a crisis:

- Take action and tell the public about it. Provide regular news updates
- State what you know and what you have and haven't done
- Use experts, third parties where appropriate
- Have a clear explanation for your action and position and next steps

## Privacy policy

*Posted on the ALS Society of Canada web site*

### We protect your privacy

The ALS Society of Canada recognizes your right to privacy and pledges to protect it. The ALS Society is aware of our responsibilities under the federal Personal Information and Electronics Documents Act (PIPEDA).

### Information collected

When visiting our web site, our web server automatically logs (records) domain name and standard information about the operating system and web browser you are using, as provided by your web browser. This information is used for statistical purposes to help us manage our site, but it does not identify you in any way.

We collect personal information about you only if you volunteer it in a survey and/or guest book and/or other "on-site" registrations and/or make a donation. We may use this information to contact you for support purposes and to answer questions you submit to the site. All information is kept confidential.

If you supply us with your mailing address online, you may receive periodic mailings from us with information about new programs and services or upcoming events, if you give permission to be contacted.

If you do not wish to receive such mailings, please let us know by calling us at the telephone numbers below or by writing to us at the address below. Please provide us with your exact name and address. We will then remove your name from our confidential list.

### Donation information

The Amyotrophic Lateral Sclerosis Society uses Secure Socket Layer (SSL) encryption technology to ensure the integrity and privacy of the personal and credit card information you provide when you make an online donation or register for an event.

We maintain records of all contributions to the ALS Society of Canada. All information is kept private and confidential, stored in a secure location and accessible only by authorized staff.

If you would like more information about the ALS Society of Canada privacy policy, please contact the Director of Communications at the telephone number in Toronto listed below or at the address below.

### Disclaimer

The ALS Society of Canada is the only national voluntary organization in Canada that supports both ALS research and services for people with ALS and their families. It is a major source of information about Amyotrophic Lateral Sclerosis, which is based on professional advice, published experience and expert opinion but does not represent therapeutic recommendation or prescription. The opinions do not necessary represent the views of the ALS Society of Canada. For specific information and advice, please consult your personal physician.

The ALS Society of Canada is an independent, voluntary health agency and does not approve, endorse or recommend any specific product or therapy but provides information to assist individuals in making their own decisions.

Any reference to a commercial or non-commercial product, process, service or company is not an endorsement or recommendation by the ALS Society of Canada. The ALS Society of Canada does not endorse or recommend products, services or manufacturers. The ALS Society of Canada assumes no liability whatsoever for the use or contents of any product or service mentioned.

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### Privacy resources

- “Your Privacy Responsibilities — Guide for Businesses and Organizations to Canada’s Personal Information Act” — available at www.privcom.gc.ca
- Canadian Standards Association “Plus 8300 – Making the CSA Privacy Code Work for You” available for purchase through the Canadian Standards Association, 416-747-4000
- “Privacy 101: A Guide to Privacy Legislation for Fundraising Professionals and Not-For-Profit Organizations in Canada” available at http://www.afpnet.org/ka/ka-3.cfm?folder_id=2086&content_item_id=12746
- Privacy Act: http://laws.justice.gc.ca/en/P-21/index.html
- The Personal Information Protection and Electronic Documents Act http://www.privcom.gc.ca/legislation/02_06_01_e.asp

## Euthanasia and assisted suicide

There is one question that is routinely asked of people connected with ALS: the issue of Sue Rodriguez and assisted suicide.

The following is the ALS Society of Canada’s position statement on euthanasia and assisted suicide:

### Statement

The role of the ALS Society of Canada is to fund research towards a cure for ALS. ALS Canada also supports provincial societies in their provision of programs and services for persons affected by ALS.

The Society advocates for access to the best palliative care and end-of-life care for all Canadians living with ALS.

As a Society, we neither oppose nor support any attempt to change the law regarding euthanasia or physician-assisted suicide. We provide support to all Canadians affected by ALS.

*Passed at the ALS Society of Canada Board of Directors meeting on May 6, 2006.*

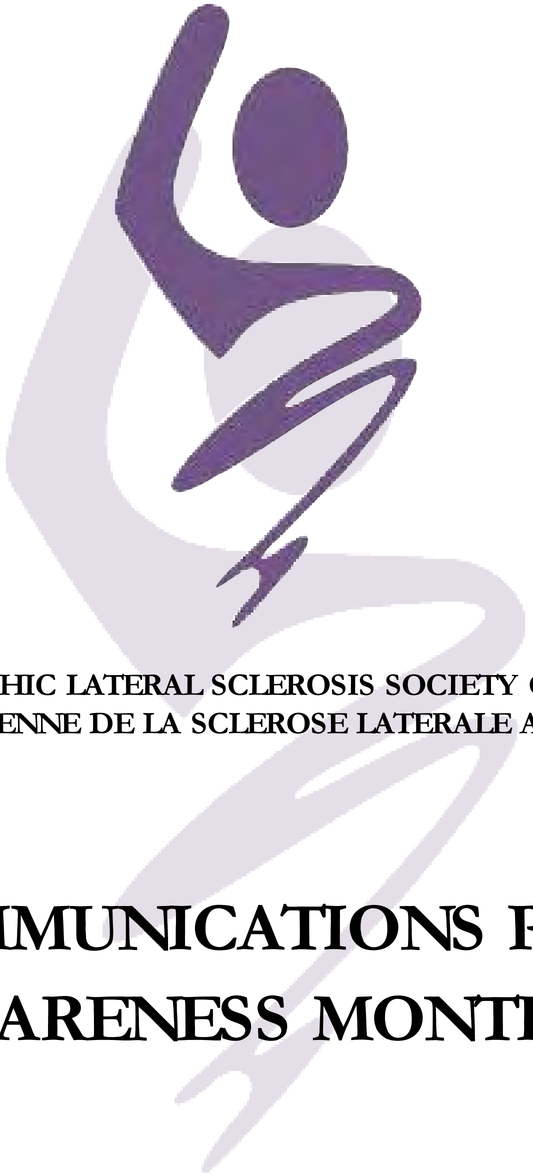
If you are giving an opinion make sure people understand that it is your own view. Before attending any media or speaking engagement it is wise to work out your response in advance.

notes

# Samples

Attached is a selection of sample resources and handouts:

- ALS Awareness Month Communications Plan
- *10 Facts About ALS* (PowerPoint)
- Biographies
  - David S. Cameron, ALS Canada President & CEO
  - Sean McConkey, Chair of ALS Canada Board of Directors
  - Lou Gehrig
- ALS Society of Canada print ads
- Sample news release (Canon Continues Commitment to WALK for ALS in 2006)
- Sample news release (Hike The Trail To Help Us Prevail)
- Video Resources
- Public Relations Resources
- Employment Programs in PR and Communications Across Canada



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SOCIETE CANADIENNE DE LA SCLEROSE LATERALE AMYOTROPHIQUE

# COMMUNICATIONS PLAN
# ALS AWARENESS MONTH, JUNE

ALS SLA

## ALS Awareness Month, June

# Table of Contents

ALS SLA

## Executive Summary

The ALS Society of Canada needs to raise awareness and understanding of amyotrophic lateral sclerosis to increase donations and raise funds for a cure.

June is ALS Awareness Month, our greatest opportunity to show the community who we are and what we stand for.

The ALS Society needs to foster and strengthen its public profile so that more people can empathize with our mission and understand who we are. The largest obstacle that the ALS Society of Canada faces is the lack of knowledge and understanding about the disease.

**People will not donate to a cause if they are not aware of it or do not understand it.**

The effect we hope to have on individuals is primarily education regarding the disease and secondarily to inform people as to how they can donate money to help fight this devastating disease.  The donation message is much more subtle. By informing people about ALS, and its effect on those living with the disease and their families and caregivers, hopefully they will then donate funds to their local unit and/or the national office.

Our success will be evaluated on three levels:

- Donations generated
- Media recognition
- Feedback from stakeholders (internal and external)

## Objectives

The objectives for the ALS Awareness campaign include:

- To promote the month of June as devoted to ALS awareness thereby leading to:
  - Increased awareness within the community about ALS
  - Increased funds raised for research and services to aid those living with ALS and their families

- To increase government support for financial resources and aid within the health-care system for those affected by ALS and their families

- To motivate and build volunteer strength

## Strategies

The strategies for the ALS Awareness campaign include:

- To provide provincial units and local chapters a variety of promotional ideas that can be developed and implemented in local communities throughout the month of June
- To distribute awareness materials to provincial and local chapters for delivery to the media so that a consistent message is sent across the country
- To encourage a unified effort throughout all ALS units regarding campaign launch dates, press releases and other media materials

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## Tactics

The tactics for the ALS Awareness Month campaign will include:

- Media strategies:
  - Distribute media advisories and/or press releases about ALS month
  - Deliver a letter of proclamation for your local mayor
  - Sample Member of Parliament/Legislature Statement in your provincial legislature/House of Commons announcing that June is ALS Awareness Month
  - Distribute information about ALS (ALS Story)
  - Distribute an information sheet/press release about the blue cornflower
  - Send material to your MPP/MLA for him/her to include in his/her newsletter (called a 10 percenter)

## Target Audiences

The key audiences for this campaign are as follows:

- **Internal:**
  - Volunteers and staff from the ALS Society
  - Donors
  - People living with ALS
  - Caregivers

- **External:**
  - General media
  - Health media
  - Local, Provincial and Federal Government(s)
  - Health-care professionals
  - General public

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FOR IMMEDIATE RELEASE

# June is ALS Awareness Month

**Name of city, Province — June 1, 200x**: June is ALS Awareness Month in Canada. Amyotrophic Lateral Sclerosis, more commonly known as Lou Gehrig's disease, is a rapidly progressive and fatal neuromuscular disorder that causes the degeneration of a select group of nerve cells in the brain and spinal cord. As the nerve cells die, people with ALS lose control of their muscles, which makes breathing, eating, and even smiling almost impossible.

ALS is a fatal disease with no effective treatment and no cure. Eighty per cent of people with ALS die within two to five years of diagnosis. Some people die within a few months. Ten per cent of those affected may live 10 years or longer.

ALS is not considered a rare disease. Approximately 3,000 Canadians currently live with ALS. ALS kills two to three adult Canadians a day.

David S. Cameron, President & CEO of the ALS Society of Canada is optimistic. "We desperately need a series of breakthroughs, and that requires more funding to push the research closer to a result that benefits those diagnosed. Presently research into this catastrophic disease is under-funded. Awareness and fundraising events can change that. Every donation gets us closer to effective treatment and an ultimate cure."

If you would like more information about amyotrophic lateral sclerosis, contact the ALS Society of Canada toll free: 800-267-4257, or visit its web site at www.als.ca.

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**Media Contact**:
Bobbi Greenberg
Director of Communications
416-497-5509 ext. 208
bg@als.ca

Sample press release

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FOR IMMEDIATE RELEASE

# National ALS Awareness Month in June

Name of city**,** Province**, June 1, 200x**: - The ALS Society of Canada will declare ALS Awareness Month across the country this June. It is a time to recognize the triumphs of those living with ALS and share their stories within communities across Canada. It is also a time to educate Canadians about ALS, recognize the advancements made through ALS research and reflect upon the many challenges facing those living with ALS and their caregivers.

The first weekend in June has traditionally been designated for the ALS Society of Canada's "Flower/Awareness Day" campaign. During the Flower Day campaign, volunteers can be seen throughout communities distributing blue cornflowers and seeking out donations to help fund ALS research. The blue cornflower was chosen as the international symbol of hope for ALS because of its fragile appearance yet hardy nature. The cornflower grows wild across most of Canada and is long-lasting with striking blue, star-like blossoms.

Another popular campaign during the month of June is the WALK for ALS, a program co-ordinated and supported nationally and executed throughout the provincial units across Canada. Businesses and families can organize teams to take part in the WALK for ALS and it has become a great way to show support for an employee or a family member who has ALS. The key goal for the campaign consists of increasing public awareness about ALS and helping to support local services that give aid to those living with ALS, their families and caregivers.

Raising awareness of ALS is a key program of the ALS Society of Canada year round. Throughout the month of June however, special initiatives are taken to create more opportunities to bring ALS to the attention of the Canadian public and to help discover a cure.

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For more information:
(media contact name, phone number and e-mail to go here)

Sample press release

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# Sample Member of Parliament Statement

*Federally called Standing Order 31*

I rise today to acknowledge those present from the ALS Society of Canada.

The ALS Society of Canada, founded in 1977, is the only national voluntary health organization dedicated solely to the fight against ALS, Amyotrophic Lateral Sclerosis, also known as Lou Gehrig's disease.

The ALS Society is the leading not-for-profit health organization working nationwide to fund ALS research and work to improve the quality of life for Canadians affected by the disease.

Imagine not being able to walk, write, smile, talk, eat and sometimes breathe on your own, and yet your mind usually remains intact and your senses unaffected. This is what having ALS is like for the 3,000 Canadians who live with the disease.

- *There is no effective treatment for ALS and no known cure — yet*
- *Eighty per cent of people diagnosed with ALS die within two to five years*
- *Two to three Canadians with ALS die every day*
- *Two to three Canadians are diagnosed with ALS every day*

Volunteers and staff of the ALS Society participate in annual fundraising events including WALK for ALS, Hike4ALS and the Concert of Hope to create public awareness about the disease and raise funds to find a cure.

I urge all Canadians to donate to their provincial ALS societies so that the dream of finding a cure can soon become a reality.

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# Proclamation
# ALS Awareness Month, June 200X

**WHEREAS:** Amyotrophic lateral sclerosis (ALS) is a rapidly progressive fatal motor neuron disease for which there is no cure, and from which two to three Canadians die each day; and

**WHEREAS:** ALS is also known as Lou Gehrig's Disease. It can strike anyone, regardless of age, gender or circumstances, requiring families to spend thousands of dollars for specialized equipment and nursing care; and

**WHEREAS:** recent advances in ALS research have produced promising leads; and

**WHEREAS:** ALS has no known cause, prevention or cure.

**NOW,**

**THEREFORE:** I, Mayor ——, on behalf of (name of city) City, do hereby proclaim **June 200x** as "**ALS Awareness Month**" to raise awareness about Amyotrophic Lateral Sclerosis and to raise funds for research and support services for people living with this disease in the City of xxx.

**[Signed Mayor ____]**

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# Frequently Asked Questions

**What is ALS?**

ALS stands for amyotrophic lateral sclerosis and is also known as Lou Gehrig's disease. It is a neuromuscular disorder that affects the nerve cells and spinal cord leading to progressive paralysis of the muscles. ALS rapidly affects the body and is usually fatal two to five years after the initial diagnosis.

Until fairly recently, it was assumed that ALS did not affect thinking. However, researchers have found that changes in the way one thinks, perceives, and processes information (cognition), and behaves will occur in some people living with ALS and sometimes early in the disease before an ALS diagnosis has been made. This is not to say these changes will occur in all persons with ALS, and the exact nature of the changes can vary from person to person.

***There is currently no cure for ALS and no treatment to significantly prolong life.***

**How does someone acquire ALS?**

In most cases the cause is unknown. Less than 10 per cent of cases are hereditary. Research has recently been investigating the possibility of genetic predisposition, viral or infectious agents, toxins, and immune disorders.

**Who gets ALS?**

ALS can strike anyone from any ethnicity at any age. It does not discriminate. ALS is not contagious and cannot be prevented. The usual age of onset is between 40 and 70 years of age, however, people as young as 20 have been diagnosed.

**What are the early symptoms of ALS?**

Usually the lower portion of the body and the legs are affected first. The arms, the throat and the upper chest are common areas as well. Some people begin to trip and fall, some lose the ability to control their arms and hands, and some find it hard to swallow and tend to slur their speech.

### What are the effects of ALS?

ALS begins to take its toll on the body very quickly. Many people are debilitated before learning they have the disease. ALS does not affect the senses: taste, touch, sight, smell and hearing. People with ALS remain conscious and aware. Those living with this devastating disease find themselves trapped in a body that does not work.

Not only does ALS affect those living with this devastating disease, but it also affects havoc on family members and caregivers. As they cope with the prospect of advancing disability and death, financial and emotional reserves are spent. ALS is a costly disease demanding both extensive nursing care and expensive equipment.

### What is the future for people living with ALS?

Because there is presently no treatment available that prolongs life significantly, those living with ALS find good planning and social and medical management focal in easing the burden placed on themselves and their family. Research is helping to find a cure and ways to treat the devastating disease.

### What is the mission of the ALS Society of Canada?

The mission of the ALS Society of Canada is to fund research towards a cure for ALS, provide information to build awareness about ALS, and support provincial ALS Societies to provide quality care for those affected by ALS. The ALS Society of Canada, founded in 1977, is the only national voluntary health organization dedicated solely to those affected by ALS.

### Research Message from Dr. Janice Robertson – ALS Researcher at the University of Toronto's Centre for Research in Neurodegenerative Disease:

The incidence of ALS is two per 100,000 individuals with 2,000-3,000 Canadians living with the disease at any one time. The average expected lifespan of someone diagnosed with ALS is two to five years, with two to three Canadians dying every day from the disease. Currently there is no cure and no effective treatment. This will change with increased support for research.

It is through research that a mutant gene causative of familial forms of the disease has been identified, and it is through research that treatments targeting this gene are being developed, providing real and palpable hope for those living with this form of the disease. More research is required to identify additional targets so that new and more widespread treatments can be developed for all forms of ALS, until the disease itself is eradicated.

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# ALS Story

**What is ALS?**

Amyotrophic lateral sclerosis — ALS — is also known as Lou Gehrig's disease, after the famous American baseball player who died of ALS in 1941. ALS is a fatal, rapidly progressing neuromuscular disease. ALS causes degeneration of the motor nerve cells. These nerve cells control movement by sending electrical impulses to the muscles. When the motor neurons degenerate, the muscles weaken, resulting in paralysis.

Definition of ALS:
A = absence
Myo = muscle
Trophic = nourishment
Lateral = side (referring to the spine)
Sclerosis = hardening or scarring

The effect on the body is catastrophic. An affected person may first notice a slight weakness in a limb, or a slight loss of co-ordination. These initial signs develop into a relentlessly progressing paralysis as the individual loses voluntary movement, and ultimately, the ability to breathe. People with ALS usually die within two to five years of their diagnosis.

Although it has been well over a century since the first complete description of ALS by French neurologist Dr. Jean-Martin Charcot, the cause of ALS is not yet known and there is no known cure. The drugs currently available do very little to prolong the life of those with the disease. ALS is the most common cause of neurological death in Canada. Approximately 3,000 Canadians are currently living with ALS and every day two to three people in Canada die of the disease.

Until recently, ALS was thought to spare the brain, the organs and the senses. We now know that ALS is very complex, and its effects are not confined to voluntary motor control. While progressive paralysis is the overwhelmingly predominant symptom, there can be subtle effects on the function of the brain (cognitive function), and the organs and senses (autonomic function).

There is currently no way to predict who will develop ALS — it strikes both men and women, of all ethnicities, all over the world. While symptoms usually first appear in middle age, the disease can also onset as early as the teen years. The causes of ALS are not well understood. ALS is not just one disease, but several, all with the same outcome: progressive motor neuron degeneration. Some forms of ALS are inherited, but this cause accounts for less than 10 per cent of cases. Most cases are classical, or "sporadic," having no family history of the disease.

Current research into the cause of ALS investigates many areas, including genetic dispositions, immune system changes, environmental toxins, infectious agents and cellular mechanisms. Research toward an effective treatment for ALS is progressing more rapidly than ever before. Some of the strategies in development include drug, gene, and stem cell therapies. Because of the complex nature of ALS, it is likely that a combination of many therapeutic strategies – to attack the disease at all levels – will be the best approach to slowing, or even stopping, the course of ALS.

## ALS Facts

- Every day, two to three Canadians die of ALS
- Approximately 3,000 Canadians currently live with ALS
- In at least 80 per cent of cases, ALS strikes individuals with no family history of the disease
- Less than 10 per cent of cases are hereditary
- ALS can strike anyone, regardless of age, sex or ethnic origin
- The usual age of onset is between 40 and 70, but some have been younger than 20
- Eighty per cent of people with ALS die within two to five years of diagnosis. While some may live longer, others die within a few short months. And, 10 per cent of those affected may live 10 years or longer
- ALS affects the whole family
- ALS is a costly disease – emotionally, physically and financially

## ALS Society of Canada

The mission of the ALS Society of Canada is:

- To support research towards a cure for ALS
- To support ALS partners in their provision of quality care for persons affected by ALS
- To provide information to build awareness about the disease

# Global Day

Every year since 1997, the International Alliance has celebrated June 21 as the global day of recognition of ALS/MND — a disease that affects people in every country of the globe.

21 June is a solstice — a turning point — and each year the ALS/MND community undertakes a range of activities to express its hope that this day will be another turning point in the search for cause, treatment and cure of this awful disease.

Members of the International Alliance undertake a range of activities to recognize ALS/MND. Many organize meetings of people diagnosed with ALS/MND and carers, some organize social events, meetings of Boards of Directors, undertake fundraising activities or simply reflect on being a part of the worldwide fight against ALS/MND.

**Why is it important?**

Global day is important because it is one day that members of the International Alliance have in common to reflect their dedication and role in the global fight against ALS/MND. Many countries already have awareness days, weeks and even a month of recognizing ALS/MND and stimulating a period of intense effort to promote awareness. But this one day allows us to recognize that we are not alone in our fight against ALS/MND, and that patients, carers, former carers, scientists, health care professionals, volunteers and many, many others, all of whom care, are all part of this fight.

**Who can be involved?**

Global Day is an event that knows no boundaries, so everybody can be involved. Any event (big or small), any activity, any act, can be a part of raising awareness of ALS/MND, and the impact it has on people, old and young.

**What can you do?**

On the day, ***You can do anything!***

You could:

- Tell 10 people you meet about ALS/MND
- Have a dinner party and charge friends to come and donate the funds to your local ALS/MND organization
- Write about ALS/MND to your local newspaper
- Have a picnic with your ALS/MND Association
- Ring up and volunteer for your ALS/MND Association

- Organize a meeting, and get a scientist to talk about research and ALS/MND
- Donate some money to your nearest ALS/MND Association (locations at www.alsmndalliance.org/directory/index.html)
- Work with a person with ALS/MND and help them tell their story of hope to a journalist for publication
- Buy some cards from an ALS/MND Association and send them to 10 of your friends, and ask each of them to tell 10 more people about ALS/MND
- Join the global chat session at http://www.alsmndalliance.org/chat.shtml

Just talk up ALS/MND!

**Remember…**

The fight against ALS/MND is a global fight. ALS/MND affects people in every country in the world, and takes no notice of race, colour, faith or economic status. It is indiscriminate, and every diagnosis affects a much larger circle of people — family, friends, relatives, workmates and others.

JOIN THE FIGHT — DO SOMETHING
ON GLOBAL DAY
TO SPREAD THE WORD

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# Key Messages: ALS Awareness Month, June

The following key messages should be applied to and maintained throughout the month of June during the ALS Awareness Month campaign.

1. The month of June is dedicated to those living with ALS, their families and caregivers. We recognize those who are fighting the disease and offer our support.

2. Raising awareness about ALS is a fundamental role that the ALS Society plays during ALS Awareness Month. We are always looking for opportunities to bring ALS to the attention of Canadians.

3. The ALS Society of Canada is committed to raising funds through various events held during ALS Awareness Month. These funds go directly towards finding treatments and a cure for ALS, and local support services for those living with this devastating disease.

**Research Message**

"Currently there is no cure and no effective treatment. This will change with increased support for research. It is through research that a mutant gene causative of familial forms of the disease has been identified, and it is through research that treatments targeting this gene are being developed, providing real and palpable hope for those living with this form of the disease. More research is required to identify additional targets so that new and more widespread treatments can be developed for all forms of ALS, until the disease itself is eradicated," says ALS researcher Dr. Janice Robertson. Dr. Robertson has established an ALS lab at the University of Toronto's Centre for Research in Neurodegenerative Disease.

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# Fact Sheet

- Two to three Canadians with ALS die every day
- Approximately 3,000 Canadians currently live with ALS
- June is declared ALS Awareness Month by Health Canada
- ALS is also known as Lou Gehrig's Disease, named after the famous baseball player who died from the disease in 1941
- Eighty per cent of people with ALS die within two to five years of diagnosis.
- ALS can strike anyone, at any age regardless of gender or ethnicity
- In at least 90 per cent of cases, ALS strikes people with no family history of the disease
- The cause of ALS is unknown
- There is currently no effective treatment that significantly prolongs life
- There is no cure — yet

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# The Blue Cornflower: Growing Awareness, Growing Hope

The blue cornflower, also known as the bachelor's button, is the ALS emblem because despite its fragile appearance, it is a hardy wildflower found throughout Canada.

This native flower was chosen for its hardiness and longevity despite an outwardly fragile appearance. The cornflower blooms in the most adverse circumstances making it the ideal emblem for the disease. Its striking blue color never fades; much like the courage and strength demonstrated by those living with ALS.

Like the cornflower, people with ALS show remarkable strength in coping with a devastating disease. Like the cornflower, awareness of ALS and funding for care and a cure is growing across Canada.

The cornflower can be found in cultivated fields and along roadsides. The stems are long, tough, wiry and slender. The leaves are narrow and long, but it is the solitary star-like blossoms with their brilliant blue color that make the cornflower stand out as one of Canada's most striking wildflowers.

The flowers are used in modern herbal remedies, as they are thought to have tonic and stimulating properties. Distilled water from the cornflower petals is believed to be a good remedy for weak eyes. The famous French eyewash, "Eau de Casselnuettes" was once made from the cornflower. The powder from the dried leaves is used to treat bruises and broken veins. Juice pressed from the petals makes good blue ink and can be used in watercolor paintings. The dried petals are also used by perfumeries for giving color to potpourri.

The cornflower and the colour blue have become synonymous with ALS around the world. Look for the blue cornflower in your community as a symbol of ALS Awareness Month this June.

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# FACTS ABOUT

# ALS

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# #1 ALS may also be called …

- Amyotrophic lateral sclerosis
- Sclérose latérale amyotrophique (SLA)
- Lou Gehrig’s disease
- Motor neuron disease (MND)
- Maladie de Charcot

# #2 ALS is a rapidly progressive fatal neuromuscular disease

- Nerve cells degenerate
- Voluntary muscles become paralyzed
- The senses are unimpaired and the intellect may remain unaffected

# #3 ALS can strike anyone

- Male or female
- Any ethnic origin
- At any age
    - Some have been diagnosed as teens
    - Usual onset is in middle age

# #4 Eighty per cent die within two to five years of diagnosis

- Some will die within a few short months
- Some will live longer than five years

# #5 Some cases are hereditary

- Less than 10 per cent are familial ALS
- ALS is not contagious

## ● 10 Facts about ALS ●

**#6 Approximately 3,000 Canadians currently live with ALS**

# #7 Every day two or three Canadians die of ALS

- ALS is the most common cause of neurological death in Canada

# #8 ALS affects the whole family

- Ninety per cent of care is shouldered by family caregivers
- ALS is a costly disease — emotionally, physically and financially

# #9 Definition of ALS

- *A* = absence
- *Myo* = muscle
- *Trophic* = nourishment
- *Lateral* = side (referring to spine)
- *Sclerosis* = hardening or scarring

# #10 The ALS Society of Canada

- **FUNDS** research to provide hope
- **SUPPORTS** Provincial Societies to serve immediate needs
- **PROVIDES** information to build awareness
- www.als.ca
- 800-267-4257

# #11 The Provincial ALS Society provides quality care to those affected by ALS

- Information and referrals
- Support for the person with ALS and their family
- Equipment
- Advocacy

# WE CAN BE REACHED AT:

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# David S. Cameron

*Biography*

David S. Cameron joined the ALS Society of Canada in September 2003 as the President & CEO. David has more than 20 years' experience in the not-for-profit realm.

Most recently he was with the Ontario Division of the Canadian Diabetes Association as the Executive Director. He held this senior position for five years and was responsible for leading more than 90 staff members in bringing in major changes within this health charity.

His other association management experience includes Executive Vice-President and Chief Operating Officer at the Purchasing Management Association of Canada for 10 years. And, he also led the Motorcycle and Moped Association as its Executive Director for five years.

David is active in the health charities field and sits on the Steering Committee of the Health Charities Council of Canada. In addition he is vice-president of the Orillia cottage association.

David is a true visionary and is leading the ALS Society of Canada through a period of growth and transformation. Under his leadership the society has undergone a major strategic planning process and developed a new vision statement: *The ALS Society of Canada envisions a cure for ALS by 2015.*

Since assuming his post, David has traveled across the country meeting with staff and volunteers at the provincial societies as well as meeting with the medical directors at the ALS clinics.

His educational background includes a BA from the University of Toronto, and an LLB from the University of Western Ontario. And, he also received his Certified Association Executive designation from the Canadian Society of Association Executives.

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# Sean G. McConkey

*Biography*

Effective April 30, 2005, Sean G. McConkey was elected to the position of Chair of the Board of Directors of the ALS Society of Canada.

McConkey's extensive experience in human resources and management will serve ALS Canada well as it strives to increase awareness of the disease and support for those who suffer from it.

“I will work to ensure that ALS Canada governs in a way that honours and supports the ALS Society’s mission statements: to support research, provide quality care to those persons living with ALS, and to build public awareness,” says McConkey.

For the past five years, McConkey has been very involved with the ALS Society of Canada. He has sat on numerous committees. Starting as the Chair of the Human Resources Committee in 2000, he quickly took on two additional posts in 2001, serving as the Fundraising Committee Chair as well as Vice Chair of the Board of Directors.

Currently, McConkey is the Director of Human Resources for Deloitte & Touche LLP. In this role he is responsible for guiding the overall HR strategy for the GTA region. These duties include planning, implementing, and managing human resource strategies through a team of HR professionals. This scope includes recruitment, compensation and benefits, training and development, employee relations, and ex-patriot programs.

McConkey holds a BSc from the University of Toronto, and completed a post graduate diploma in Human Resources Management at Humber College of Applied Arts and Technology.

He resides in Burlington with his wife and three daughters and enjoys gardening and skiing in his spare time.

Founded in 1977 as a national voluntary organization, the ALS Society of Canada funds research towards a cure for ALS, supports provincial ALS societies in their provision of quality care for persons living with ALS, and provides information to build awareness about this devastating disease.

ALS (also known as Lou Gehrig's disease) is a fatal neuromuscular disease that paralyzes the body's voluntary muscles. Since ALS does not impact the senses and the mind may remain unaffected, people with ALS are aware of what is happening to their bodies. Every day two or three Canadians die from ALS.

ALS SLA
AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF CANADA
SOCIÉTÉ CANADIENNE DE LA SCLÉROSE LATÉRALE AMYOTROPHIQUE

# Lou Gehrig

*Biography*

Lou Gehrig was born on June 19, 1903, in New York City, the son of German immigrants and the only one of four children to survive. In 1921, he went to Columbia Univerisity on a football scholarship. He was banned from intercollegiate sports during his freshman year for unwittingly playing summer professional baseball under an assumed name.

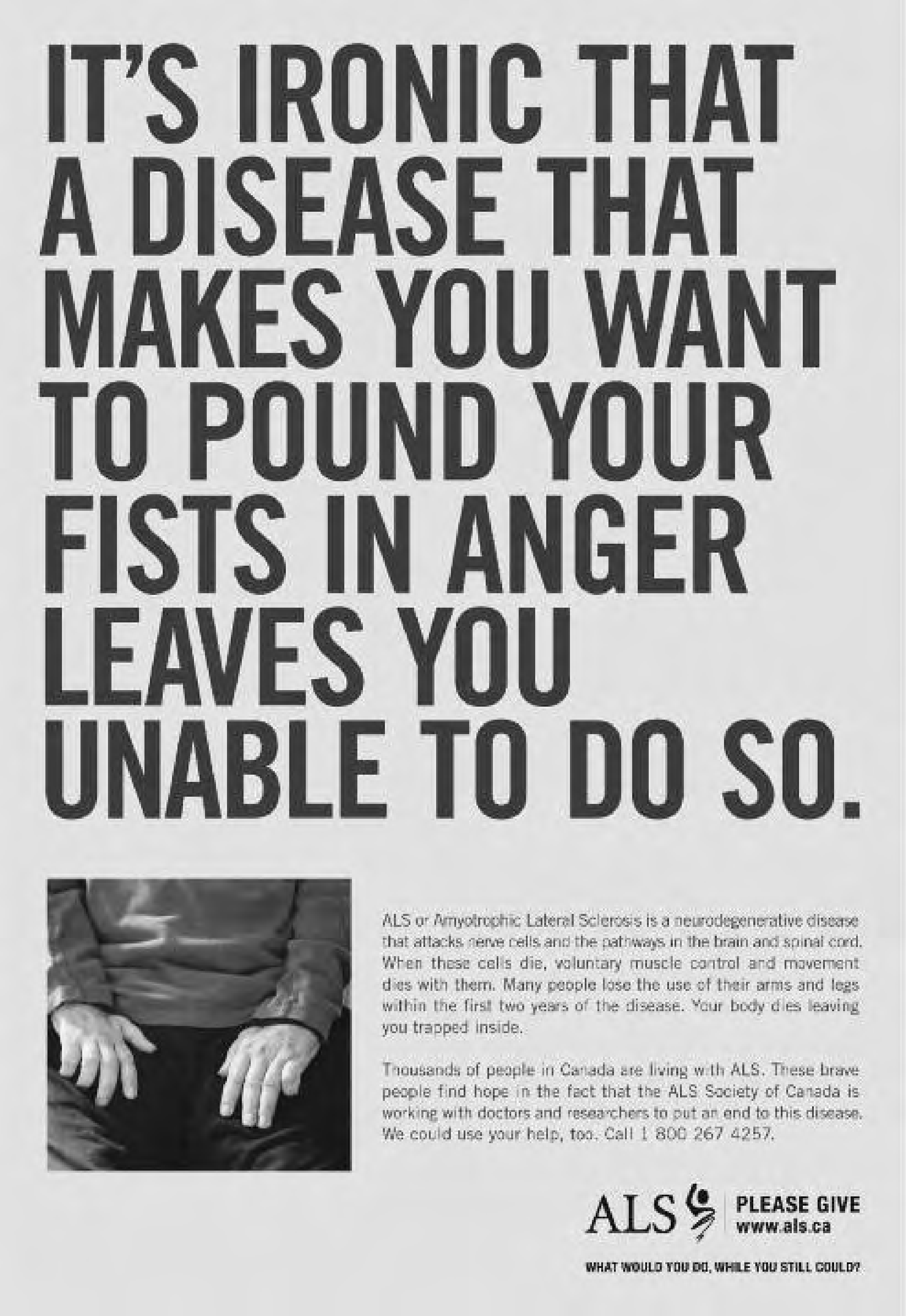
Gehrig returned to sports as a fullback at Columbia during the 1922 football season and then pitched and played first base for the Columbia baseball team in 1923. That year, he was signed to the New York Yankees and began the consecutive game streak of 2,130 that earned him the nickname “The Iron Horse.” That record stood until Cal Ripkin Jr. broke it in 1995. On June 3, 1932, Gehrig became the fist American Leaguer to hit four home runs in a game.

In 1938, Gehrig's game started to slip. He lacked his usual strength and was hitting poorly. At first he was diagnosed with a gall bladder condition, but it soon became clear that his problem was more serious than that. On May 2, 1939, he retired from baseball. He went to the Mayo Clinic for tests on June 13, and on June 19, on his 36th birthday, he was diagnosed with ALS. On July 4, 1939, the Yankees retired Gehrig's uniform number 4, making him the first player in history to be afforded that honour. He died two years later on June 4, 1941.

Lou Gehrig was known and loved by his fans for his quiet humility. At his farewell ceremony at Yankee Stadium there were more than 62,000 fans in attendance, and when he gave his emotional farewell speech they stood and applauded for more than two minutes. This was his speech.

> *Fans, for the past two weeks you have been reading about a bad break I got. Yet today, I consider myself the luckiest man on the face of the earth. I have been to ballparks for seventeen years and I have never received anything but kindness and encouragement from you fans. Look at these grand men. Which of you wouldn’t consider it the highlight of his career just to associate with them for even one day? Sure I’m lucky. Who wouldn’t have considered it an honor to have known Jacob Ruppert? Also, the builder of baseball’s greatest empire, Ed Barrow? To have spent six years with that wonderful little fellow, Miller Huggins? Then to*

*have spent the next nine years with that outstanding leader, that smart student of psychology, the best manager in baseball today, Joe McCarthy? Sure, I'm lucky. When the New York Giants, a team you would give your right arm to beat and vice versa, sends you a gift, that's something. When everybody down to the groundskeepers and those boys in the white coats remember you with trophies, that's something. When you have a father and mother who work all their lives so that you can have an education and build your body, it's a blessing. When you have a wife who has been a tower of strength and shown more courage than you dreamed existed, that's the finest I know. So I close by saying that I might have had a bad break, but I have an awful lot to live for. Thank you.*



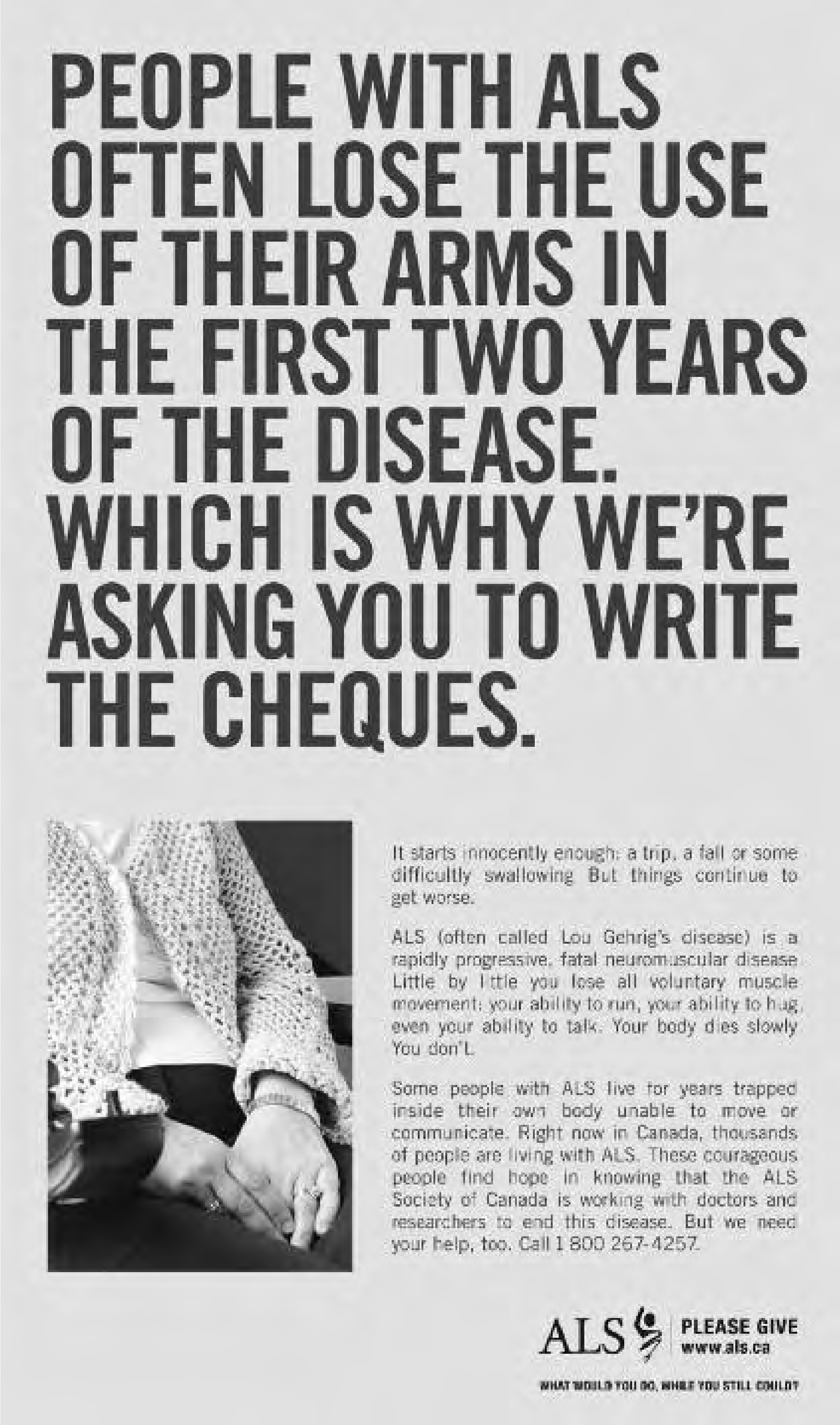
# IT'S IRONIC THAT A DISEASE THAT MAKES YOU WANT TO POUND YOUR FISTS IN ANGER LEAVES YOU UNABLE TO DO SO.

ALS or Amyotrophic Lateral Sclerosis is a neurodegenerative disease that attacks nerve cells and the pathways in the brain and spinal cord. When these cells die, voluntary muscle control and movement dies with them. Many people lose the use of their arms and legs within the first two years of the disease. Your body dies leaving you trapped inside.

Thousands of people in Canada are living with ALS. These brave people find hope in the fact that the ALS Society of Canada is working with doctors and researchers to put an end to this disease. We could use your help, too. Call 1 800 267 4257.

ALS | **PLEASE GIVE**
**www.als.ca**

**WHAT WOULD YOU DO, WHILE YOU STILL COULD?**



# PEOPLE WITH ALS OFTEN LOSE THE USE OF THEIR ARMS IN THE FIRST TWO YEARS OF THE DISEASE. WHICH IS WHY WE'RE ASKING YOU TO WRITE THE CHEQUES.

It starts innocently enough: a trip, a fall or some difficultly swallowing. But things continue to get worse.

ALS (often called Lou Gehrig's disease) is a rapidly progressive, fatal neuromuscular disease. Little by little you lose all voluntary muscle movement: your ability to run, your ability to hug, even your ability to talk. Your body dies slowly. You don't.

Some people with ALS live for years trapped inside their own body unable to move or communicate. Right now in Canada, thousands of people are living with ALS. These courageous people find hope in knowing that the ALS Society of Canada is working with doctors and researchers to end this disease. But we need your help, too. Call 1 800 267-4257.

ALS | **PLEASE GIVE**
**www.als.ca**

**WHAT WOULD YOU DO, WHILE YOU STILL COULD?**

ALS SLA
AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF CANADA
SOCIÉTÉ CANADIENNE DE LA SCLÉROSE LATÉRALE AMYOTROPHIQUE

# Canon Continues Commitment to WALK for ALS in 2006

Name of city — Get ready to walk through the streets in support of the local people living with ALS. Families, friends, volunteers and donors are getting geared up for the annual WALK for ALS. Returning sponsor Canon Canada is putting put their best foot forward raising funds for research and local support services.

“We are extremely excited to have Canon back as a national sponsor of the WALK for ALS,” says Joseph Mangoff, development co-ordinator for the ALS Society of Canada. “Canon has been with us since 2002 and their continued commitment is greatly appreciated. The WALK for ALS is an excellent opportunity for family and friends to rally around someone living with ALS and do something positive and healthy to help out.”

ALS, or amyotrophic lateral sclerosis, also known as Lou Gehrig's disease, stops messages from the brain reaching the muscles, leading to eventual paralysis despite the mind staying alert. This fatal neurological disease attacks the motor neurons making it difficult to walk, speak or gesture. The purposes of the walks are to raise money to support those living with this devastating disease as well as to raise awareness of the disease.

“In 2005, more than $1.7 million was raised in 63 communities nationwide, our goal is to beat that record at the 2006 WALK for ALS,” says Mangoff. “ALS can affect anyone, regardless of the age group, we need to come together as a community and help find a cure.”

The disease was named after New York Yankees first baseman Lou Gehrig, who played in a record 2,130 consecutive games before ALS forced a premature retirement in 1939. There are approximately 3,000 Canadians who currently live with ALS. Amongst them, two to three will die every day. ALS Society's new ad campaign asks: “What would you do, while you still could?” Created by BBDO Canada, this public service advertising campaign will help raise awareness about ALS and the ALS Society's efforts to support research towards a cure for the disease. More information about the WALK for ALS can be found on ALS’s web site at www.als.ca

**June is ALS Awareness Month in Canada.**

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*(You could modify this release for your local community)*

Media Contact:
Bobbi Greenberg, Director of Communications
416 497 2267 Ext. 208, bg@als.ca

ALS SLA
AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF CANADA
SOCIÉTÉ CANADIENNE DE LA SCLÉROSE LATÉRALE AMYOTROPHIQUE

# Hike The Trail To Help Us Prevail

Toronto — May 4, 2005: For the 3,000 Canadians who suffer from the debilitating effects of ALS, taking even small steps requires a big effort. The ALS Society of Canada has decided to match those efforts and are taking steps for those who cannot.

Hike 4 ALS is a new and innovative program inspired by those living with ALS around the globe. It was created to parallel their tenacity and hope towards finding a cure and is being executed nationally through the ALS Society of Canada. Hike 4 ALS targets outdoor enthusiasts of all fitness levels to participate in hikes that take place in local communities across Canada. The hikes are designed to offer something for hikers of all skill levels and people from all backgrounds are encouraged to participate in this unique and fun event. The objectives of Hike 4 ALS are to support ALS research and support services for those living with ALS and their families. Participants can register online to join the hike and are able to take advantage of some wonderful electronic fundraising tools.

Joseph Mangoff, Development Officer for the ALS Society of Canada, would like to see participation in this year's hike span coast to coast and wants everyone to feel included. "We want people to recruit their friends and family to join in the fight against ALS," Mangoff says. "Our goals are optimistic, we hope to raise $100,000 for ALS through this event. Volunteers are a crucial part of making an event such as Hike 4 ALS a success. The ALS Society would like to bring on partners to aid in supporting, promoting and fueling the fight to find a cure."

Mangoff states, "Part of the reason we are excited about the program is because we want to find new people to join the ALS team. The ALS community is relatively small and by creating a new event that people can relate to it gives us the opportunity to introduce new donors and volunteers to the ALS Society and engage them into further programming."

Local hikes are being held in several locations across Canada in 2005. If you would like to participate in Hike 4 ALS or for more information visit www.als.ca/events.

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Media Contact
Bobbi Greenberg, Director of Communications
416-497-5009 ext. 208
bg@als.ca

ALS SLA

# Video Resources

The ALS Society of Canada has produced two videos designed for health-care providers treating people facing a life-threatening illness.

The videos are intended to encourage discussion of issues important to an individual living with a life-threatening illness, their feelings, expectations and fears.

## *Making Hard Decisions: Insights for Health-Care Providers*

*Making Hard Decisions* is a 20-minutes video, with an accompanying study guide, designed for health-care professionals to assist those with life-threatening diseases to discuss the "hard decisions." The video shows Karen and Dr. Barry Smith, the former Dean of Medicine, Queen's University, then living with ALS in conversation with broadcast journalist Judy Maddren. The Smiths discuss in a frank and intimate way their feelings, expectations and fears in the context of a life-threatening illness. Dr. Smith shares some valuable advice for all providers caring for dying people and their families.

The video is also intended to enable health-care providers to facilitate the difficult decisions that will arise about their patients' future health-care needs.

Some questions that the study guide highlights to stimulate discussion include:

- What do you find particularly difficult when caring for a dying patient?
- What do you think would help you to improve the care you provide to dying patients and their families?
- How do you deal with your own feelings of sadness, grief, anger, etc.
- How can you avoid conflict or deal with conflict regarding treatments at the end of life?

## *Making Hard Decisions: The Essence of Being Human*

This 30-minute video is designed to be viewed by people diagnosed with a life-threatening illness, their families and caregivers. It is intended to encourage discussion of issues important to an individual living with a life-threatening illness, their feelings, expectations and fears. It is also intended to enable them to face the difficult decisions that will arise about their future health-care needs.

Dr. Smith shares his thoughts, hopes, fears and anxieties when confronted with the diagnosis of ALS. The video and its accompanying discussion guide are designed to facilitate discussions between people diagnosed with a life-threatening illness and their families, the sometime difficult discussions of their own values, hopes, fear and feelings about life sustaining interventions.

Some questions that the study guide highlights to stimulate discussion include:

- How do you discuss your feelings, your fears with others?
- What are your feelings about being diagnosed with your illness?
- In view of your illness, what decisions do you think you will need to face? Which decisions will be hardest for you?
- How did you share your diagnosis with your family?
- What would give you joy and happiness in the time you have left?
- How do you manage? What helps you get through the day?

Another excellent video is Elizabeth's Hope.

***Elizabeth's Hope*** (VHS Format)

*Elizabeth's Hope* is the inspiring story of one woman's personal and public crusade against ALS. The one-hour documentary captures the passion of Elizabeth Grandbois, a person living with ALS and the organizer of a yearly benefit concert to raise funds and awareness about this disease. She was diagnosed with ALS in 1997 and has vowed to spend the rest of her life helping to accelerate the search for a cure and to improve the quality of life for others who suffer from the disease. Grandbois and her committee of volunteers have raised more than 1.6 million dollars.

Both videos are available free of charge from LM Media Marketing Services Ltd. 1-800-268-2380, lmmedia@rogers.com

ALS SLA

# Public Relations Resources

The Multiple Sclerosis International Federation has a number of excellent resources in their "How to" Series. You can download their booklets from their web site. *How to Work with the Media* and *How to Influence Public Policy* at www.msif.org/en/publications/how_to_series/index.html. These publications are only available in English.

The Health Communication Unit at The Centre for Health Promotion, University of Toronto, has published a good resource publication entitled *Media Advocacy Workbook*, which can be downloaded from their web site at www.thcu.ca/infoandresources/media_advocacy.htm. It is only available in English.

Impacs has a number of good resource publications available in English and French. *Developing Effective Media Communication Skills,* (in French, *Communications efficacies avec les medias).* Other good resource publications include: *Plan the Work: A Handbook for Strategic Communications Planning for Not-for-Profit Organizations* (available in English only), *Developing a Strategic Communications Plan* (in French, *Planification des communications), IMPACs Media Toolkit*, (in French, *Boîte à outils – communication avec les médias outils – communication avec les medias*). These documents are available at www.impacs.org/communications/PubResources/

**Media Release about MND Week**

This is a good release which you may want to modify for ALS Month:

Motor Neurone Disease Week 2nd April to 8th April 2006

VICTORIA — National Motor Neurone Disease Week aims to raise awareness of MND and foster support for working towards a world without MND.

Each year in Australia more than one person will be diagnosed with MND every day, while another will die. Yet most Australians know little about MND and its devastating effects.

Motor Neurone Disease (known as ALS in many other parts of the world, and as Lou Gehrig's disease in the USA), is the name given to a group of diseases in which damage to motor neurones occurs. These nerve cells control the movement of voluntary muscles, including the muscles of the trunk, limbs, speech, swallowing and breathing.

With no nerves to activate them, muscles gradually weaken and waste, and paralysis occurs. Weakness is often seen first in the hands or feet, or the first sign may be swallowing difficulty or slurred speech. In the majority of cases the senses, intellect and memory are not affected. MND has often been described as “deadly, creeping paralysis.” Average survival time after diagnosis of MND is two to three years or less, with a few people surviving five or more years.

In Australia approximately 1,300 people are living with MND. “MND can strike anyone at any time,” says Chief Executive Officer of the Motor Neurone Disease Association of Victoria, Rodney Harris. “It strikes people down, robbing them of their independence, communication and their ability to influence their surroundings. There’s no cure, but we offer hope through care and support for people living with MND and their families through the services of the MND Association, and research to find causes, treatments and a cure for this rotten disease.”

During MND Awareness Week, and especially on Blue Cornflower Day (Friday 7 April) blue cornflowers — a symbol of hope — can be purchased from a variety of outlets around Victoria, with all proceeds going to help MNDA continue its essential work with the community.

People living with MND and their carers are available for interviews to tell their story of the impact of Motor Neurone Disease on their lives.

ALS SLA

# Employment Programs in PR and Communications Across Canada

The ALS Society of Canada and its provincial partners operate on a slim budget, and when the work piles up, there is not necessarily enough money in the coffers to hire a full-time employee with benefits, or even a temporary helper. University and college employment programs can be lifesavers in this situation. The students from these programs are sometimes paid a salary for their efforts, but that salary runs to the low end, and more often than not, students expect to be paid a discretionary honorarium, a stipend, or nothing at all. As a bonus, these students are usually keen, energetic, and willing to put in long hours.

The work component of a student's education is usually one of three types—field placement, co-operative education (co-op), or internship.

- **Field placement programs** are a mandatory educational component in some courses, where the student must work a minimum number of hours in a field related to their studies. These positions are unpaid, but students are sometimes reimbursed for expenses.
- **Co-op programs** combine school and work experience. Students work full time for one to three semesters, depending on the program. The student, the employer, and the school cooperate to ensure that the student's academic requirements and the employer's needs are met. Co-op students are paid for their work.
- **Internship programs** offer work options during or following an academic program. Interns work anywhere from three to 12 months, depending on the program. Internships may be paid or unpaid and are not necessarily related to the student's academic field. Interns usually work with an on-the-job mentor.

For more information on employment programs in Canada, go to the Service Canada web site at www.youth.gc.ca/yoaux.jsp?&lang=en&flash=0&ta=5&auxpageid=787.

Below is a sample of some of the college and university employment programs in Public Relations, Communication, and Technical Writing available across Canada.

## Algonquin College

Ottawa, ON

*Program:*
Two-year diploma program in public relations, with field placement.
One-year post-graduate program in technical writing, with field placement.

*Work Term:*
PR program: Two seven-week field placements, one in January/February, one in March/April.
Technical writing program: Eight-week field placement in May and June.

*Range of Pay:*
Students are not paid.

*Process:*
Employer submits job description to the program co-ordinator, who reviews it and offers student referrals.

*Contact:*
Jim Catton, Technical Writing Program Co-ordinator
(613) 727-4723 ext. 3327
cattonj@algonquincollege.com

Peter Larock, Public Relations Co-ordinator
larockp@algonquincollege.com.

*Web site:* www.algonquincollege.com/highband/swf/index.htm

## University of Calgary

Calgary, AB

*Program:*
BA in Communications Studies.

*Length of Work Term:*
Four work terms of 12—16 weeks each. Work terms may be done consecutively.

*Range of Pay:*
To be determined by the employer within their organization's wage structure.

*Posting Deadline:*
Work terms begin in January, May, and September, and students begin looking for placements in the third week of September, the third week of January, and the third week of May.

Process:
Employers post job descriptions and students post resumés on the intranet; the co-op director arranges interviews.

*Contact:*
Geoff Cragg, Director, Co-op/Internship Program
(403) 220-4843
cragg@ucalgary.ca

*Web site:* www.ucalgary.ca

## Centennial College

Scarborough, ON

*Program:*
One-year post-graduate program in corporate communications and public relations, including internship.

*Length of Co-op Term:*
Eight week internship, end of term.

*Range of Pay:*
Pay is at the discretion of the employer; typically an honorarium ranging between $600 and $2000 for the eight-week period.

*Posting Deadline:*
April-May placement: late February.
August-September placement: late May.

*Process:*
The employer posts a job description; a co-op co-ordinator arranges interviews and works with students and employers to find a match.

*Contact:*
Jessie-May Rowntree
(416) 289-5000, Ext. 8820
jrowntree@centennialcollege.ca

*Web Site:* www.thecentre.centennialcollege.ca/index.html

## Durham College

Oshawa, ON

*Program:*
Ontario College Advanced Diploma in Public Relations; three-year program (five semesters).

*Work Term:*
During the fourth semester, students work one day per week at a non-profit agency implementing a communications plan. At the conclusion of the final year, students take part in an off-site 14-week corporate field placement.

*Range of Pay:*
The one-day-a-week non-profit work is unpaid.
Payment for the 14-week field placement is at the discretion of the employer; typically around $9.00 per hour.

*Process:*
Employer posts job description with the field placement coordinator, who serves as a go-between for students and employers, handling job postings and student resumés, arranging interviews, and matching employers with students.

*Contact:*
Lynn Gough, Field Placement Coordinator
lynn.gough@durhamcollege.ca

*Web Site:* www.durhamc.on.ca

## Grant MacEwan College

Edmonton, AB

*Program:*
Ten-month diploma program in public relations, field placement.

*Length of Work Term:*
Eight week field placement at end of term.

*Range of Pay:*
Payment is at the discretion of the employer.

*Posting Deadline:*
Contact college for information.

*Contact:*
Frank Saccucci
(780) 497-5618

*Web Site:* www.gmcc.ab.ca/web/home/index.cfm

## Humber College

Toronto, ON

*Program:*
Three-year advanced diploma program, including field placement.
One-year post-graduate certificate program, including field placement.

*Length of Work Term:*
Diploma program: 16 week field placement.
Certificate program: Eight-week field placement.

*Range of Pay:*
At the discretion of the employer; usually an honorarium or competitive salary.

*Posting Deadline:*
November to December for the16 week internship.
April and August for the eight week internship.

*Process:*
The employer submits a job description to the program coordinator, who arranges interview with students.

*Contact:*
Ed Wright, Program Co-ordinator
(416) 675.6622 Ext. 3012
ed.wright@humber.ca

*Web site:* www.humber.ca/

## Kwantlen University College

Richmond, BC

*Program:*
Two-year diploma program in public relations, including internship.

*Length of Co-op Term:*
Four week end-of-term internship in March and April.

*Range of Pay:*
Payment is not required, but expenses are usually paid by the employer and an honorarium is often given.

*Posting Deadline:*
No deadline, but earlier a job is posted, the more students an employer will have to choose from.

*Process:*
The employer provides information on position by e-mail, which is then distributed to the class. Students apply directly to the company, the employer conducts interviews and chooses the student who best fits the company's needs. The work done by the student must be 80 per cent public relations work, and only 20 per cent administrative in order to meet the requirements of the program.

Contact:
Terri Smolar, Coordinator, Public Relations Diploma Program
604-599-2625
terri.smolar@kwantlen.ca

Web site: www.kwantlen.ca/

## Lethbridge Community College

Lethbridge, AB

*Program:*
Two-year diploma program in Communication Arts, specializing in public relations, including practicum.

*Length of Co-op Term:*
Three-week practicum to be completed some time before the end of the student's second year.

*Range of Pay:*
Payment is at the discretion of the employer.

*Posting Deadline:*
There is no specific deadline. Students usually choose to take a placement in the summer months, either between first and second year or after their second year, and are available from April to August.

*Process:*
Employers send job descriptions to the practicum co-ordinator who will post the jobs for students. Students submit resumés directly to the employer.

*Contact:*
1 800 572-0103 ext.3298
Fax: 403 394-7370
theworks@lethbridgecollege.ab.ca

*Web site:* www.lethbridgecollege.ab.ca

## Mount Royal College

Edmonton, AB

*Program:*
Four-year baccalaureate applied degree in public relations.
Four-year baccalaureate applied degree in technical communication.

*Length of Work Term:*
16-week work term.

*Range of Pay:*
$10.00-$12.00 per hour, no benefits.

*Posting Deadline:*
Varies by semester.

*Process:*
The Career Services Department serves as go-between for students and employers, handling job postings and student resumés, arranging interviews, and matching employers with students.

Contact:
Career Services
(403) 440-6307
Fax: (403)440-6655
studentjobs@mtroyal.ca

*Web site:* www.mtroyal.ab.ca/

## Mount Saint Vincent University

Halifax, NS

*Program:*
Four-year baccalaureate degree program in public relations, including three co-op terms.

*Length of Work Term:*
Four months co-op session for three terms.

*Range of Pay:*
First term—$200-$400/week
Second Term—$300-$525/week
Third term—$$340-$545/week

*Posting Deadline:*
Deadlines vary due to multiple work terms.

***Process:***
A co-op coordinator serves as go-between for students and employers, handling job postings and student resumés, arranging interviews, and matching employers with students.

Contact:
Marilyn Power, Co-operative Education
(902) 457-6493
Fax: (902) 457-1514
co-op@msvu.ca

*Web site:* www.msvu.ca

## Nova Scotia Community College

Halifax, NS

*Program:*
One-year advanced diploma course in public relations, including internship.

*Length of Work Term:*
Six week internship, end of term.

*Range of Pay:*
Pay is at the discretion of the employer; typically an honorarium or competitive salary.

*Posting Deadline:*
Job postings are accepted from February until the internship term begins in May, but employers are encouraged to post early.

*Process:*
The employer posts a job description with the Public Relations Department. Students submit resumés directly to the employer.

*Contact:*
Amy Thurhlow, Department: Public Relations
(902) 491-4689
Amy.Thurlow@nscc.ca

*Web Site:* www.nscc.ca

## Royal Roads University

Victoria, BC

*Program:*
Royal Roads University offers Canada's only MBA in public relations and communications management. MBA students complete an organizational consulting project (OCP) consisting of 360 hours of work where they apply theoretical knowledge to real-world situations.

*Work Term:*
360 hours.

*Range of Pay:*
The consulting job is done on a pro bono basis, although the client may be expected to cover expenses; in some cases, the client may pay a stipend.

*Process:*
Students arrange their own OCPs, but the school can be contacted by employers who have a high-level strategic communications project available.

*Contact:*
Mike Thompson
mike.thompson@RoyalRoads.ca

Web site: www.royalroads.ca

## Seneca College

Toronto, ON

*Program:*
One-year Ontario College Graduate Certificate in Corporate Communications, including co-op term.
One-year Ontario College Graduate Certificate in Technical Communication, including co-op term.

*Work Term:*
Corporate Communications: 12-week final semester co-op session.
Technical Communication: 12-week mid semester co-op session.

*Range of Pay:*
Typically between $13.00 and $17.00 per hour; sometimes an honorarium.

*Process:*
The employer posts a job description and students post resumés on a secure online posting system. The co-op coordinator serves as a go-between for students and employers, handling job postings, arranging interviews, and matching employers with students.

*Contact:*
Yvonne Gilbert
(416) 491-5050 Ext. 3764
Yvonne.Gilbert@senecac.on.ca

Web site: www.senecac.on.ca/cms/

## Simon Fraser University

Burnaby, BC

*Program:*
Communication Co-op is designed for students with 45 credit hours completed in Communication Studies.

*Length of Co-op Term:*
Varies; average 15-16 weeks. Students have the option of staying on with an employer for a second term.

*Range of Pay:*
$1500-$3000 per month.

*Posting Deadline:*
Posting begins in January and there is continuing placement through to May.

*Process:*
Employer e-mails a job description and the co-op coordinator posts it on the Intranet site. Jobs are open to students from all programs at SFU, so the employer will likely receive a broad range of packages which will include resumes from business and arts students, as well as from communications students.

*Contact:*
Marcia Shimizu, Co-op Coordinator
604.291.3862
mshimizu@sfu.ca

Erika Wah, Co-op Coordinator
604.291.5542
ewah@sfu.ca

*Web site:* www.sfu.ca

## Links

Here are some helpful links from Service Canada web site:

- Human Resources Management
  hrmanagement.gc.ca/gol/hrmanagement/site.nsf/en/index.html
  This is a part of the Service Canada web site and provides links to wage assistance and subsidy programs for employers
- Youth Employment Strategy
  www.youth.gc.ca/yoaux.jsp?&lang=en&flash=0&ta=5&auxpageid=659
  This is also a Service Canada site, and it offers financial assistance through the Skills Link, Career Focus, or Summer Work Placement programs.
- Co-operative Education Directory
  http://www.cafce.ca/pages/home.php
  This site lists information on co-op programs in Canada
- CampusWorklink
  http://campus.workopolis.com/index.html
  This Workopolis.com site provides employers with access to a database of résumés and the option to post jobs
- CareerEdge
  http://overview.careeredge.ca/index.asp?FirstTime=True&context=0&FromContext=1&language=1
  This site helps to connect students and employers for internships
- AbilityEdge
  http://www.abilityedge.ca/index.asp?language=1
  This site offers the same internship services as CareerEdge, but for students with disabilities
- Association of Canadian Community Colleges
  http://www.accc.ca/english/colleges/programs_database.htm
  This site provides a directory of community colleges in Canada
- Association of Universities and Colleges in Canada
  http://oraweb.aucc.ca/showdcu.html
  This site provides a list of Canadian universities and the programs offered