Inspired by memories, ignited by hope

ANNUAL REPORT 2001-2002

HUNTINGTON SOCIETY OF CANADA

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RALPH MCDOUGALL WALKER

JANUARY 14, 1939 - MARCH 22, 2002

IN MEMORIAM

Huntington's Visionary

The Huntington's community in Canada and around the world lost a great supporter and leader on March 22, 2002, with the death of Ralph Walker.

Moved by compassion to help those who could not help themselves, Ralph and his wife, Ariel, founded the Huntington Society of Canada in 1973. Leaving a successful career in education, Ralph became the Society's first Executive Director, a position he held for 24 years until his retirement in 1997.

Under Ralph's leadership, and through his vision, the Huntington Society of Canada has grown from Ralph and Ariel's kitchen table to an internationally recognized and respected organization, made up of a vital network of volunteers and professionals driving strong programs in research, family services and education. Through hard work and an uncanny ability to connect with people on a very personal level, Ralph almost single-handedly turned the isolation so typical of Huntington disease in the 1970's into what is now a supportive, motivated community heading into the promise of the 21st Century. Ralph was known and respected across Canada and around the world for his dedication to the Huntington's cause, for his expertise, and for his compassion for people throughout the Huntington's community.

For Ralph everything was personal (his handwritten notes were his trademark), and nothing was too much trouble if it helped someone else. His passing brought a response from anyone and everyone who knew him - an outpouring of sadness, support for Ralph's family, and reflection on the unique contribution he had made.

"For those of you who never had the opportunity to meet Ralph, let me say that no other individual with the exception of Marjorie Guthrie has gone to their rest having made a greater contribution to HD advocacy, services, education or research. Many of the publications families read now here in North America were products of his work, sharing or prompting. I'm certain that each one of us who knew him, as friend or acquaintance, are deeply saddened by this news. Quite literally no one on this planet has worked harder, smarter or longer to realize the vision of a world free of Huntington's disease than he did. Rest in peace, brother Ralph. Rest assured we will carry on."

– Jim Pollard, Lowell, MA

Ralph leaves behind a large and loving family, especially his wife and friend of 36 years, Ariel; daughter, Lara and her husband, Tim; son, Matthew and his wife Tori; and four grandchildren.

We owe him a huge debt and we will miss him.

WHAT IS HUNTINGTON DISEASE?

Huntington disease (HD) is an inherited brain disorder with devastating effects on both mind and body. One in every 1,000 Canadians is touched by HD, directly or as a family member or caregiver.

Every child of a parent with HD is burdened with a 50% risk of inheriting the disease. Symptoms include uncontrollable jerking movements, and progressive cognitive, emotional and behavioural impairment. Over its lengthy course, HD leads to incapacitation and death.

HD remains incurable, and there are no effective treatments.

THE SHADOW OF HUNTINGTON'S –
DIGITAL IMAGE CREATED BY, AND USED WITH PERMISSION
FROM MR. JERALD BLACKSTOCK, CALGARY, AB.

THE HUNTINGTON SOCIETY OF CANADA

The Huntington Society of Canada is a national network of volunteers and professionals working together to find new treatments and, ultimately, a cure for Huntington disease; and to improve the quality of life of individuals with Huntington disease and their families. Across Canada, the Society pursues programs in:

RESEARCH

To provide hope for the future.

SERVICES

To meet the urgent needs of the HD community.

EDUCATION

To promote improved understanding and awareness of HD.

THE HUNTINGTON SOCIETY OF CANADA is a national voluntary health charity, governed by a volunteer Board of Directors. Elected by the membership and representing the Huntington's community across Canada, the Board of Directors is responsible for the Huntington Society's strategic direction, policy, and financial integrity; and ensures that the Society is fully accountable to its members, donors and supporters, government, and the general public. The Huntington Society subscribes to the Canadian Centre for Philanthropy's *Ethical Fundraising and Financial Accountability Code*.

Special thanks to all HSC volunteers and other contributors for the images contained in this report.

MESSAGE FROM THE CHAIR AND EXECUTIVE DIRECTOR

Vern Barrett
Chair, Board of Directors

Isla Horvath
Executive Director

The past year was a time of both reflection and achievement for the Huntington Society of Canada. The title of this annual report, *Inspired by memories, ignited by hope*, is indeed appropriate.

This past spring, Ralph Walker, the founder of the Huntington Society of Canada, died unexpectedly. Ralph established much of the foundation upon which our organization is built, and his vision and values are interwoven through the fabric of the Society. Although Ralph retired from our organization over five years ago, his legacy lives on – we are inspired by the memory of Ralph's work. He was a friend to both of us for many years, as he was to countless others, and we will miss him.

In the pages of this booklet, you will read about some of our most remarkable achievements during the past year. Our increased commitments and exemplary programs in research, services and education have continued to make a difference for the Huntington's community.

We continue to be proactive on the research front. With increased financial investment in our NAVIGATOR Coalition program, the Society has contributed strategically to scientific discovery in Huntington disease research. Among the many innovative research projects we have funded are Dr. Blair Leavitt's Centre for Experimental Therapeutics in Animal Models, and Dr. Ray Truant's work on the protein aggregates which form in brain cells of people with HD. Our Research Council believes that these and other projects that we fund will add significantly to the growing knowledge about Huntington disease. Scientists are excited about the possibilities of their research, and ignite in all of us the hope that HD will soon be a distant memory.

As always, providing support and services to those with Huntington disease and their families was a strong priority for us in the past year. Since our inception over 25 years ago, we have been committed to the principle that no HD family should live with the challenges of the disease in isolation. This year, we expanded our network of trained professionals who provide hands-on support to HD families, so that our reach now extends even further across the country.

In the same way that we successfully expanded our efforts in research and services, we continued our highly successful work in education, leading the way as Canada's premier clearing house for information about Huntington disease. Through our newsletter, information brochures for families, and resource booklets for health professionals, we are committed to being an information beacon for those dealing with this disease until such time as a cure is found.

Our achievements and exemplary progress would not be possible without the support of thousands of people across the country who have rallied to fight Huntington disease. As always, our volunteers are pivotal to our success. Their successes in public awareness, fundraising and in building community are astounding. We are also most grateful to the many individuals, corporations, clubs, foundations and other organizations that have provided financial support to our cause. Some are listed in this annual report; all are crucial to our success.

This is an exciting time for the Huntington Society of Canada! We are inspired by the Ralph Walker legacy and solidly committed to making his dream a reality. We are continually moved by the passion and dedication of our community who work tirelessly and give their time, talent, or treasure to defeat Huntington disease. We are all ignited by hope!

Vern Barrett Isla Horvath

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2002-2003 MESSAGE FROM THE CHAIR OF THE CORPORATE CAMPAIGN COMMITTEE

Huntington disease does not touch my family life personally, yet I've seen first-hand the devastation caused by the disease. And I've seen what a difference the Huntington Society of Canada can make in the life of someone living with the reality of HD.

A good friend of mine is at risk for Huntington disease. She watched her mother's physical and mental capabilities decline over many years, and, at the age of 29, she was there when her mother died. Now in her 30's, my friend – a successful advertising executive – has a family of her own. Now she lives with the fear that she could face the same fate as her mother. Worse still, she lives with the fear that her children could, too.

Personally knowing this family is what prompted me to get involved with the Huntington Society of Canada. Learning that it is a professionally-run, fiscally-responsible and compassionate organization is what keeps me involved. I've seen how the Huntington Society helps my friend and her family – providing educational materials and direct support, and offering hope that Society-funded research will soon put an end to this disease.

I, and the other members of the Corporate Campaign Committee, are devoted to doing what we can to help fight this terrible illness that takes such a toll on families. Please, join us in our efforts.

Sincerely,

Stephen C. Beatty
Managing Director
KPMG

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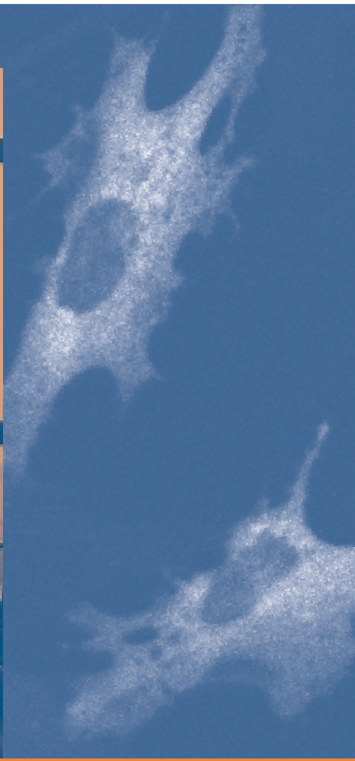
HOPE IGNITED BY DISCOVERY

TOXIC HUNTINGTIN PROTEIN IN A BRAIN CELL



> “Today, the world is a different place because

It was not too long ago when nobody knew what caused Huntington disease. The gene that causes HD had not been discovered, and people could only guess what prompted the gene to “turn on” at a certain point, and start causing the symptoms of HD.

Today, the world is a different place because of what is known about Huntington disease. Thanks to the work of scientific investigators from around the world a genetic marker for HD was identified in 1983; the gene was cloned in 1993; and in 1998 the first mouse model for exploring research theory was developed. The pace of discovery continues to accelerate. Today, through a special computerized microscope, scientists can actually see inside a living cell and witness the effects of HD first-hand. Each research discovery leads directly to the next, fueling hope for those dealing with this disease.

The Huntington Society of Canada contributed strategically to research in Huntington disease during the past year through several projects including those described below.

■ At the University of British Columbia, Dr. Blair Leavitt received a grant to help establish the Centre for Experimental Therapeutics in Animal Models of Human Disease, thanks to a special gift from TELUS Community Connections. An additional grant – supporting the testing of therapeutic compounds on mouse models of HD – is expected to help speed up the process of moving promising drugs to human clinical trials.

NAVIGATOR

■ Also at the University of British Columbia, Simon Warby has been working in Dr. Michael Hayden's laboratory. He has been studying the protein produced by the HD gene to see if it contains a protective region whose function is lost when the protein breaks into pieces.

■ Dr. Ray Truant at McMaster University in Hamilton, Ontario, is trying to understand how and why the toxic protein huntingtin (created by the mutant gene that causes Huntington disease) enters the nucleus of brain cells, and to find out what effect, if any, preventing huntingtin from entering the nucleus of a brain cell has on the process of cell death in Huntington disease. Dr. Truant can actually see how huntingtin moves into the nucleus of a living brain cell by using a very sophisticated microscope (one of a kind in Canada), funded in part by the Huntington Society's NAVIGATOR Coalition grant.

■ In Nova Scotia, Dr. Harold Robertson and Dr. Eileen Denovan-Wright at Dalhousie University have been studying changes in gene expression in the HD brain. In addition, Susan Crocker has been working under Dr. Robertson's supervision to study the mechanisms that lead to progressive cell death in HD mice, and to identify new strategies for arresting the disease process.

■ We renewed our support to Dr. Ira Shoulson for the Huntington Study Group this year. This international consortium of researchers is looking at potential new treatments for HD. A range of possible therapeutic options has been identified, and the HSG will work to move them forward to clinical trials. The Huntington Society of Canada was a founding partner of the Huntington Study Group.

> of what is known about Huntington disease."

■ At the University of Alberta, Dr. Susan Andrew is looking at what makes Huntington disease occur. Specifically, she is studying the expansion of the repetitive DNA sequence of trinucleotide repeats that occurs in Huntington disease. Dr. Andrew's work involves examining the DNA sequences of a newly generated mouse model for HD. If researchers can get at the root of what causes the trinucleotide expansion, the next step is to explore the potential for repairing the damaged DNA.

The Huntington Society's NAVIGATOR Coalition research program is overseen by a group of skilled professionals, under the leadership of Dr. Harold Robertson. The Research Council makes strategic recommendations for the program and reviews all research applications, ensuring that we are investing in research projects with the greatest potential for critical discovery in Huntington disease. The Society is determined to contribute directly to the search for a treatment and cure for HD.

RESEARCH COUNCIL 2001-2002

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Dr. Samuel Weiss
University of Calgary

INSPIRED TO SERVE

MARGUERITE EVANS – ALLIANZ CANADA'S 2001 CAREGIVER OF THE YEAR, AND HUNTINGTON'S CAREGIVER

ALBERTA HD CAMP – SNOW IN MAY

ONTARIO AND ATLANTIC HUNTINGTON'S CAMP

“...there is a community of caring and committed

The Individual and Family Services program is a significant part of the living legacy of Ralph Walker, the Society's co-founder. In 1973, when Ralph and his wife, Ariel began the Huntington Society of Canada there were minimal resources available to families and to health professionals. No one understood the disease, and many families lived in complete isolation, not knowing that there were others who were also trying to cope with the devastation of HD. Ralph and Ariel worked with families and professionals across the country to share what little information there was to as many people as possible. They linked families to others in similar circumstances for mutual support. Almost thirty years later, the Huntington Society has expanded on this initial effort to sustain what is now a vibrant system of nine Resource Centres and thirteen Support Workers – all highly trained professionals. Each day, in every province across Canada, they respond to hundreds of families and health professionals who require information, training, counselling and support. (This past year, a Support Worker was hired to provide services in Newfoundland and Labrador, a first for the province.)

Over the past year, the Services team has responded to families in some of the following ways:

- 6,500 contacts with families and individuals (phone contacts, home, clinic and office visits, mail and email requests);
- 150 support group meetings and information sessions for individuals and families;
- Reaching out to more than 150 new families who have needed our services for the first time;
- Three camp programs providing over 50 individuals with HD the opportunity to meet with others in an environment of acceptance, caring and sharing and providing more than 200 family members and caregivers some form of respite from the demands of caring for a person with HD;
- Over 2,600 requests for information and educational materials.

Health professionals working with families in their communities continue to make use of the knowledge and expertise of the Services team. They are able to call for consultation on their cases; access up-to-date information regarding care for individuals with Huntington disease; and link with other professionals across Canada who have experience in providing care and services to people dealing with HD.

professionals who are there to help.”

BC HUNTINGTON'S CAMPERS

Over the past year, the Services team has responded to professionals in some of the following ways:

- 5,500 professional contacts by phone, meetings, mail and email;
- 100 in-service/training sessions with over 1,000 professionals attending;
- Services team members have attended over 65 neurology and genetics clinics as part of multi-disciplinary teams providing services to individuals and families with Huntington disease;
- 600 referrals to and from community health professionals.

The Individual and Family Services program demonstrates to families every single day that there is a community of caring and committed professionals who are there to help. Thanks to the example set when the Society was first created, and thanks to the unbelievable courage and resilience demonstrated by Canada families who are facing this disease, the Huntington Society is able to fill its Services team with committed professionals who are inspired to serve.

“Twenty five years ago, most people with Huntington disease lived and died in mental institutions. My uncle died a number of years ago with HD. He lived his entire life in his home with the support of his family and home care. Because of the Huntington Society, his family and the community professionals had the knowledge and the help they needed to care for him.”

— Ellen Barrett, Winnipeg, MB

IGNITING HOPE WITH KNOWLEDGE

This past year featured another series of successes in the Society's education and communications efforts, continuing the long tradition of excellence established from the very beginning of the organization. In all media, the Huntington Society of Canada continues to expand its reach.

The Society continues to make its educational material available to anyone and everyone who is in need of information about HD. The Society's newsletter, *Horizon*, has an international readership as it tracks the latest research, shares stories about people dealing with HD, and celebrates the activity of a vibrant community. True to its roots of "spreading the word," the Huntington Society also produced two new booklets of value to the Huntington's community and health professionals across Canada.

Personal Perspectives on Genetic Testing for Huntington Disease, a collection of stories compiled and edited by Susan M. Cox, Ph.D. sheds light on the pressures faced by the Huntington's community caused by the ability to have a definitive genetic test. The booklet holds nothing back as people talk about what was going through their minds as they grappled with the decision to have a genetic test that would tell them whether they had the gene that causes HD, and it explores how people subsequently lived with the decisions they made.

The Society also produced a French translation of one of its most important booklets for health professionals, *A Caregiver's Handbook for Advanced-Stage Huntington Disease*. The new booklet, *Manuel sur le stade avancé de la maladie de Huntington à l'intention des personnes soignantes*, has been of great use to francophones in Canada and abroad.

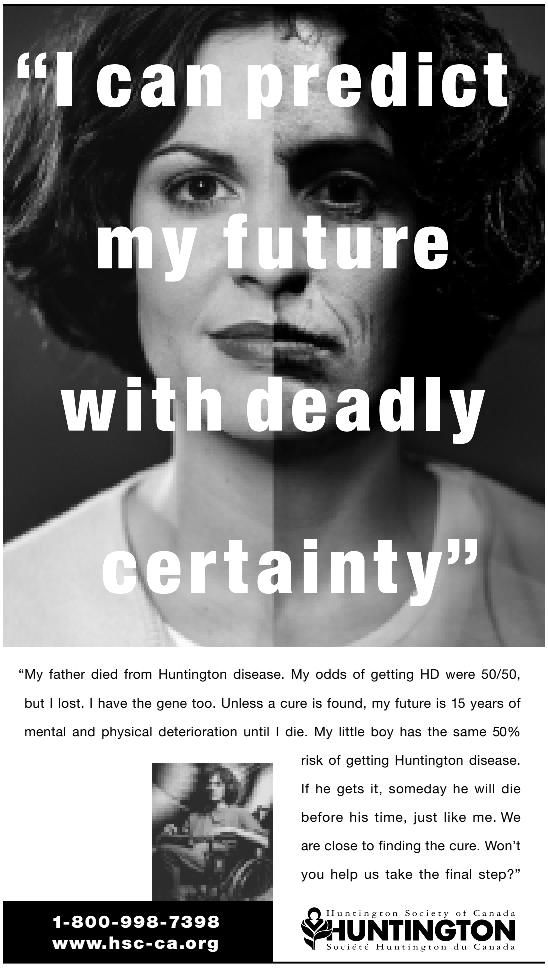
"In all media, the Huntington Society of Canada

RALPH WALKER MAKING A PRESENTATION IN 1995

One of the most significant communications accomplishment of 2001-2002 was the development and launch of a new communications video, entitled *Partners in Hope*. Using the story of the Carmichael family of Halifax, Nova Scotia to highlight the realities of Huntington disease, *Partners in Hope* has proven to be an effective tool for reaching out to the public to explain about the disease and its impact on families, as well as the work of the Huntington Society of Canada.

But the fastest growing hub of activity in the Society's communications program would be its Web site. Receiving just under one million hits during the past year, the site also had more than twenty-thousand downloads of electronic versions of the Society's educational materials. If sharing knowledge by printed word was at the heart of the Society's past, electronic media is proving to be a significant part of the Society's communications future.

continues to expand its reach."



"I can predict my future with deadly certainty"

"My father died from Huntington disease. My odds of getting HD were 50/50, but I lost. I have the gene too. Unless a cure is found, my future is 15 years of mental and physical deterioration until I die. My little boy has the same 50% risk of getting Huntington disease. If he gets it, someday he will die before his time, just like me. We are close to finding the cure. Won't you help us take the final step?"

1-800-998-7398
www.hsc-ca.org

Huntington Society of Canada
HUNTINGTON
Société Huntington du Canada

Manuel sur le stade avancé de la maladie de Huntington à l'intention des personnes soignantes

Personal Perspectives on Genetic Testing for Huntington Disease

A collection of stories compiled and edited by Susan M. Cox, Ph.D.

INSPIRATION & HOPE FROM WITHIN

NEWFOUNDLAND AND LABRADOR VOLUNTEERS (STANDING) WITH THE MAYOR OF CORNERBROOK, NF – PROCLAIMING MAY AS HUNTINGTON DISEASE AWARENESS MONTH

MANITOBA VOLUNTEERS – MAKING A DIFFERENCE IN THEIR COMMUNITY

> “Most volunteers are not only taking on the Society’s cause, they are

Inspired by a vision of a world free of HD, the work of Huntington Society volunteers translates into almost half of our revenue in a given year, and the majority of the public awareness work that the organization undertakes. Ensuring that volunteers have the tools they need to be successful, and to feel successful, in their volunteer work, is something that the Society takes very seriously.

Thanks to financial support from Health Canada, three years ago the Huntington Society launched its Volunteer Training Initiative (VTI) program. Senior volunteers in the organization recognized that the Society needed a more targeted and structured approach to enhancing the skill sets of volunteers to further enhance our communications and development efforts.

The result is a multi-stepped training program that starts from the orientation basics and will ultimately lead to focused modules dealing with, among other things, the finer points of media interviewing, corporate solicitation and volunteer recruitment. In the spirit of the program being “for volunteers and by volunteers,” a train-the-trainer approach has been taken to capitalize on the wealth of experience that experienced volunteer leaders in the organization already have.

This past year, the Society conducted six regional training sessions to roll-out Level I and Level II of the VTI. More than 150 volunteers across the country participated in Level I sessions, with another dozen taking Level II and learning how to be trainers. The program and its approach has attracted significant attention from other charities, and the Huntington Society has been sharing its success with many interested organizations.

Most volunteers are not only taking on the Society’s cause, they are also living the realities of Huntington disease in their own families. Each and every year, the Huntington Society’s achievement is inspired by the commitment of volunteers as we all hope for the year that sees an end to this disease.

FUNDRAISING SUCCESS

Revenues for our fiscal year which ended on June 30, 2002 reached an unprecedented $2 million, enabling the Society to advance in all of its program areas. This growth in revenue is due, in no small part, to the generous support of donors from many sectors: corporations, foundations, service clubs, individuals and other organizations.

But at the heart of our success is the hard work of our volunteer community. Volunteer fundraising accounted for nearly $900,000. National programs like the Huntington's Indy Go-Kart Challenge and the Amaryllis Campaign included volunteers and supporters from all across Canada. The net revenue from the Indy topped $125,000, while the Amaryllis campaign netted more than $90,000. In addition, these programs increased the profile of the Huntington Society and Huntington disease in countless communities across the country.

> also living the realities of Huntington disease in their own families.”

New this year was the *Rally the Sleds for HD* event held in Manitoba. Not only did the Winnipeg Chapter raise nearly $30,000 in this event's inaugural year, but they are also in position to enter the Guinness Book of World Records for the longest, continuous line of moving snowmobiles! Perennial favourites, like the *BC Hike 4 Huntington's*, the *Hamilton Dinner/Dance*, the *Gems of Toronto Walk*, the Corner Brook *Moonlight Ski for HD* (to name just a few), were skillfully organized and executed by our Chapters and Area Representatives. Golf tournaments in Brandon, Toronto and Quebec saw hundreds teeing-off for the HD cause, while bingos and our Nevada ticket program raised nearly $350,000.

Individuals from across the country supported other fundraising initiatives, such as our direct mail campaign and membership drive. A new monthly giving program attracted people who wanted to make steady commitments to our programs, and who contribute a combined total of about $30,000 per year. *Our Shining Stars* program is also off to a successful start, with nearly 30 tribute “Stars” on our night-sky mural. Each star pays tribute to a special person in the Huntington's community. Finally, our *Family Funds* program launched this year raised $75,000 – $15,000 annually for the next five years – and represents a significant and long-term commitment to the cause.

311 SNOWMOBILES GETTING READY TO SET A NEW GUINNESS RECORD

Our Corporate Campaign Committee worked hard to ignite interest in the HD cause throughout the corporate sector, with obvious success: businesses across Canada contributed nearly $150,000 to the work of the Society, and foundations, both private and corporate, donated an additional $150,000.

A special fundraising project, *The Laura's Hope Fund*, was launched by HSC member Warren Evans. Drawing on his personal and business connections, Warren inspired members of the professional speaker's community around the world to commit to the HD research cause, and raised $70,000. Thank you to the many donors, fundraising event participants and sponsors who contributed to the Society's programs this year – their support made our achievements in research, services and education possible.

2002 Huntington's Indy Go-Kart Challenge Tracks

Magic Valley Fun Park, Pictou County, Nova Scotia ■ Atlantic Playland Park, Bedford, Nova Scotia ■ The Sandspit, Cavendish, Prince Edward Island ■ Eurokarting, Montreal, Quebec ■ Kingston Family Fun World, Kingston, Ontario ■ Goodwood Kartway, Stouffville, Ontario ■ Playdium Mississauga, Mississauga, Ontario ■ Indoor Formula Kartways, Brampton, Ontario ■ Benmar Family Fun Centre, Brantford, Ontario ■ Sportsworld, Kitchener, Ontario ■ Blue Mountain Go-Karts, Collingwood, Ontario ■ Family Funland, Kincardine, Ontario ■ East Park Kartland, London, Ontario ■ Thunder Rapids Amusement Park, Winnipeg, Manitoba ■ Parkland Go-Karts, Saskatoon, Saskatchewan ■ Maxwell's Amusements, Regina, Saskatchewan ■ Whitemud Drive Amusement Park, Edmonton, Alberta ■ Rickybob Raceland, Calgary, Alberta

MEMORIES INSPIRE COMMITMENT

HUNTINGTON SOCIETY STAFF HOLDING A CHEQUE FROM BARC FOR $36,193

> “...we can’t help but look at the past and have

The Huntington’s community is built on a foundation of memories. For many of our volunteers, members and donors, their commitment to the HD cause was inspired by memories of people who have lived with – or are still living with – Huntington disease. Their memories ignite in them the desire to contribute to the cause.

OUR SHINING STARS — Paying tribute to loved ones

A new tribute program launched this year gave families and friends an opportunity to contribute to the Society, and to honour their own Shining Stars.

The program features a “wall of tribute” which depicts a twilight sky, filled with golden stars. At the base of the wall, outlined groups of figures, or families, look up together at the night sky. The sky is filled with shining stars, each bearing the name of someone whose life has been touched by HD, or who has made a great contribution to the Huntington Society of Canada.

Some stars honour people who are living with Huntington disease today, while others recognize people who do not have a personal fight with HD, but have been touched by it in some way.

Many of the stars are remembrances of loved ones who are no longer with us. These remind us especially of the courage shown by so many individuals, and inspire us to continue working together in the fight against HD.

As we look at the stars in honour of these remarkable people, we can’t help but look at the past and have hope for all of the future stars in our lives.

The following people are honoured by friends and family members with engraved stars on *Our Shining Stars* tribute wall:

David B. Adams
Dora Anzovino
Alan Bergeron
Barbara Jean Branston
Goetz Buchbinder
Roger Cyr
Beverly Durksen
Hillary Guest
Clarice Costea & Thomas Hanney
Ruby Horsfall
John Houston
Stephen & Glenda Hurst
The McBurnie Family
Marjorie McCaw
Delbert McGovern
Thelma McLeod
Arvene Morden
Henry W. Mueller
Alice Ruth “Grandy” Napper
Laurel Noble
David Pyper
Lyle Grace Rivard
John Rose
Mary Sterling

The Huntington Society's achievements this year would not have been possible without the continued support and collaboration that it has with businesses and organizations across Canada, including:

AGF Group of Funds
Bezeau Family Fund
British Automobile Racing Club (BARC)
Canadian Institutes of Health Research
CB Richard Ellis
Co-op Atlantic
Cormex Research
The Geoffrey H. Wood Foundation
The Healthpartners Fund
Laycock Trust
McKeil Marine Limited
OgilvyOne worldwide
Scarborough Men's Hockey Club
The Joseph S. Stauffer Company
TELUS Community Connections
George Weston Limited

hope for all of the future stars in our lives."

Family Funds —
Long-Term Investments in the HD Cause

Seven families have joined the Family Fund program, demonstrating their desire to make a long-term commitment to the fight against Huntington disease. Each has pledged funds for a period of several years, to ensure the ongoing success of the Society. Some joined the program to express their deep dedication to the cause; some involve several members of one family joined together in their desire to provide significant support; and some pay tribute to loved ones, who either live with the disease or who have lost their battle with HD. All are passionate in their hope for a future without HD.

We are grateful to those who have established the first Family Funds through this program:

Bloom Family Fund
Rick and Norma Brock Fund
Chaplin Family Fund
Cranston-Dorr Family Fund
Sylvia Hickson Family Fund
Sterling Family Fund
Wright Family Fund in memory of Helen-Mary Wright

The Laura's Hope Fund —
A special memorial

Laura Evans was a beautiful young woman who lost her fight with HD last fall, after living with the juvenile form of the disease for 15 years. Shortly after Laura's death, Andrea, her older sister, was diagnosed with adult-onset Huntington disease. Their parents, Warren and Arlene, were devastated, and determined to do what they could to put an end to this disease.

Warren, a professional speaker, immediately started calling upon his colleagues in his professional community to join him in his fight. Together, Warren and Arlene initiated the *Laura's Hope Fund*, a special private family fund designed to support research. The fund is administered within the Huntington Society of Canada, and operates in conjunction with the Society's NAVIGATOR Coalition research program. Within the first six months, Warren and his colleagues had raised $70,000 – and the fund continues to grow.

Laura's Hope Fund – an incredible testament to the power that memories hold, and what they can inspire us to achieve.

INSPIRED TO GIVE

Distinguished Donors ($5,000+)

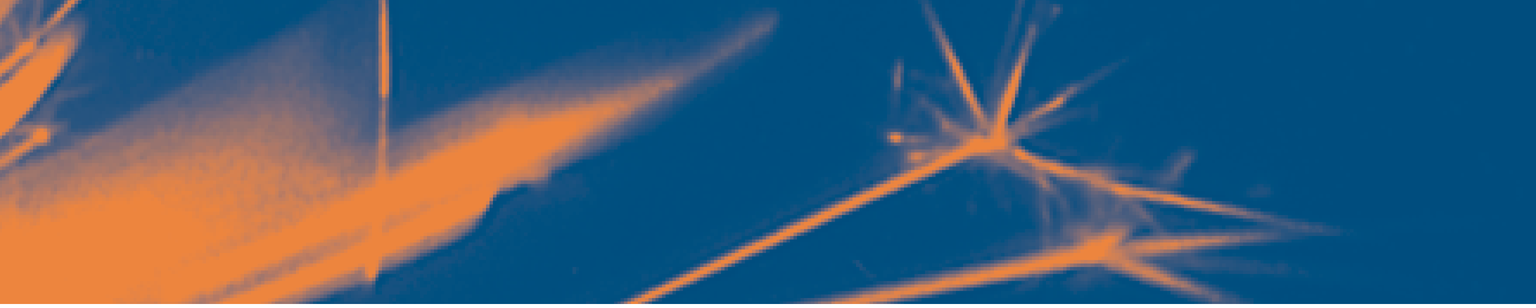
265355 Manitoba Ltd.
AGF Group of Funds
Allianz Canada
J.P. Bickell Foundation
Co-op Atlantic
Connor, Clark & Lunn Foundation
Cooper Communications
George Weston Ltd.
The Henry White Kinnear Foundation
McKeil Marine Ltd.
NABS/Paul Mulvihill Humanitarian Award
Royal Bank of Canada Charitable Foundation
SaskTel
Service Excellence Group Inc.
TELUS Community Connections
The Geoffrey H. Wood Foundation

Leadership Circle Sponsors ($1,000-$4,999)

A & W Food Services of Canada Ltd.
Albert Gale Realty
The Bank of Nova Scotia
Banque de Montréal
Bell Canada, Employee Volunteer Program
British Automobile Racing Club
Cable T.V. of Camrose Inc.
Canac Kitchens Ltd.
CIBC Charitable Foundation
City of Saskatoon
The City of Winnipeg Employees' Charitable Fund
The Clemmer Group Inc.
D.B. Service (1993) Inc.
The Edper Group Foundation
The Edwards Family Charitable Foundation
La Fondation EJLB
The Equitable Life Insurance Company of Canada
Fidelity Investments
Fountain of Hope
Gottardo Contracting Inc.
The Guarantee Company of North America
HighSpin Consulting Inc.
Husky Charitable Fund
Imperial Tobacco Canada Limited
Invar Building Corporation
John Deere Foundation of Canada
John Shea Insurance Brokers Inc.
The Julie-Jiggs Foundation
Leeswood Design/Build Inc.
Lightguide Systems Inc.
M.D. Morton Insurance Agency Inc.
Manulife Financial
The Mayvon Foundation
McGeachy Charitable Foundation
Maunders McNeil Foundation Inc.
Merck Frosst Canada Inc.
Monarch Development Corporation
The N.R. Murphy Foundation
The National Life Assurance Company of Canada
NCE Flow-Through (2001-1) Limited Partnership
On The Right Track Training & Consulting
Pacific Avenue Billiards
Polaris Realty (Canada) Limited
Power Corporation du Canada
Price Waterhouse Coopers
Rallye International D'Autos Neige de Chibougamau Ltee
RBC Foundation
Rockwell International Canadian Trust
Ronson Shoe Stores Ltd.
The Royal Canadian Legion, Galt Branch #121
Samuel, Son & Co. Limited
Sobeys Inc.
Suncor Energy Foundation
Tabrdo Management Ltd.
Talisker Properties Inc.
Talisman Energy Canada
Telephone Chebucto Club
Telus Communications
The Royal Canadian Legion Ladies Auxiliary, Branch #143
The Toronto-Dominion Bank
Val-Temp Sales Ltd.

Generous Supporters ($500-$999)

119931 Canada Inc.
AECON Group Inc.
Alcan Inc.
Armadale Properties Limited
ATCO Electric ECHO Foundation
ATCO Gas Employee Community Service Fund



Bank of Montreal
Banyan Capital Partners
BCE Emergis Inc.
Belrock Construction Design Build Inc.
Bentall Property Management
Camp Forming Limited
The Canada Life Assurance Company
Canada Steamship Lines
Canadian Association of Professional Speakers
Chevalier de Colomb NDL Conseil 10999
Clearwater Fine Foods Inc.
Corner Brook Pulp & Paper Ltd.
Crane Fund for Widows & Children
Credit Union Central of British Columbia
Du Pont Canada Inc.
Dysart & District Lions Club
The Empire Life Insurance Company
Équipements Sigma inc.
First Gulf Group Commercial Development
FundSERV Inc.
Great Gulf Homes
Hampton Leasing
The Joan and Clifford Hatch Foundation
Healthcare Materials Management Services
Hewlett-Packard (Canada) Ltd.
Holy Trinity Parish of New Westminster, B.C.
Hope Learning Systems Inc.
The Hustler Young Men's Bible Class
The Hydrecs Fund
Jiffco International Ltd.
Kiwanis Club of West Vancouver
Kruger Inc.
Fondation Banque Laurentienne
The Joseph & Wolf Lebovic Foundation
Levi Strauss and Company Community Involvement Team
Lombard Canada Ltd.
M & R Holdings
Mainway Electric Ltd.
Marks Supply Inc.
Matelas René Inc.
Medis Health & Pharmaceutical Services Inc.
Meloche Monnex Inc.
Menkes Developments Inc.
Metrus Properties Limited
Morris Industries Ltd.
Olco Petroleum Group Inc.
Pacific Coast Total Solutions Inc.
Papier Laurentide Ltée
Railing Excellence
Reitmans (Canada) Limited
Rexdale Ready Mix
RGA Life Reinsurance of Canada
Rotary Club of Brampton
The Rotary Club of Cambridge North 1974
Royal Bank Charities Fund
Royal Bank Financial Group Employees' Charity Trust
Royal Bank of Canada - Employee Volunteer Program
The Royal Canadian Legion, Galt Branch #121
Safeguard Elevator Maintenance Ltd.
St. George Lions Club
St. Paul's Presbyterian Church
The Standard Life Assurance Company
Tillinghast-Towers Perrin
Union Gas (HO) Employees' Charities Fund
Vancouver Rotary Club Foundation
The Wawanesa Mutual Insurance Company
Staff Assoc.Charity Trust- Workplace Safety & Insurance Board

Matching Gift Supporters

Atco Gas
Clarica Life Insurance Company
Dynamic Fund Foundation
Sir Joseph Flavelle Foundation
Husky Charitable Fund
Reader's Digest Foundation of Canada
SaskTel
SaskTel (Estevan Telcare Fund)
TELUS Community Connections
Union Gas (HO) Employees' Charities Fund

Gift-in-Kind Leadership Donors ($500 +)

Air Canada
Atco Gas
Fairmont Banff Springs Hotel
Trotter & Morton Limited

COMBINED STATEMENTS OF FINANCIAL POSITION

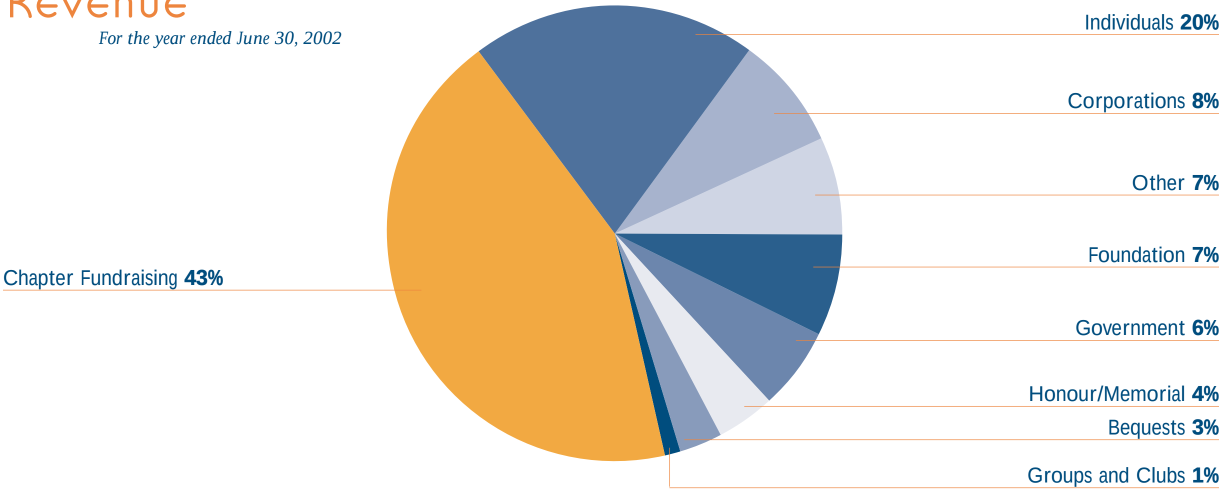
	30 June 2002	30 June 2001
Assets		
Cash	**$ 337,496**	$ 160,083
Investments – at cost[1]	**$ 2,480,163**	$ 2,418,217
Accounts Receivable	**$ 98,935**	$ 99,051
Accrued Interest Receivable	**$ 94,903**	$ 94,809
Prepaids	**$ 33,699**	$ 39,369
Fixed Assets – net of depreciation	**$ 31,957**	$ 24,057
Total Assets	**$ 3,077,153**	$ 2,835,586
Liabilities		
Accounts Payable	**$ 66,953**	$ 59,969
Deferred Revenue	**$ 608,660**	$ 384,905
Total Liabilities	**$ 675,613**	$ 444,874
Designated Funds		
Ralph Walker Research Fund[2]	**$ 803,728**	$ 768,393
Laura's Hope Fund[2]	**$ 112,494**	$ 0
Endowment Fund[3]	**$ 1,509,087**	$ 1,509,087
Undesignated Funds		
General Fund	**$ -23,769**	$ 113,232
Total Funds	**$ 2,401,540**	$ 2,390,712
Total Liabilities and Funds	**$ 3,077,153**	$ 2,835,586

NOTES TO THE STATEMENTS

1. The market value of the investments at 30 June 2002 was $2,666,964 and at 30 June 2001 was $2,554,292.
2. The Ralph Walker Research Fund is used to fund research projects into Huntington Disease. The Laura's Hope Fund was established in honour of Laura Evans, by her parents, to fund, among other things, immediate clinical research.
3. The Endowment Fund was established through a generous grant from the Trillium Foundation. Interest from the fund's capital is used to help support ongoing programmes of the Society. Special projects or unbudgeted annual deficits may be funded from the Fund under exceptional circumstances and subject to a two-thirds approval of the Board of Directors of the Huntington Society.
4. All research awards are expensed as payments are made.
5. The Huntington Society of Canada has made the decision to report separately in these financial statements on governance and accountability expenses, such as annual audit and Board meetings, etc. These are expenses which must be incurred as a charity, to maintain compliance with by-laws and other legal requirements, and to meet all responsibilities to stakeholders, donors and regulators.

Revenue

For the year ended June 30, 2002

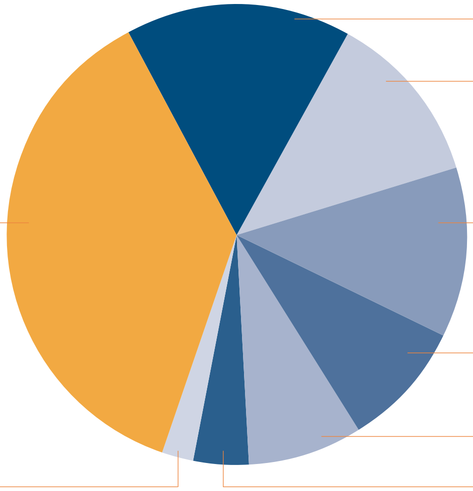


COMBINED STATEMENTS OF REVENUE AND EXPENDITURES

General Funds	**30 June 2002**	30 June 2001
Revenue		
Chapter Fundraising	**$ 912,844**	$ 806,504
Individuals	**$ 424,107**	$ 302,347
Bequest	**$ 71,328**	$ 28,558
Honour/Memorial	**$ 88,119**	$ 59,396
Corporations	**$ 170,750**	$ 129,915
Foundations	**$ 154,321**	$ 105,244
Groups & Clubs	**$ 26,629**	$ 112,496
Government	**$ 121,534**	$ 112,513
Other (including interest)	**$ 149,814**	$ 183,655
Total Revenue	**$ 2,119,446**	$ 1,840,628
Expenditures		
Research[4]	**$ 337,273**	$ 271,813
Individual and Family Services	**$ 776,778**	$ 781,564
Education and Awareness	**$ 249,097**	$ 240,555
Volunteer Training and Development	**$ 196,075**	$ 138,436
Meetings and Workshops	**$ 168,631**	$ 84,535
Governance and Accountability[5]	**$ 47,666**	$ 44,578
Fundraising	**$ 254,364**	$ 205,749
Administration	**$ 78,736**	$ 69,333
Total Expenditures	**$ 2,108,620**	$ 1,836,563
Excess (deficiency) of revenue over expenditures	**$ 10,826**	$ 4,065

Expenditures

For the year ended June 30, 2002



Huntington Society of Canada
HUNTINGTON
Société Huntington du Canada

151 Frederick Street, Suite 400 • Kitchener, Ontario N2H 2M2

Telephone: (519) 749-7063 • 1-800-998-7398 • Fax: (519) 749-8965

info@hsc-ca.org • www.hsc-ca.org

Charitable Registration Number: 11896 5516 RR0001