



## **Annual Report 2003-2004**

Box 22017, 1670 Heron Road, Ottawa ON K1V 0C2, T: 613-789-8943, F: 613-789-6985,  
[info@autismsocietycanada.ca](mailto:info@autismsocietycanada.ca), [www.autismsocietycanada.ca](http://www.autismsocietycanada.ca)



**Autism Society Canada**  
**Société canadienne de l'autisme**

Serving Canadians since 1976, Autism Society Canada (ASC) is a national incorporated non-profit charitable organization committed to creating better lives and opportunities for children and adults with ASDs, their families and their communities.

Through its 2003-2004 programming, Autism Society Canada renewed its commitment to:

- support for the nation-wide provincial and territorial member societies who provide direct service to individuals with ASDs and their families;
- providing public education, awareness, information and referral on ASD issues;
- advocating for the implementation of ASD surveillance in Canada and increased funding for autism research;
- working to ensure universally accessible, scientifically validated treatment and educational programs; and,
- collaborating with many partners to support improved service delivery and accommodations for children, youth and adults with ASDs; and to ensure adequate supports for families.

ASC believes that Canadians with ASDs will one day live in an environment that fully supports their well-being, enabling all

individuals with ASDs to reach their full potential as participating members of their communities.

### **Establishing a National Presence**

2003-2004 marked a year of transition and important organizational development at ASC.

With the addition of representation from the Yukon and Northwest Territories Autism Society Canada is now comprised of autism societies across the country from east to west and north to south.

ASC moved its offices from Orangeville, Ontario and established a stronger national presence by relocating in Ottawa. A search committee was set up to find an experienced Executive Director who could bring new energy and administrative focus to the organization. Louise Fleming was contracted in March 2004 and the Board feels she will be a great asset to the organization. Working in Ottawa allows Louise to collaborate easily with government and other national community partners and has resulted in a higher community profile for the agency. Additional contract service providers have assisted with communication and administrative activities.

### **Organizational Restructuring**

As a representative organization, Autism Society Canada has worked diligently over the past several years to improve its capacity to be representative of and to the national ASD community.



**Autism Society Canada**  
**Société canadienne de l'autisme**

During 2003-2004 the Board laid the groundwork toward a major revision of its By-Laws (in April 2004). These changes will allow for greater representation at the national level of individuals with ASDs and of other ASD-related national organizations.

### **Supporting Our Members**

ASC is the national representative for a federation of Canada-wide provincial and territorial autism societies, who, along with their member groups in each region, represent the largest group of people with ASDs in Canada.

ASC's member provincial and territorial autism societies each appoint one representative to ASC's Board of Directors. Regular Board and Committee meetings, as well as the AGM in August, 2003 allowed members across the country to share current information on ASD research, treatment availability, education and accommodation supports and other regional concerns. These meetings provide a unique opportunity to build on the expertise developed in these organizations from parents, people with ASDs and other professionals.

The Scientific and Public Affairs Committee (SIPA) and our Fundraising & Membership Committee have proven to be very useful standing committees through which to vet issues and develop recommendations.

### **Programs**

2003-2004 was a year of high activity for the organization; major projects included:

### **Awareness, Education and Referral**

Providing information and general referrals to the public regarding all aspects of ASD continued to be an integral part of our day-to-day work in 2003-2004. ASC received approximately 400 requests for information via our website and through our toll-free phone line. The public is very much in need of reliable information on ASD and requests for referrals to resources, services and quality programs are ongoing.

ASC is frequently the first point of contact for many affected families and in 2003-2004 we continued to provide pro-active family support and referral.

### **ASC: A Media Resource**

Communication with the media increased dramatically this year, to the point where ASC is now approached on a regular basis as a source of current information about Canadian autism issues. Numerous letters to the editor from ASC Executive Members were published and media articles and interviews appeared in *Today's Parent*, *The Globe and Mail*, CBC Radio, CBC TV and daily newspapers across the country.

ASC continued to make its Public Service Announcement available and also continued distributing its Autism Awareness Pins.

### **Reaching Canadians on the Web**

Resources added to our website this past year include:

- autism related IEP links;
- autism research funding sources;
- new autism media coverage; and



**Autism Society Canada**  
**Société canadienne de l'autisme**

- *ASC's White Paper: A Canadian Autism Research Agenda and Canadian Autism Strategy.*

It is hoped that in future the website will become a central piece of ASC's public awareness and education agenda.

**Communication with Government**

Communication with federal government officials and politicians grew significantly in this period. People with autism and their families need the federal government to take a leadership role with regard to Autism Spectrum Disorders. Numerous meetings, briefings, information sessions and collaborations were held with our federal government partners, which included:

- Health Canada;
- HRDC/SDC, ODI;
- Senator Landon Pearson;
- Finance Canada;
- Auditor General's Office; and,
- SSHRC, Canadian Institutes of Health Research (CIHR).

ASC also presented a Brief to the Minister of Public Health regarding the role of the new Public Health Agency in serving Canadians with ASDs.

**Community Networking and Development**

In 2003/04 ASC worked diligently to establish a strong networking base with other agencies and organizations involved in ASD and related disability issues. Our partners this year included:

- Canadian Alliance for Mental Illness and Mental Health;

- Canadian College of Physicians and Surgeons;
- Canadian Paediatric Society;
- Canadian Autism Research Intervention Network;
- Learning Disabilities Association of Canada;
- Miriam Foundation; and,
- numerous other agencies working on behalf of children's health and ASD-related issues.

ASC national office staff and representatives from almost all ASC's provincial and territorial membership attended the Canadian Autism Intervention Research Network (CAIRN) annual conference in March, 2004. ASC was also represented at the Canadian Coalition for Family Supportive Policy meeting, ensuring autism issues were included in common advocacy statements in support of families with members with disabilities.

As a member of the Canadian Alliance for Mental Illness and Mental Health (CAMIMH), ASC presented to the Kirby Commission; participated in a luncheon with members of the Standing Senate Committee on Social Affairs, Science and Technology dealing with Mental Health issues; and participated in a feedback meeting regarding the Canadian Mental Health Association report (March 2004). ASC also participated in the development of a revised CAMIMH document entitled "Time for Action" calling for a national action plan for mental health and mental disabilities.



**Autism Society Canada**  
**Société canadienne de l'autisme**

ASC was also happy to take part in Autism Society Ontario's very successful *Cycle for Autism*, assisting with media promotion and on-site support.

**Supporting ASD Research**

ASC continues to encourage research and increased funding for research in fields relevant to ASD. Research has been a major focus of Autism Society Canada's work in 2003-2004.

ASC's *White Paper: A Canadian Autism Research Agenda and Canadian Autism Strategy*; was published in March 2004. The *White Paper* provides:

- a summary of the proceedings and recommendations from the Canadian Autism Research Workshop (hosted by ASC);
- a Canadian Autism Research Agenda and a Canadian Autism Strategy;
- an inventory of current Canadian autism research; and,
- a comparison of Canadian and American autism research funding.

The *White Paper* was distributed to all MPs, Senators, Canadian Universities, major hospitals, federal government officials responsible for autism issues, federal agencies with autism interests, as well as provincial premiers, Health, Social Service and Education ministers, and provincial health research funding organizations.

ASC believes that our ongoing work to promote autism research in Canada has had a positive influence on the dramatic

increases in interest and funding of ASD research in Canada.

**Autism Spectrum Disorders Screening Training Program**

Autism Society Canada hopes to initiate a program to collaborate with the broader medical, health professional, education and child care communities to develop an Autism Spectrum Disorders Screening Training Program. Excellent initial progress was made with written commitment from several national organizations. ASC was successful in obtaining a grant from the Canadian Institutes of Health Research (CIHR) in support of this project

**Legal Actions**

ASC continued its support of actions to ensure universally accessible treatment opportunities for people of all ages with ASDs. As of 2004, about 1,600 Canadian families were engaged in various autism-related legal actions

ASC will be intervening at the Supreme Court of Canada in support of the litigation (referred to as the *Auton Case*) initiated by families in BC seeking the provision of Intensive Behavioral Intervention autism treatment for their children with autism in the form of Lovaas therapy. This was the first case where a provincial appeal court upheld a lower court's decision that Charter rights require a provincial government to pay for a specific health treatment. The case was appealed by the B.C. government to the Supreme Court of Canada. ASC acted as an intervener in the case and with the generous assistance of Gowling Lafleur Henderson



**Autism Society Canada**  
**Société canadienne de l'autisme**

LLP, is preparing a factum to the Supreme Court of Canada. ASC will argue that all people in Canada share the right to accessible effective treatment for their medical conditions.

**ASD Surveillance**

Development and implementation of a national ASD surveillance mechanism continues to be a priority at ASC. As national government surveillance is still non-existent, ASC began to collect current autism data based on enrollment figures from three provincial departments of education. These data indicate an ASD prevalence rate of more than 1 in 200 Canadians.

**Looking Ahead**

2004-2005 promises to be an exciting year for Autism Society Canada. We will have the opportunity to make an oral presentation, through our lawyers, at the Supreme Court regarding the Auton Case. ASC will continue to champion the rights of individuals with ASDs to access timely evidence-based treatment and accommodations regardless of age.

ASC will continue with its Board development and By-Law restructuring to include more individuals with ASDs in decision-making at the national level. Development of the Board and our Advisory Group will be key areas of focus and energy in 2004-2005.

Plans are underway to begin a complete overhaul of the ASC website in French and English in order to provide an up-to-date nationally focused resource on all aspects of

ASDs. ASC's revamped on-line presence will reach new audiences and increase our capacity to meet the high volume of information and referral requests we are currently receiving.

Making ASD a national priority will also be high on ASC's 2004-2005 agenda. Plans are being developed to provide an information session for MPs and Senators on Parliament Hill and collaborations on research development and the ASD Screening Training initiative will continue in the coming year.

ASC looks forward to working with all of its partners to reduce the profound impact of ASD on individuals and their families; to improve ASD service delivery across the country; and to address national issues and concerns common to our provincial and territorial member societies.





**Autism Society Canada**  
**Société canadienne de l'autisme**

**Our Supporters**

The work of ASC is made possible by grants from the Office of Disability Issues at HRDC/SPC. Thanks also to the CIHR for their support in 2003-2004.

**Our 2003-2004 Corporate Donors**

We would like to extend our heartfelt thanks to the following corporations and foundations for their generous contributions in support of autism. Many of our activities would not be possible without their support.

REJEAN GUINDON CONSTRUCTION CORP  
 GOWLING LAFLEUR HENDERSON LLP  
 SHOPPERS DRUG MART  
 THE FRANK COWAN FOUNDATION  
 EECOL ELLECTRIC (SASK.) INC.  
 THE COOPERATORS INSURANCE/FINANCIAL SERVICES  
 PPG CANADA  
 KODAK EMPLOYEE CHEST, TORONTO  
 NATIONAL LIFE  
 CHUM CHARITABLE FOUNDATION  
 MARITIME LIFE  
 SHAWCOR ENERGY SERVICES  
 SC JOHNSON & SON, LIMITED  
 REEL IMPACT COMMUNICATIONS, INC.  
 INCO LIMITED  
 GILLETTE CANADA  
 FOUR SEASONS HOTEL TORONTO  
 EXTENDICARE, INC.

**Many thanks also to our numerous private donors for their generous donations and many bequests during the 2003-2004 year.**

**Statement of Operations**

**Year ended March 31, 2004**

|                                |                  |
|--------------------------------|------------------|
| <b>Revenue</b>                 |                  |
| SDC grant                      | \$124,240        |
| CIHR grants                    | 5,000            |
| Donations                      | 47,378           |
| Public awareness pins          | 2,900            |
| Interest                       | 710              |
| Membership fees                | 700              |
| <b>Total Revenue</b>           | <b>\$180,628</b> |
| <b>Program Expenses</b>        |                  |
| Contracted services            | 50,014           |
| Fundraising                    | 16,959           |
| Information and referral       | 8,286            |
| Board meetings                 | 12,444           |
| Legal fees                     | 11,581           |
| Public awareness               | 6,248            |
| Research                       | 21,801           |
|                                | <u>127,333</u>   |
| <b>Administration Expenses</b> |                  |
| Administration                 | 11,036           |
| Amortization of capital assets | 2,681            |
| Bank charges                   | 163              |
| Insurance                      | 1,923            |
| Professional fees              | 9,091            |
| Telecommunications             | 9,464            |
|                                | <u>34,358</u>    |
| <b>Total Expenses</b>          | <b>\$161,691</b> |
| <b>Surplus at Year End</b>     | <b>\$18,937</b>  |

**For more information, please contact:**

Louise Fleming  
 Executive Director/Directrice générale  
 E-mail: [louise@autismsocietycanada.ca](mailto:louise@autismsocietycanada.ca)  
 Box 22017, 1670 Heron Rd.,  
 Ottawa ON  
 K1V 0C2  
 T 613-789-8943, F 613-789-6985,  
**E-mail:** [info@autismsocietycanada.ca](mailto:info@autismsocietycanada.ca)  
**Website:** [www.autismsocietycanada.ca](http://www.autismsocietycanada.ca)