Amyotrophic Lateral Sclerosis Society of Canada
Annual Report 2003

change and opportunity

ALS. Three letters that change peoples lives. FOREVER.
Each year presents challenges and opportunities. Increasingly the ALS Society of Canada is able to accommodate the challenges and maximize the opportunities.

In 2003 the SARS crisis in Ontario had a minimal impact on our organization and thanks to technology we were able to have our annual meeting by teleconference on the date planned. While not ideal we did accomplish our objectives.

A good part of the year was a transition period between the leaving of Suzanne Lawson and the arrival of David S. Cameron as National Executive Director. While, by definition, an unsettled time, this transition was managed well with Helene Vassos in the role of Interim Executive Director. The work of the organization moved forward making for an easy hand-over in September to our new National Executive Director, David S. Cameron.

We increased the resources in our research fund through the continued and growing success of events such as the WALK TO D’FEET ALS, Elizabeth’s Concert of Hope, and the Tim E. Noël Golf Outing. These achievements enabled us to enhance our research program. The groundwork is now laid for an expanded program of fellowships and studentships to encourage young researchers to focus their considerable talent and energy toward the ALS field.

The Neuromuscular Research Partnership continues to fund excellent research which is experiencing results. For the second year in a row, Dr Jean-Pierre Julien’s research has resulted in a breakthrough announcement that received wide notice. The significant work of others is highlighted in our new publication THE NORTHERN NEURON – ALS Research in Canada.

The growing strength of the Provincial ALS Societies complements our mission. We are pleased to have supported the merger of the ALS Societies of Ontario and Toronto. There have been numerous collaborative ventures among the ALS partners to enhance and strengthen their capacity to serve the immediate needs of those Canadians affected by ALS. Our own survey of services and education, funded in part by a Health Canada grant, will set the direction for our future collaborations.

These relationships with our provincial partners are stronger than ever. We thank them and congratulate them on all their work and enthusiasm to assist people with ALS and their caregivers.

Awareness of ALS is growing across Canada, facilitated by the network of opportunities to share the compelling ALS stories through public service announcements featuring our newest spokesperson, Wendy Crewson, a documentary on Elizabeth Grandbois, local features on people living with ALS, as well as widespread interest in the WALK TO D’FEET ALS.

Hope for a cure or treatments for ALS is growing rapidly with each advance in research. This hope sharpens our focus as we all strive to fulfill our mission in the coming year. With the remarkable group of volunteers on our Board of Directors and the very capable staff team of the ALS Society of Canada we will accomplish our goals.

Michael Mayne
President

Strategic Imperatives

The Society has identified five strategic imperatives necessary to accomplish its missions:

- Develop programs that support volunteers across Canada.
- Diversify revenue sources.
- Provide assistance to Partners in their delivery of services to persons with ALS, their families, and caregivers.
- Take an active facilitating role in enhancing ALS research.
- Be the national advocate for ALS and pilot advocacy strategies for Partners.
# Table of Contents

1. To support research towards a cure for ALS
2. To support ALS Partners in their provision of quality care for persons affected by ALS

## Provincial Societies

<table>
<thead>
<tr>
<th>ALS Society of Alberta (and NWT)</th>
<th>CALGARY, AB</th>
<th><a href="http://www.alsab.ca">www.alsab.ca</a></th>
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<tr>
<td>ALS Society of Saskatchewan</td>
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</tr>
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ALS. Three letters that change people's lives. FOREVER.
report from the
national executive director
David S. Cameron

I am delighted to have joined this forward-thinking organization which is clearly held in high regard within the Canadian health-charity community. Being here through the final quarter of 2003 has enabled me to learn a great deal, some of which I would like to share with you at this time.

| WHAT I DISCOVERED |

The ALS Society of Canada has been doing the right things at the right time in the right way and is well-regarded in the field for its initiatives and forward-looking philosophy.

| RESEARCH PARTNERSHIPS |

We have a very successful relationship with our partners Muscular Dystrophy Canada and the Canadian Institutes of Health Research through the Neuromuscular Research Partnership (NRP) to fund Canadian scientists engaged in neuromuscular research. Excellent and relevant research has been funded again this year. ALS Canada has contributed a total of $1.6 million to the NRP over the four-year history of the relationship and this has leveraged a total $12.3 million of neuromuscular research in Canada. The work done this year is establishing the foundation for significant and new initiatives for 2004 and beyond.

| PARTNERSHIP AMONG ALS SOCIETIES |

We are strong in the area of partnerships both within and beyond the society. Within ALS Canada we have developed a unique relationship with each of the provincial societies that is regarded by outside observers as a benchmark for the health charities community. Our Partnership Agreement with our 10 Provincial Society partners is an ongoing expression of the trust among these individual partners dedicated to the same purpose -- Cure and Care.

The sharing of responsibilities between the national body and the provincial societies allows for an efficiency not often seen in large national entities like ours.

| STRENGTH OF VOLUNTEERS |

While a comparatively small number of Canadians live with ALS, the Society has many and willing volunteers who are dedicated beyond usual expectations. The nature of this disease is that people are motivated to become volunteers and to help in the efforts of the societies across the country to make a difference in the lives of those with ALS. We can be proud of the dedicated and long-term support our volunteers provide.

| SPEAKING FOR OURSELVES |

Our advocacy program works to change public policy to benefit those affected by ALS. Compassionate care leave and increased funding for research have been introduced, in part, as a consequence of our efforts. The model of this program is spreading to Provincial Societies.
| FUND DEVELOPMENT |
This is a strong, financially healthy organization with a substantial reserve position to take us into the future. It is important for all of us as it allows us to plan for the next opportunities on the horizon as well as allowing us to continue our present work.

| ENHANCING SERVICE AND EDUCATION |
We responded to the results of a national needs and opportunity assessment by creating a new position of Director of Services and Education to improve our ability to provide quality care for those affected by ALS. This position works closely with the provincial societies to fulfill our mandate to provide support for services at the provincial level.

| OUR FUTURE |
BUILDING ON A STRONG FOUNDATION & BRANCHING OUT
There are two areas that are key to our future. I offer a brief sketch of where we will be headed.

We will develop new research partnerships, fund more excellent and relevant research, cultivate our relationship with the ALS research community, and encourage a new generation of scientists to work for a cure.

We will increase resources, both human and financial, to further enhance our growing profile in Canada. More and more information is being seen in media of late and we are well-positioned to build on that awareness.

2004 will be an exciting year.
Please join us in the experience.

David S. Cameron
National Executive Director
ALS Society of Canada

2003 in Review
- We sought and received a grant from Health Canada for a project entitled “Enhancing Service and Education”. The purpose of the project was to conduct a nation-wide needs assessment of all services and educational opportunities currently delivered locally and provincially in support of all Canadians affected by ALS and to conduct an opportunities assessment of what could be delivered in support through an examination of what other ALS organizations world-wide are doing.

The resulting report was completed and can be found on the ALS Canada website. The needs we identified were such that it warranted the creation of a new position at the ALS Society of Canada, that of Director of Education and Services.

ALS SOCIETY OF CANADA Awards

<table>
<thead>
<tr>
<th>Myra Rosenfeld</th>
<th>William Fraser</th>
<th>Exceptional Public</th>
<th>Brett Yerex Exceptional</th>
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<tbody>
<tr>
<td>Voluntary Award</td>
<td>Leadership Development</td>
<td>Awareness Award</td>
<td>Advocacy Award</td>
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<tr>
<td>Ruth McFeat</td>
<td>Award</td>
<td>George Goodwin</td>
<td>Audrey and Duncan McKinnon</td>
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</tbody>
</table>

Honorary Life Members

- Joyce Sinclair
- Marie Salamoun-Dunne

Mary Pollock WALK TO D’FEET ALS Award
- Dan Maloney

Betty’s Run for ALS Award
- Dan Maloney
It has been more than a century since the first complete description of ALS by Dr. Jean-Martin Charcot. For most of those 130 years, researchers who took on the study of ALS have known little success and much frustration. But recent advances are showing exciting new promise in the field.

“The past decade, beginning in 1990, was dramatically different from any of the past decades combined,” announced Dr. Christopher Shaw, Senior Lecturer in Neurogenetics at King’s College London, UK, at the 14th International Symposium of ALS/MND in Milan, Italy, last fall. Shaw cited advances in drug development, patient care, stem cell and gene therapy, animal models and an increased collaboration among researchers as some of the reasons for the accelerated pace in the field. “Many exciting vantage points steadily unravel the enigma of ALS, and new ideas are rapidly translated from laboratory to clinic. After many long dark years, we finally see a bright light on the horizon.”

“I do think things are accelerating,” says Dr. Neil Cashman, researcher at the University of Toronto’s Centre for Research in Neurodegenerative Diseases. Currently establishing clinical trials using stem cells to treat ALS, Cashman is on the front lines of change in the field. “More people are working on ALS than ever before, and more funding is targeted to the disease. There has been a ‘confluence’ of novel technologies including proteomics, high-throughput genomics, and neuroscience methods that have definitely increased the rate of discovery.”

Technology is often cited as the main reason for the new rate of progress. McGill University researcher in neurogenetics, Dr. Guy Rouleau, who with colleagues discovered two of the genes for familial ALS says, “Technology allows us to do things we weren’t able to do before, including cloning and manipulating the genes. A key element is the investigation of genetics, but that is the result of technology.” Rouleau
also cites advances in computer tools, databases, and communication as helping speed up the pace.

Along with better communication has come increased collaboration in the scientific community, especially among the neurodegenerative diseases, where disease mechanisms can be very similar. Every advance affects not just one disease field, but many. “All science has a dynamic that feeds off success,” says Dr. Nigel Leigh, Director of the Motor Neuron Disease Centre at King’s College London, UK. Leigh established the clinical trials of Riluzole, the only drug licensed for use in ALS as an agent that modifies disease progression.

The new tools and recent progress are attracting young researchers, eager to work in the field of ALS, says the ALS Association’s Science Director Dr. Lucie Bruijn. “This is a very exciting time for those of us working on ALS. We now have the tools to test the important questions.” Bruijn lists the discovery of new genes, new disease models, and more human drug testing on the imminent horizon, adding, “Investigators are thinking of applying stem cells in a more innovative way, not just to replace dying neurons, but also to replace healthy neighbouring cells.”

Of course, new technologies and the current rate of progress can only continue with reliable funding. “There is more need for funding now,” says Dr. Guy Rouleau, “and the need is for constant funding. We’ve been plagued by government changes in funding decisions. The disease associations such as ALSA, MDA and ALS Society of Canada have really saved us in that way. They have actively encouraged the research and brought new researchers into the field.”

Both researchers and financial donors are deciding ALS is a disease worth investing in. “This disease is fascinating and yet so devastating,” says Dr. Bruijn. “The need to make an impact is absolutely compelling.”

2003 in Review

- The premier issue of the ALS Canada publication on research, The Northern Neuron, was published. It profiles the work of 11 researchers doing work in Canada, many of them funded in that research through the Neuromuscular Research Partnership between ALS Canada, Muscular Dystrophy Canada and the Canadian Institutes for Health Research. Plans for Issue #2 are underway for publication in 2005.

- Discussions began to take place over the fall into methods to expand our research initiatives and several concepts were presented to the Board of Directors of ALS Canada in November. Work will continue on these concepts and they will reach fruition in 2004 and 2005.

- ALS Canada placed two volunteers on the Health Charities Council of Canada (HCCC) working groups: Doretta Thompson on the Project Advisory Committee and Richard Thompson on the Science, Research, and Policy Committee. HCCC is a lobbying body representing approximately 35 health charities in Canada and provides us with a voice in Ottawa.

- The International Alliance of ALS/MND is a world-wide group of health charities dedicated to the cause of ALS and they meet once annually to share advances in the field. The 2003 meeting was in Milan, Italy where the suggestion was made that a future meeting of the International Alliance should be held in Canada. Subsequent efforts made by ALS Canada have resulted in the awarding of the 2007 International Conference to us, to be held in Toronto.
2003 was an excellent year overall. There is much to be hopeful about as the financial performance of the Society remains strong. In fiscal 2003, overall revenues of the Society increased by 4% over 2003, while expenses during the same period decreased by 5.4%.

As our awareness grows, our ability to fund raise increases; as we broaden our fund raising approach, we attract new donors to our mission; as we develop volunteer resources across the country, families with ALS have more support to manage their situation; as we mature as a voluntary organization, we attract strong leadership volunteers and excellent staff.

THE GOOD NEWS BEHIND THE NUMBERS

- **The Walk to D’Feet ALS CONTINUES ITS UPWARD GROWTH** - This exceptional event continues to inspire the organization, our volunteers, our capacity to raise funds for research and service. It has an enormous impact at every level. Nine provinces now have walk events. While the number of Walk to D’Feet ALS venues in 2003 rose to 46, more than $1.55 million was raised with over $560,000 directed to our research fund.

- **GROWING TOWARD THE MILLION MARK** Elizabeth’s Concert of Hope in 2003 followed on its original success contributing $111,000 for research, with an equal amount going to the ALS Society of Ontario for support services.

- **FUNDING RESEARCH** - $500,000 enables $3,000,000 of funding for 10 new projects. Once again in 2003 our Neuromuscular Research Partnership with Muscular Dystrophy Canada funded significant research that will get us closer to treatments and a cure for ALS. The ALS Society contribution of $500,000 was leveraged through the NRP in partnership with the Canadian Institutes of Health Research to fund 10 projects totalling just over $3 million of research. Again in 2003, Dr Jean-Pierre Julien announced encouraging results in delaying the onset of ALS in mice through administration of a three drug ‘cocktail’.

- **SHARING THE RESEARCH STORY** - This and other research is highlighted in the new publication *THE NORTHERN NEURON* – ALS Research in Canada. Recommended reading for all.

- **HOW WE CAN ASSIST OUR PROVINCIAL SOCIETY PARTNERS** - A grant from Health Canada of $75,000 allowed us to carry out an exhaustive needs and opportunities assessment of services and education. The results of this provide significant direction for how the ALS Society of Canada can increase its support to provincial ALS societies and makes a strong case for the need for ALS Society of Canada staffing in this area.

Bud Roberts
Treasurer
ALS Society of Canada
### FUND BALANCE SHEETS

**As at December 31, 2003**

**ASSETS**

<table>
<thead>
<tr>
<th></th>
<th>Tim E. Noël Endowment Fund</th>
<th>Neuromuscular Administration Fund</th>
<th>Neuromuscular Research Fund</th>
<th>Research Fund</th>
<th>General Fund</th>
<th>2003 Consolidated</th>
<th>2002 Consolidated</th>
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<td><strong>Total Assets</strong></td>
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<td>(3,335)</td>
<td>1,685,577</td>
<td>1,773,898</td>
<td>447,290 5,158,044</td>
<td>4,415,010</td>
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**LIABILITIES**

|                  |                             |                                   |                             |               |              |                   |                   |
| **Current**      |                             |                                   |                             |               |              |                   |                   |
| Accounts payable |                             |                                   |                             |               |              |                   |                   |
| Research grants payable |                         |                                   |                             |               |              |                   |                   |
| Deferred revenue |                             |                                   |                             |               |              |                   |                   |
| **Total Current Liabilities** | 421,018                    |                                   |                             |               |              |                   |                   |
| **Long-term research commitments** | 402,207                    |                                   |                             |               |              |                   |                   |
| **Total Liabilities** |                             |                                   |                             |               |              |                   |                   |

**ACCUMULATED SURPLUS**

|                  |                             |                                   |                             |               |              |                   |                   |
| General Fund     |                             |                                   |                             |               |              |                   |                   |
| Research Fund    |                             |                                   |                             |               |              |                   |                   |
| Neuromuscular Research Fund |               |                                   |                             |               |              |                   |                   |
| Neuromuscular Administration Fund |         |                                   |                             |               |              |                   |                   |
| Tim E. Noël Endowment Fund | 1,254,614                 |                                   |                             |               |              |                   |                   |
| **Total Accrued Surplus** | 1,254,614                 | (3,335)                            | 862,352                     | 1,773,898     | 100,000 3,987,529 | 3,259,825 |

**STATEMENT OF CHANGE IN FUND BALANCES**

**As at December 31, 2003**

|                                |                             |                                   |                             |               |              |                   |                   |
| Balance, beginning of year     | 1,125,400                   | (2,904)                            | 774,026                     | 1,263,303     | 100,000 3,259,825 | 2,800,931 |
| Excess (deficit) revenue over expenses | 129,214                    | (431)                              | (461,674)                   | 811,949       | 248,646 727,704 458,894 |
| Inter-fund transfers           |                             |                                   | 550,000                     | (550,000)     | 248,646 (248,646)   | (248,646)   |
| **Balance, end of the year**   | 1,254,614                   | (3,335)                            | 862,352                     | 1,773,898     | 100,000 3,987,529 | 3,259,825 |
## STATEMENT OF REVENUE AND EXPENSE

**As at December 31, 2003**

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<tr>
<th>fund</th>
<th>Tim E. Noël Endowment Fund</th>
<th>Neuromuscular Administration Fund</th>
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<th>Research Fund</th>
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<td>$775,444</td>
<td>$296,333</td>
<td>$1,025,650</td>
<td>$623,546</td>
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<td>$69,950</td>
<td>$926,383</td>
<td>$775,444</td>
<td>$296,333</td>
<td>$1,025,650</td>
<td>$623,546</td>
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<tr>
<td>General fund raising</td>
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<td>$69,950</td>
<td>$926,383</td>
<td>$775,444</td>
<td>$296,333</td>
<td>$1,025,650</td>
<td>$623,546</td>
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<tr>
<td>Tim E. Noël Endowment fund</td>
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<td>$69,950</td>
<td>$926,383</td>
<td>$775,444</td>
<td>$296,333</td>
<td>$1,025,650</td>
<td>$623,546</td>
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<tr>
<td>Direct mail</td>
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<td>$69,950</td>
<td>$926,383</td>
<td>$775,444</td>
<td>$296,333</td>
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<tr>
<td>Sales &amp; other income</td>
<td>$129,214</td>
<td>$69,950</td>
<td>$926,383</td>
<td>$775,444</td>
<td>$296,333</td>
<td>$1,025,650</td>
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<td>$69,950</td>
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<td>$775,444</td>
<td>$296,333</td>
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<td>Interest Income</td>
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<td>$775,444</td>
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<tr>
<td><strong>Total revenue</strong></td>
<td>$129,214</td>
<td>$69,950</td>
<td>$926,383</td>
<td>$775,444</td>
<td>$296,333</td>
<td>$1,025,650</td>
<td>$623,546</td>
</tr>
</tbody>
</table>

| Charitable program expense | $531,624 | $1,059,882 | $1,591,506 | $1,619,217 |
| Research grants | $500,000 | $500,000 | $423,626 | $423,626 |
| Public awareness | $423,626 | $423,626 | $394,637 | $394,637 |
| Volunteer & organizational development | $139,984 | $139,984 | $175,974 | $175,974 |
| Client support & education | $119,841 | $119,841 | $212,921 | $212,921 |
| Support of ALS regional units | $119,841 | $119,841 | $212,921 | $212,921 |
| Project costs | $139,984 | $139,984 | $175,974 | $175,974 |
| Other research support | $163,510 | $163,510 | $182,323 | $182,323 |
| **Total charitable program expense** | $531,624 | $1,059,882 | $1,591,506 | $1,619,217 |

| Other expense | $1,842,896 | $2,545,755 | $2,690,147 |
| Fund raising | $170,804 | $170,804 | $170,804 |
| Administration | $170,804 | $170,804 | $170,804 |
| Governance | $170,804 | $170,804 | $170,804 |
| **Total other expense** | $170,804 | $170,804 | $170,804 |

| Excess (deficit) revenue over expense | $129,214 | $458,894 | $811,949 | $727,704 | $248,646 | $727,704 | $458,894 |

### 2003 in Review

- Our website has undergone a significant review and update, resulting in a more user-friendly design. The usage of the site has increased each month and our “hits” continue to expand. Many positive comments have been received on the changes made.
- Our biennial Leader’s Symposium was held in November in Toronto, at which volunteers, staff and health-care partners met to expand their knowledge and share experiences. The volunteer awards dinner that was postponed from May (as a consequence of SARS) was held and recognition was given to many dedicated volunteers for the ALS Society of Canada. We reaffirmed our reliance on volunteers for our success and our future achievements.
- ALS Canada continued its partnership with other organizations within the health charities field. David Cameron was appointed to the Steering Committee Group of the newly reconstituted Health Charities Coalition of Canada which is working to rebuild and demonstrate value to its constituents. He also sat on the panel that did the evaluations for the CIHR Partnership Award. We are an active member of Health Partners, the Federal civil service equivalent of United Way and one of our national staff sits on their Board of Directors.
- A meeting was had with representatives of the Stem Cell Network and opportunities for collaborative activities were discussed. A link to their website and back is imminent and other possible projects will be considered in 2004.
our donors

Third Party Special Events

7th Annual Gillis Golf Classic
Dynamic Mutual Funds Ltd.
Triax Capital Holdings Ltd.
–
Gillis, Jack

Climb For A Cure
Gama Calgary
Gerrie Electric
Wholesale Limited
Investors Group Financial Services Inc.
Les Soeurs de L’Assomption De La Ste-Vierge Procure Prov.
M & B Paintball
Manulife Financial
Tidal Energy Marketing Inc.
Waterdown Martial Arts Academy
–
Cavallo, Lou
Entwistle, Mark
Gordon, Dorothy
Iascone, Angelo
LeBoeuf, Michael
Maille, Roger
Smith, Barbara

Golf Classic
Hare, Jim

Jim Hughes Golf Tournament
Aircraft Kitchens
Cameron Trucking
Cooper Wealth Management
Grantham Lions

Corporations

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Bailey Metal Products Limited
Bell Canada - Helping Hands
Open Hearts
Burnabrea Farms Limited
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Cut and Dried Flower Farm
EMJ Data Systems Ltd.
Glorada Holdings Ltd.
Goodkey, Wedmark & Associates Limited
Greater Toronto Sewer and Watermain Contractors Association
HECLA Contracting Ltd.
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Inco Limited
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Ontario Power Generation Employees Charity Trust
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Protax Financial Services
Reitmans (Canada) Limited
Sanofi - Synthelabo Canada Inc.
Sauder Industries Ltd.
Shadowcorp
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St. Anthony Lions Club
Summit Restoration Ltd.
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Group Limited
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Trouper Belle Productions
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Elizabeth’s Concert of Hope

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Algoma Steel Inc.
Aventis Pharma Inc.
Bailey Metal Products Limited
Ball Corporation
Bank of Montreal
Bank of Nova Scotia
Canada Life Assurance Company
CanWest Global Communications Corporation
CIBC Asset Management Inc.
CIBC World Markets
CROWN Metal Packaging Canada LP
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Top Hat Marching Band
Tyandaq Municipal Golf Course
Tyler Investments Inc.
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