



ALS SLA

ALS Society of Canada

MILESTONES

FUNDING RESEARCH | SUPPORTING CARE | SPREADING AWARENESS



*With your help
together we will
end ALS!*

Amyotrophic lateral sclerosis (also known as Lou Gehrig's disease) is a fatal neurodegenerative disease. People living with the disease become progressively paralyzed due to degeneration of the upper and lower motor neurons in the brain and spinal cord. Eighty per cent of people with ALS die within two to five years of diagnosis – unable to breathe or swallow. Ten per cent of those affected may live for 10 years or longer.

According to the World Health Organization, neurodegenerative diseases are predicted to surpass cancer as the second leading cause of death in Canada by 2040.

ALS has no known cure or effective treatment yet. For every person diagnosed with ALS, a person living with ALS dies. Approximately 2,500 - 3,000 Canadians currently live with this fatal disease.

The ALS Society of Canada is committed to funding research towards a cure for ALS and supporting the provincial ALS societies in their provision of quality care for people living with ALS and their families.

ALS Canada identifies and initiates excellent, peer-reviewed ALS research, conducted by some of the most renowned scientists in the world, working in Canada. Recent developments have been encouraging. Please visit our web site, www.als.ca, for reports on the work being done by ALS Canada funded researchers. Canadians can become involved in our important cause by holding events to raise funds for ALS research and programs. Using proceeds from these initiatives, our research funding commitments will total \$1.7 million in 2011.

1977 | ALS Society of Canada is incorporated as non-profit charitable organization in response to a request by Pat and Noel Rutland. It is the only national voluntary health organization dedicated solely to the fight against ALS and support for those with ALS.

1981 | British Columbia Society is registered as a charity.

1982 | Saskatchewan Society is registered as a charity.

ALS Societies of Alberta, British Columbia, Manitoba, Nova Scotia and Saskatchewan become affiliated with ALS Canada.

1983 | Quebec Society is registered as a charity and becomes affiliated with ALS Canada.

1984 | An agreement is negotiated with the Muscular Dystrophy Association of Canada to provide equipment not covered by provincial health care plans or insurance.

ALS Societies of New Brunswick and Prince Edward Island become affiliated with ALS Canada.

1985 | Ontario Society becomes affiliated with ALS Canada.

1986 | New Brunswick Society is registered as a charity.

1988 | Revenue exceeds half a million dollars.

Research grant funding reaches \$225,000.

National Society adopts the mission statement "To eradicate ALS."

Ontario and Alberta Societies are registered as charities.

1989 | Fundraising strategy is developed to guide the future.

"Buried Alive" public awareness campaign begins.

1990 | Health Canada declares June "ALS Awareness Month."

First Lou Gehrig Week is held in Toronto.

Governor General accepts Vice Regal Patronage with the ALS Canada.

Six education modules for the care and management of ALS are developed and distributed.

1991 | National Support Manual is developed.

ALS Canada sponsors the third IBRO World Congress of Neuroscience Satellite Symposium on "Phenotypic Disorders in Neurodegenerative Disease."

Research Policy and Patient Services Committees are developed.

Direct mail is introduced as a major fundraising initiative.

1992 | Sue Rodriguez, who has ALS, makes assisted suicide a national issue.

International Alliance of ALS Associations is formed to stimulate research and improve the exchange of information. ALS Canada is a founding member.

Overall revenue increases by 10.5 per cent.

1993 | Doctors Denise Figlewicz and Guy Rouleau are two of the prominent investigators from an international team responsible for the discovery of SOD1, the first gene responsible for causing a familial form of ALS. This breakthrough discovery paves the way toward the creation of laboratory models to study the pathogenesis of ALS and to the development of treatment for the hereditary form of ALS.

1994 | The first "risk" gene for sporadic forms of ALS is identified by doctors Denise Figlewicz, Guy Rouleau and Jean-Pierre Julien.

Harrod & Mirlin win the Certificate of Merit Marketing Award for an ALS Canada ad.

1995 | ALS Canada establishes a task force to keep the three principles of cause, cure and care as the central focus.

New symbolic identity developed to explain ALS: physical degeneration and mental alertness. The logo is created to serve as a platform from which to educate the public about ALS and reinforce the need for donor support. The logo depicts a figure with a wasted body and strong mind. The purple image was designed to be proprietary, timeless, universally appealing, easily recognizable and memorable, and complement the ALS mission statement.

1996 | Launch of ALS Canada's web site.

1997 | Nova Scotia Society is registered as a charity.

1998 | First edition of *Coast to Coast* newsletter is published.

Dr. Jean-Pierre Julien and his team succeed in slowing the progress of the familial form of ALS in mouse models.

1999 | New partnership agreement is introduced to link regional, provincial and national societies. The role of provincial units is to deliver support services and programs to people affected by ALS and support ALS Canada through research fundraising. ALS Canada funds ALS research in Canada and supports the provincial ALS

societies.

ALS Canada partners with the Muscular Dystrophy Association of Canada to form the Neuromuscular Research Partnership (NRP) to jointly fund neuromuscular research. The partnership is supported by the Canadian Institutes of Health Research.

Benchmarks of Excellence launches. The voluntary health sector development project offers a process for strengthening strategic planning, building team leadership, operational planning and individual leadership skills. It is co-sponsored by Health Canada and is widely praised.

Canadian Congress of Neurological Sciences makes ALS symposium an annual event.

ALS Canada becomes a charter member of the new Health Charities Council of Canada.

Vancouver hosts the tenth International Symposium on ALS/MND, making front page news in the Vancouver Sun. Manitoba Society is registered as a charity.

2000 | NRP holds its first research competition, awarding grants worth \$1,173,030.

ALS Canada visits Parliament Hill to meet with cabinet ministers, senators, members of Parliament and public servants whose work is connected to our mission.

First Annual Tim E. Noël Charity Golf Classic raises more than \$500,000. The Tim E. Noël Endowment Fund is established.

ALS Canada increases revenue by 26.7 per cent over 1999.

Ninety-nine Cineplex Odeon Theatres nationwide show 30-second public service announcements about ALS.

ALS Canada publishes the first edition of the *Manual for People Living with ALS*.

2001 | First Elizabeth's Concert of Hope in Hamilton, ON raises approximately \$290,000.

National Walk program is introduced.

Mike Halls of London, ON, donates \$5 million to ALS research. The donation funds ALS research conducted at the Roberts Research Institute and the Lawson Health Research Institute, creating the Mike Halls Centre for ALS Research and funding the Centre's infrastructure and equipment. A portion of the funds also establishes the endowment for the Arthur J. Hudson Chair in ALS Research. Dr. Michael Strong is named chair.

2002 | More than \$3 million in research is funded through the NRP.

WALK for ALS triples 2001 results and breaks the \$1 million mark.

Actress Wendy Crewson receives the Gemini Humanitarian of the Year Award for her work on behalf of the ALS Society.

ALS March of Faces launches as an awareness tool for local ALS Society activities.

ALS Canada hosts the first Symposium on Achieving Excellence in Awareness, Leadership, Service and Care in Toronto.

2003 | WALK for ALS raises approximately \$1.7 million across Canada.

Research grant commitments reach \$1.6 million for the first time.

Victoria, BC canvassers establish a new record for Flower Days, collecting more than \$29,500 in six hours.

ALS volunteers Kate Hall and Brett Yerex are awarded Queen's Jubilee Medals for their work with the organization.

First edition of the *Northern Neuron* is published.

Second edition of the *Manual for People Living with ALS* is published.

2004 | Elizabeth's Concert of Hope passes the \$1 million mark in total funds since its inception.

Elizabeth Grandbois is awarded the Governor General's Meritorious Service Award for her work with the ALS Society.

Team of 15 Investors Group representatives from across Canada raise \$1 million for ALS by climbing Mt. Kilimanjaro.

ALS Canada approves the vision statement, "To find a cure for ALS."

ALS Canada holds its first research forum to review and recommend priorities and direction for the research program.

ALS Canada partners with the Canadian Institutes of Health Research (CIHR) to create two doctoral student research grants worth \$21,000 per year for up to three years.

ALS Canada partners with the ALS Association in the United States to jointly fund research projects.

Director of services and education position is created.

Launched public service advertising campaign, "What would you do, while you still could?" to raise awareness about ALS and efforts to support research for a cure. The two 30-second ads, "Running" and "Hugging," are created by BBDO Toronto on a pro bono basis. The ads air nationally in Famous Players Cinemas and on CBC, CTV, The Weather Network, The Food Channel, Much Music, The Score and ichannel. Print ads run in The National Post, the Montreal Gazette, La Presse and the Vancouver Province. Strategy, Marketing Magazine and PR Canada News cover the campaign.

Second ALS Symposium on Achieving Excellence in Awareness, Leadership, Service and Care is held in conjunction with the annual meeting of the Canadian Congress of Neurological Science in Calgary.

ALS Society holds the First Annual ALS Client Services Conference.

2005 | A third, expanded edition of the *Manual for People Living with ALS* is published in English and French.

ALS Canada initiates the Service and Education Enhancement and Development (SEED) Grant program to assist provincial ALS societies with outreach and service delivery. The funding for 2005 is \$65,000. Five grants are awarded.

First Hike 4 ALS raises more than \$45,000 across Canada.

ALS volunteers attend Hill Day to meet with members of Parliament, senators and staff to discuss key messages, including the stability of the NRP. CIHR agrees to extend

funding until March 2006 and beyond.

The first International Research Workshop on Frontotemporal Dementia in ALS is held in London, ON, sponsored in part by ALS Canada.

BBDO wins several awards for the "What would you do, while you still could?" campaign:

- The Bronze Lion at the Cannes International Advertising Festival
- The Silver Award at the 2005 Canadian Marketing Awards
- The Bronze Award at Strategy Magazine's 2005 Agency of the Year Awards
- Finalist recognition at the 2005 Bessies

ALS Society hosts the Second Annual Client Services Conference.

ALS Canada introduces an electronic guide, *A Guide to ALS Care for the Primary Care Physician*. The guide is available in English and French.

2006 | Dr. Denise Figlewicz is appointed as the first director of research for ALS Canada.

ALS Canada joins the University of Toronto to co-fund a new initiatives program.

ALS secures the rights for the U2 song "Walk On."

ALS Canada hosts the Second Annual Canada Research Forum in Toronto.

Elizabeth Grandbois is awarded the Ontario Medal for Good Citizenship.

Canadian Idol judge Zack Werner becomes the national chair and spokesperson for the WALK for ALS.

WALK for ALS raises approximately \$2 million nationwide, bringing the overall amount raised to \$8.7 million.

ALS Canada launches *ab411*, a web site-based information and support program for young children and teens who are directly affected by ALS. The site is available in English and French.

First Tim E. Noël Fellowship in ALS Research is awarded.

Betty's Run for ALS marks its tenth anniversary, raising \$2.4 million for ALS awareness, patient services, equipment and research.

ALS Canada wins the Silver Mercury Award for the publication *Research News*.

ALS Canada surpasses \$1 million in research funding.

ALS Society hosts the Third Annual Client Services Conference. The conference is changed from one to two days because of increased interest.

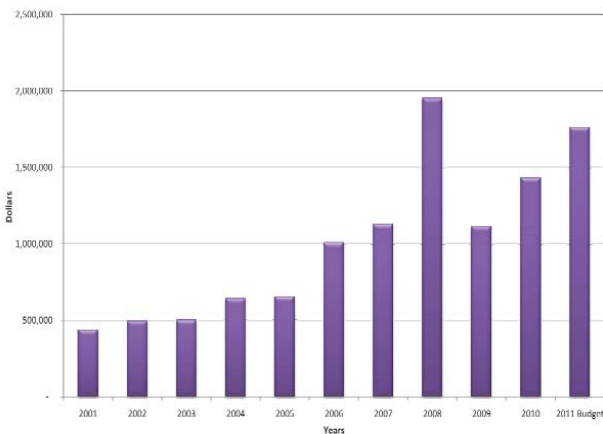
Newfoundland and Labrador Society is registered as a charity.

2007 | *The Globe and Mail* supplement about ALS is produced, bringing awareness to *The Globe's* 1.3 million readers nationwide.

Elizabeth Grandbois is inducted into the Terry Fox Hall of Fame for her contributions to fundraising and increasing awareness of ALS.

The Second International Frontotemporal Dementia in ALS Research Conference is held in London, ON, sponsored in

ALS Canada - Annual Research Spending



part by ALS Canada.

ALS Canada hosts the Third Annual Canada Research Forum in Toronto.

ALS Canada hosts the 15th Annual Meeting of the International Alliance of ALS/MND Associations and 18th International Symposium on ALS/MND in Toronto.

ALS Society-funded researchers Avi Chakrabarty and Janice Robertson co-author a landmark publication in *Nature Medicine* which may improve understanding of the pathogenesis of familial and sporadic ALS and allow for earlier diagnosis.

ALS Society hosts the Fourth Annual Client Services Conference in Edmonton.

ALS Canada's 2005 Annual Report wins a Golden Hermes Creative Award, an international competition for creative professionals involved in the concept, writing and design of marketing and communication programs and print, visual and audio materials.

2008 | The Eighth Neuromuscular Research Partnership is awarded, funding grants to 11 Canadian research studies regarding ALS and neuromuscular diseases. The grants are awarded as a part of a partnership with CIHR.

ALS Canada's Board of Directors approve \$900,000 for a joint US-Canadian lithium clinical study beginning in November – the largest research funding commitment ever made by the board.

The first Bernice Ramsay Discovery Grants, valued at \$200,000 in total, are awarded to Avi Chakrabarty, PhD, of the University of Toronto and Alex Parker, PhD, of Université de Montréal for pursuing new, promising directions in ALS research.

ALS Canada receives the prestigious 2008 Partnership Award of the Year from the Institute of Neurosciences, Mental Health, and Addiction (INMHA). The award recognizes the Society's contributions to the Neuromuscular Research Partnership and support for the INMHA's mandate.

More than 60 communities across Canada participate in the 2008 WALK for ALS and raise more than \$2 million in total. This year's Walk also launches its new fundraising web site, www.walkforals.ca.

Elizabeth Grandbois receives the 2008 Thérèse Casgrain Volunteer Award in recognition for her outstanding contributions to the ALS community. She has raised more than \$2.5 million for ALS research and support services to date. She is chosen from a selection of more than 970 entries from 23 countries.

Two *als411* publications, *When Your Parent Has ALS: A Booklet for Teens and When Someone Special Has ALS: A Booklet for Children*, win the silver and bronze 2007/08 Mercury Awards.

A three-part series about ALS and ALS Canada is

published in May in *The Globe and Mail* on May 14, 21 and 28.

2009 | Thanks to the generous donors of ALS Canada, the research budget reaches the largest amount in the Society's history – \$2,033,000 (an increase of \$380,000).

In June the Government of Canada commits \$15 million to the Neurological Health Charities Canada (NHCC) to fund research into neurological conditions – the first of its kind in Canada. ALS Canada is one of the founding members of the NHCC.

ALS Canada supports the formation of the Canadian ALS Research Network (CALS) a strong clinical trial network. The clinics are able to enrol patients within one year of the first CALS meeting. CALS proves its efficiency by quickly determining the ineffectiveness of lithium as a treatment for ALS.

Another successful Hill Day occurs as ALS Canada advocacy committee members, researchers, volunteers and staff meet with numerous MPs, bureaucrats and the Prime Minister Stephen Harper.

ALS Canada hosts the opening night of Tuesdays with Morrie at the Winter Garden Theatre in Toronto, ON.

ALS Canada's advertisement campaign, "Head and Shoulders" is produced to raise awareness for ALS – created pro-bono by advertising firm, LOWE ROCHE. It receives positive acclaim and wins the 2009 Applied Arts Design & Advertising Award for the best single television commercial over 30 seconds.

Toronto-based artist, Elizabeth Berry, creates four new paintings of cornflowers in full bloom and donates them to ALS Canada. The paintings are used as cards to raise awareness for ALS.

To attract a new generation of ALS researchers to the field of ALS, ALS Canada in partnership with CIHR, offers a new fellowship providing three years of funding at \$55,000 per year – the Ronald Peter Griggs Memorial Fellowship. The fellowship will be awarded to an individual scientist in 2010, 2013 and 2016.

The first Georgetown-Acton WALK for ALS raises a record \$230,000. With more than 1,500 participants it becomes the most successful WALK for ALS to date. The success is largely attributed to Jeff Sutherland, MD, a respected doctor in the community diagnosed with ALS in 2007.

The first Whitehorse WALK for ALS is held in September, on the scenic Millennium Trail along the Yukon River. ALS Canada moves to our new location on Steeles Avenue in Markham, ON.

This new space provides us with ample room to grow and expand our activities.

2010 | On October 15, the Honourable

Jean-Pierre Blackburn, Minister of Veterans Affairs Canada, announces that veterans living with ALS will now be eligible for increased benefits. After a series of advocacy efforts, veterans are now eligible for benefits, treatments, and home-care support; such as eligibility for adapted wheelchairs, medical resources and housekeeping services.

The WALK for ALS continues to bring together thousands of people to raise awareness and funds for ALS. Reaching its highest achievements yet, 78 communities participate in the Walks raising more than \$2.6 million.

The Canadian Newspaper Association, in conjunction with the Canadian Community Newspapers Association announces the winners of the Extra Awards for 2010. ALS Canada wins both a silver and bronze award for their awards entitled "Helping" and "Shaving." Both pieces were created as part of a "No Signal" advertisement series by LOWE ROCHE – ALS Canada's pro-bono advertising agency.

ALS Canada holds its first Youth Engagement Retreat in September at the Hockley Valley Resort, in Orangeville, ON, from September 24-26. The event brought together youths aged 15-24 from across the country who have been directly affected by ALS to promote peer support and positive coping skills.

ALS Canada publishes two new *als411* booklets, to help children and youth deal more easily with having ALS within their families. Talking with Young People About ALS is intended to be used in schools to give educational professionals a better understanding of ALS and how it affects youth. Talking to Your Patient's Children About ALS is designed for health-care professionals to help young children understand the diagnosis and management of their loved-one's illness.

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For more information please visit www.als.ca or call our fund development team at 1-800-267-4257

ALS SOCIETY OF CANADA

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www.als.ca | www.als411.ca
www.walkforals.ca | www.golfforals.ca

Most people with ALS lose the use of their legs in the first two years of the disease.

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