Huntington Society of Canada

HORIZON

Société Huntington du Canada

RESEARCH - SERVICE - EDUCATION

5*5 — BECAUSE *IT'S TOMORROW NOW*

A Message from the Executive Director

The goal of the ***5*5 Campaign*** is to boost the Huntington Society's yearly revenue by $500,000 within the next five years — to approximately $2.3 million — and significantly expand our programmes in services and research.

Why is this campaign so important? Because it's tomorrow now — new treatments for Huntington disease, once just a hope for the distant future, are being designed and tested in Canada and around the world, and the Huntington Society is committed to leadership in the search for a cure.

Why is this campaign so important? Because the needs of individuals and families who are living with Huntington's today have never been greater. A cross-Canada support network has finally become a reality, but we must ensure that we can maintain and enhance our ability to serve the HD community.

Success will require an extraordinary effort by all members of the HD community. The vision and commitment of volunteers and supporters has enabled the Society to build an enviable record of achievement since 1973 — ***5*5*** is the next step.

The ***5*5 Campaign*** involves new donation programmes, including the Tribute programme and the Family Fund programme (see p. 5); new ideas and resources for chapter fundraising across Canada; and new publicity and promotion materials. We'll be telling you more about the Campaign in this and future issues of *Horizon*.

The launch of this important campaign has received a tremendous boost right at the outset through a wonderful pledge from **The Geoffrey H. Wood Foundation** (see p. 3). We know that there will be much more good news to follow.

The ***5*5 Campaign*** encapsulates the Society's determination to find a cure for Huntington disease, and to offer support to individuals and families who are struggling every day with the devastation of HD. We know that our volunteers and supporters across Canada will help to ensure that the Campaign is a resounding success. — RM

INSIDE

No. 100
Spring 2001

A new strategy for fighting HD?

Using the new YAC (yeast artificial chromosome) transgenic mouse developed in Dr. Michael Hayden's laboratory, investigators at the University of British Columbia have discovered that the normal version of the huntingtin protein (called the "wild-type" protein) can protect cells from the toxic effect of mutant huntingtin.

Dr. Blair Leavitt and his colleagues have been working with YAC72 mice which express both mutant human huntingtin protein and varying levels of the endogenous, or wild-type, protein. Huntingtin protein is expressed at the highest levels in brain tissue and the testes.

Mice expressing mutant huntingtin but not any wild-type huntingtin experience massive cell death in the testes, are infertile, do not produce sperm, and have testicular atrophy.

However, says Dr. Leavitt, when increased amounts of wild-type protein are present, "the mice breed normally and have no evidence of increased testicular cell death". In the YAC46 mouse (which has a smaller number of polyglutamines than the YAC72 model), there is less cell death in general, and increasing the levels of wild-type protein seems to have an even more dramatic effect in preventing cell death. YAC mice which express huntingtin with 18 polyglutamine repeats do not have any cell death, even in the absence of wild-type huntingtin.

These findings are of tremendous interest. First, they demonstrate the link between polyglutamine repeat length and cell death. Second and more importantly, says Dr. Leavitt, "they provide the first direct evidence that normal huntingtin protein may have therapeutic potential for reducing cell death in HD." — RM/BL

See B. Leavitt, J. Guttman, G. Hodgson, G. Kimel, R. Singaraja, W. Vogl and M. Hayden (2001). Wild-type huntingtin reduces cellular toxicity of mutant huntington in vivo. *Am J Hum Genet* 68:313-324.

Huntington Society of Canada
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Horizon is the newsletter of the Huntington Society of Canada. Published quarterly (Winter, Spring, Summer, Fall), its purpose is to convey information to individuals with Huntington disease and their families, health care professionals, friends and supporters.

Huntington disease is a hereditary brain disorder which has devastating effects on both body and mind. The symptoms, which may include uncontrollable jerking movements and relentless cognitive and emotional impairment, usually appear between the ages of 30 and 45, and gradually worsen over the 10-25 year course of the disease. As yet, there is no cure.

The Huntington Society of Canada is a national non-profit organization founded in 1973 to help individuals with Huntington disease and their families.

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Horizon welcomes your comments, ideas and suggestions for future articles. Please contact:
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How big is the HD population?

"Population genetics" is the study of variation in natural populations. It has been used to examine questions ranging from the origins of humans to the evolution of the AIDS virus. Now researchers at the University of British Columbia and Kyushu University in Japan have applied ideas inspired by population genetics to the challenge of understanding the occurrence of Huntington disease.

Using a new mathematical model to measure "mutational flow", Dr. Daniel Falush and his colleagues have concluded that new mutations in the Huntington's gene occur more frequently than has been suspected until now.

"Approximately 10% of individuals who develop clinical disease," says Dr. Daniel Falush, "have parents who, on the basis of their own health history, would not have been considered to be carriers of HD."

Working in collaboration with Dr. Michael Hayden and his research group, Dr. Falush also suggests in the February 2001 issue of the *American Journal of Human Genetics* that current estimates of the size of the HD population are probably too low. The difficulties of recognizing the disease in individuals with fewer than 44 CAG repeats — largely because of the likelihood of late onset — have led to "systematic underascertainment".

The investigators conclude that "clinicians should not assume that HD is rare outside families known to be affected or that most cases have onset at under 50 years of age." — RM/DF

See D. Falush, E. Almqvist, R. Brinkman, Y. Iwasa, and M. Hayden (2001). Measurement of mutational flow implies both a high new-mutation rate for Huntington disease and substantial underascertainment of late-onset cases. *Am J Hum Genet* 68:373-385.

Announcing ...

FIVE FIVE

The Geoffrey H. Wood Foundation

A NEW LEADER IN THE FIGHT AGAINST HD (AND A $250,000 CHALLENGE)

The Geoffrey H. Wood Foundation has just given the Huntington's community cause for celebration — and a very exciting challenge.

Through an extraordinary pledge of $250,000, the Foundation has accepted the role of *Founding Partner* in the Society's new NAVIGATOR Coalition (see p. 4).

John Broley, President and Executive Director of The Geoffrey H. Wood Foundation, explains the rationale behind the Foundation's decision to invest $50,000 per year for the next five years in HD research:

"As a medium-sized foundation with a strong interest in medical research, we are always looking for projects where we can make a difference and where potential project outcomes can be of benefit to a large number of people. The NAVIGATOR Coalition project was tailor-made for our needs, particularly in light of the possible benefits for other neurodegenerative disorders such as ALS, Alzheimer and Parkinson diseases."

Committed to ensuring that their investment generates the greatest possible return — and the largest possible amount of world-class research — Mr. Broley and his colleagues on the Foundation's Board of Directors have made one-half of their pledge, $125,000, conditional. They are looking to the entire Huntington's community to rise to a special challenge.

By June 30, 2002, the Society must demonstrate to The Geoffrey H. Wood Foundation that it has secured $125,000 in new gifts and pledges for the period July 2001-July 2006. (It is not necessary that all the funds be received by next June, simply that the Society demonstrate that we will receive at least this amount in new funding by the summer of 2006.)

This wonderful gift from The Geoffrey H. Wood Foundation gives the HD community a powerful message for all potential new donors, and to current donors who might consider increasing their support. *Every new dollar raised, up to $125,000, will be matched dollar for dollar by The Geoffrey H. Wood Foundation* — ***every $1 will be worth $2 of HD research***.

Through *Horizon* and our mail appeals, we'll be providing additional details on opportunities to contribute to The NAVIGATOR Coalition. If you'd like any advance information, please contact Isla Horvath at the Society's office (1 800 998 7398).

The Huntington Society extends its deepest gratitude to The Geoffrey H. Wood Foundation. — RM

FIVE FIVE

Geoffrey H. Wood (1896-1995)

Geoffrey Hutchence Wood was born in Stony Stratford, England on 6 May 1896. During the early 1900s as he was nearing completion of his studies at school in Stormington, at age 13, he became infatuated by the great new dominion, Canada. By the age of 16 his application to government officials in Alberta for immigration and employment opportunities had been accepted.

Mr. Wood founded G.H. Wood & Company Limited in Toronto in 1922. He rapidly became Canada's largest manufacturer and distributor of sanitation products to the health care and commercial sectors coast to coast. He subsequently expanded the company to the United States and overseas, trading under the well-known registered trademark and slogan, "Sanitation for the Nation".

After devoting 65 years of his life as Chairman and CEO of the company, Mr. Wood at age 91 was inducted into the Canadian Business Hall of Fame on 2 April 1987.

Later that year, G.H. Wood & Company was sold and with the proceeds from the sale of the company's real estate, Mr. Wood created The Geoffrey H. Wood Foundation — "to thank Canada for the good fortune that I have enjoyed".

Mr. Wood remained active in the Foundation for many years until his passing in his 100th year, in 1995.

Thanks to a remarkable philanthropist, Canadian hospitals, universities and inner city charities have to date benefited from Foundation grants in excess of $7.5 million.

This biography is reprinted with the generous permission of The Geoffrey H. Wood Foundation, and includes excerpts from Mr. Sanitation, the authorized biography of Geoffrey H. Wood, by Samuel Tughan.

THE NAVIGATOR COALITION

NAVIGATOR

Founding Partner: The Geoffrey H. Wood Foundation

In 1998-1999, the Huntington Society of Canada launched a new research programme, called NAVIGATOR, with a view to significantly expanding the Canadian contribution to the global HD research effort.

NAVIGATOR was designed to build on the growing momentum of HD research since the 1993 gene discovery, and to respond to the determination of the Canadian Huntington's community to find a cure for HD. Developments over the past few years have left no doubt about the accelerating pace of Huntington's research. There is now an unshakeable conviction within the scientific community that new treatments for Huntington disease are within reach, even that a cure will soon be found.

To build quickly on the early successes of the NAVIGATOR initiative, the Huntington Society is now preparing to launch the next stage in its research programme: the NAVIGATOR Coalition. This project will:

- bring Canadian investigators currently active in HD research together in a network;
- give increased support to scientific research into Huntington disease in Canada;
- provide a platform for recruiting outstanding new laboratories to HD research.

Given the immediate relevance of Huntington's research to various neurodegenerative and other disorders, the NAVIGATOR Coalition will also serve to enhance the traffic of scientific insights relevant to Parkinson disease, Alzheimer disease, ALS, and other illnesses. It will also provide an excellent foundation for collaborative research.

Management of the Coalition will be placed in the hands of a special Steering Committee of internationally-regarded experts, including Dr. Gillian Bates of King's College, London (the scientist who developed the first animal model of Huntington disease), Dr. Steven Hersch of Emory University (a leader of the Huntington Study Group and the HDSA's Coalition for the Cure), and Dr. Marcy MacDonald of Harvard Medical School (who played a leading role in the discovery of the HD gene). These and other experts will be working in close collaboration with the Huntington Society of Canada and its Research Council to ensure that the NAVIGATOR Coalition achieves its goals.

Scheduled for launch in July 2001, the NAVIGATOR Coalition will be the flagship of Huntington's research in Canada. — RM

The NAVIGATOR Coalition will bring Canadian investigators currently active in HD research together in a network.

FIVE FIVE

NEW OPPORTUNITIES FOR GIVING

The success of the Huntington Society owes so much to the many individuals who contribute every year, often two or three times, to the Society's programmes.

Whatever the size and frequency of your giving, the Huntington Society is developing exciting new plans for recognizing your support through the ***5*5 Campaign***. We will be launching new initiatives over the course of the ***5*5 Campaign***. To get the ball rolling, we are pleased to announce two new giving opportunities: the Family Funds and the Tribute programmes.

The Tribute Programme

We never want to forget the many wonderful people who form the Huntington's community: those whose lives are touched by Huntington disease, and those who have made the Society such a vibrant national organization. To this end, we announce a the new Tribute programme.

For a donation of $250 or more, you can have a photo of a special person and a name plaque mounted on the Tribute Wall in the Society's office. This is a wonderful way to recognize an individual who is living with Huntington disease today, or someone whose fight with Huntington's has ended. Or, you could recognize someone special who does not have a personal fight with HD, yet whose life is touched by it in some way.

The Wall will have special meaning, as it fills with the images of individuals, coast to coast, in the Huntington's community.

The Family Funds Programmes

The Huntington Society's new Family Funds programme is another important part of the ***5*5 Campaign***.

The gifts we receive from our supporters each year come in all different sizes. All of them, large and small, are of tremendous importance. The Family Fund programme offers special opportunities to those who are able to contribute at a higher level, and who wish to increase their own giving to the Society, or to challenge other members of their family to increase their gifts, or both.

The Society's first Family Fund was started by the Chaplin Family, from Cambridge, Ontario. Jim Chaplin has been a long-time supporter of the fight against Huntington disease, both as an individual donor and as a member of our corporate campaign committee.

Jim is happy to be able to contribute in this new way. He says, "The Family Fund enables us to make a sustained commitment to the Society over the next five years. What's really exciting, too, is that our donation will be matched, dollar for dollar, by The Geoffrey H. Wood Foundation. Our gift is doubly valuable."

Named after your family (or an individual family member you wish to honour or memorialize), Family Funds involve a multi-year commitment to the Society's programmes. Whether it's $1,000, $2,000 or $5,000 per year, the total pledge can come from an individual or from a group of family members, and the gift schedule can be tailored to meet your needs.

Family Fund:	**$1,000 per year (total pledge equal to $5,000)**
Partnership Fund:	**$2,000 per year (total pledge equal to $10,000)**
Leadership Fund:	**$5,000 per year (total pledge equal to $25,000)**

The special fund in your family's name will be recognized in the Society's newsletter, Annual Report and other special publications which will be appearing over the course of the ***5*5 Campaign***. All Family Funds will also be recognized with brass name plaques on the Tribute Wall at the Huntington Society's office.

Family Funds offer you and your family a chance to attach your support to our services programme or to the new NAVIGATOR Coalition. If your preference is research, and if your Family Fund represents an increase in your total donation to the Society, the amount of the increase will be matched on a dollar for dollar basis by The Geoffrey H. Wood Foundation (see p. 3), up to $125,000. — RM/IH

Contributions to the Family Funds and Tribute programmes will be recognized with brass name plaques on the Tribute Wall at the Huntington Society's office.

The Cheque is in the Mail

Many *Horizon* readers will have received our latest mail appeal just before Christmas. Thanks to all who responded so generously. Donors contributed 635 gifts, totalling over $70,000, to the campaign.

We have a database of more than 4,000 current donors who believe in the HD cause, and who know that they can make a difference with their gifts. Last year, these individuals contributed over $120,000 through mail appeals.

The potential for growth is significant, and we are always looking at ways to increase revenue in this area. We recognize that our most loyal donors are HD family members; these donors contributed the bulk of that $120,000 last year. But we have room to grow even here — consider that there are more than 15,000 Canadians living at risk for HD.

We also need to encourage donations from outside of the HD community. This is the reason we've decided to conduct a special mail campaign to attract new donors. As *Horizon* readers are aware, the Society is testing a traded list as one strategy for extending our reach and our revenue. We trade only the names and addresses of donors who are willing to help in this way. Nothing else is traded — no donation information and no personal history.

These supporters of the fight against HD are contributing in a unique way. By allowing us to trade their names and addresses, they are helping us to build relationships with potential new donors.

The Huntington Society is fiercely committed to honouring the wishes of our donors. If you would prefer not to participate in the programme, but haven't yet registered your preference, please let us know. We will adjust our records accordingly, and ensure that your name is not traded. (Our records were updated after the Christmas appeal to reflect the preferences of anyone who checked the "Do Not Trade" box on the return form.)

Also, if you would like us to write to you just once per year, tell us, and we'll make sure you get only one request at the time of year that you would like to receive it.

The bottom line is that our donors are important to us. If you have any questions about our mail appeal programme, don't hesitate to contact us.

What can a small national health organization hope to achieve by building its database of supporters? We recently chatted with staff at the ALS Society. ALS (or Lou Gehrig's Disease), like Huntington's, is quite rare. But the ALS Society has been consciously building up its mail programme since 1991, and now has a database of 40,000 active donors who, it is estimated, will contribute more than $900,000 this year through mail appeals.

Imagine what we could do with an additional $800,000 in our research and family services programmes. – IH

Development Department Grows

We are pleased to welcome a new member to the national development team. Jen Love joined the Society in January as Development Coordinator: Chapter Operations.

Jen will be working on both fundraising projects and chapter development. Some components of Jen's job include management of the national Amaryllis Campaign, coordination of the Service Club appeal, and volunteer development.

Both Jen and Cindy Lewis (Development Coordinator: Fundraising Programmes), are available to work with volunteers across the country on their fundraising projects. They can be reached at the Society's office at 1-800-998-7398. – IH

Participants needed for the PHAROS study

For more information about the PHAROS study and how to participate, please contact the Huntington Society of Canada at 1-800-998-7398, or the study site nearest you (see list below).

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Looking to the Horizon

By Ralph Walker, HSC Founder and Shawn Mitchell, Director of Communications

Horizon has come a long way from its initial roots. In 1973, the newsletter for the Ontario Chapter of the Committee to Combat Huntington's Disease was distributed to just over 200 families and professionals. Today, the Huntington Society of Canada distributes its quarterly newsletter to over 7,000 families, health professionals, and donors in Canada and around the world.

What truly makes *Horizon* great, is that it has always responded to a need and demand for information. In 1974, there were 500 names on the mailing list, each neatly recorded on a recipe card and stored alphabetically in two shoe boxes, one for families and the other for professionals.

Since 1974, the Society has moved well beyond the days of working out of Ralph and Ariel Walker's home. Mailing lists have grown, the newsletter is published four times per year, *Horizon* became the newsletter's official title in 1984, and the design has changed several times.

While the *Horizon* of today looks different than its previous incarnations, its purpose and spirit have never changed. *Horizon* continues to meet the need for information about HD that exists in communities across Canada. It is filled with news about the rapid advances of research and of ever-expanding supports for families; shares stories about people in the HD community; and announces the arrival of new publications and related resources. The Huntington Society of Canada has come a long way, and so has its newsletter.

Most important of all, however, has been the volunteers who have played such an integral part in making sure that *Horizon* gets to its many readers. At the beginning, the job was taken up by the members of the Cambridge Alpha Rho Chapter, Beta Sigma Phi, and a small circle of Ralph and Ariel's friends and family, who gathered around their dining room table to collate, stuff and stamp the newsletters. Over the years, that group expanded as the mailing list grew and postal regulations increased. Today, and some hundreds of thousands of copies later, this is the first issue of *Horizon* that has not been prepared for mail by volunteers, many of whom have contributed to this process for years. On behalf of the entire Huntington's community – thank you.

Dr. Nancy Wexler Venezuela Research Team

Horizon

NAVIGATOR

New Research Program Charts the Course to a Cure

Inside:

Horizon then and now. (Top) Newsletter#1 from 1974; (Middle) Issue #35, featuring the new name of the newsletter, Horizon; (Bottom) Issue #89, a new look for Horizon in the Society's 25th year.

A different Hillary climbing a different mountain

by Shawn Mitchell, Director of Communications

"When Dr. George Huntington first identified Huntington disease in 1872, he stated that the disease 'manifests itself only in adult life'. It is now known that Huntington disease can occur in individuals younger than five years of age."*

Hillary Guest is nine years old. He has a baby brother, Zackary, who is not quite two, and his parents, Al and Carole, both work with adults with disabilities at the Oshawa-Clarington Association for Community Living. Both Hillary and his father Al have Huntington disease.

"Diagnosing juvenile Huntington disease can be very difficult. Juvenile HD is extremely rare, and few physicians will have encountered the disease before. This can lead to a great deal of time being spent eliminating other possibilities."*

Carole, Hillary's mother, first noticed something wasn't quite right with Hillary before he was even two years old. It became apparent that rather than gaining skills as he got older, he was regressing, and actually losing certain abilities. By the time he was four years of age, he was falling a great deal, frequently requiring stitches. It often looked as though Hillary lacked proper reflexes – if he started to fall, he would do nothing to stop himself.

For more than six years, Carole and Al took Hillary to a variety of doctors and specialists to try and establish what was wrong with their son. Dyslexia, autism, and other conditions were ruled out. By the age of five, Hillary was clearly quite ill. It wasn't until he started working with a therapist, after having been diagnosed with Step III Integration Dysfunction (inability to sense where one's body is in space), that it was suggested that Hillary should see a neurologist. Ultimately, it was decided that Hillary should have a predictive test for HD.

"Early signs of juvenile Huntington disease include: rigidity; awkwardness in walking; clumsiness and frequent falls; difficulty in speaking; choking and drooling. … Disease onset before the age of six years is extremely rare."*

At the age of eight, Hillary had tested positive for the gene that causes HD, and was diagnosed with the juvenile form of the disease. Today, Hillary has difficulty swallowing and has had a feeding tube inserted into his stomach to ensure that he receives proper nourishment; he drools a great deal; has scoliosis; has an extremely stiff gait and often uses a wheelchair; and is unable to communicate verbally. Despite all of these "adult" challenges, Hillary is still a little boy.

After school (he attends a special school on a part-time basis), he comes home and either watches a favourite video, or plays a favourite CD. "His musical tastes are quite varied," says Carole, "he likes to listen to Amanda Marshall, the Beatles, Creedence Clearwater Revival, and Joe Cocker."

Even though eating is something that Hillary does not like to do (and technically, because of his feeding tube, no longer has to do), there are certain meals that he wants to be around. "Often if I've made something he likes, he'll suddenly appear at the table, without anybody asking him, set himself down, and eat what he can."

"Like its adult counterpart, juvenile HD remains incurable, and there are no treatments which can stop or slow the course of the disease. However, dramatic advances in research have given rise to tremendous optimism that new forms of therapy will soon be within sight."*

In August 2000, Nancy Webb, Toronto Resource Centre Director for the Huntington Society of Canada, approached Carole and Al about submitting an application to the Children's Wish Foundation on their behalf. They agreed, and to their surprise, within a couple of weeks they had received a call from the Foundation asking when they would like to go to Disney World in Florida. Arrangements were made to go for a week at the end of September.

"The whole experience was fabulous," says Carole. The entire family was picked up in a stretch-limousine at their home in Bowmanville, and driven to Lester B. Pearson Airport in Toronto. They flew to Tampa, Florida, and were supplied with a mini-van to take the family to Orlando.

In addition to being supplied with ground transportation and flight, the family was supplied with passes to Disney World, Universal Studios, and SeaWorld; full hotel accommodation; and US $1,200 spending money for their week in Florida. Days were spent seeing the sights, evenings were spent at the hotel watching movies and taking advantage of hotel amenities. The whole trip was set up to be as easy as possible. "We didn't even have to stand in line to enter any of the theme parks," says Carole.

"As the illness progresses, children with HD are capable of doing less."*

For Hillary, highlights of his Florida adventure included the Disney World Magic Kingdom theme park (especially the Curious George pavillion), the Haunted House ride and the animals at SeaWorld. It is not hard to imagine Hillary and his family having a wonderful time, building special new memories of time spent together.

"Families should enjoy and celebrate all the happy moments and small victories life brings – a new skill, a good day at school, a joyous family get-together. The emphasis should be on *living* with juvenile HD."*

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* Excerpt from *Juvenile Huntington Disease: A Resource for Families, Health Professionals and Caregivers*, Huntington Society of Canada, 2000.

Lives Interrupted

Toronto HD Family to be featured on Vision TV and WTN

Ignatius "Iggy" Pace (shown here at the HSC Summer Camp in 1998) and her three children will be featured on Vision TV and WTN's Lives Interrupted series. — Photo courtesy of Rob Laycock.

Ignatius "Iggy" Pace is 61 years old, and is in the advanced stages of Huntington's. Her daughters Ann and Margaret live at home with their mother, and her son John lives a five-minute walk away. Together, the three siblings have made adjustments in their lives so that they can care for their mother in her home. Their story will be featured in a new thirteen-part series that is in production for Vision TV and WTN.

"Lives Interrupted" will feature half-hour segments that examine in vivid, emotional and poignant detail how people rework their lives after chaotic experiences. The three-act shows include first-person interviews, dramatic re-enactments and the testimony of experts.

The series explores how people recover from life-changing events and transform themselves after severe adversity and tragedy. Episodes include stories dealing with rape, murder, incarceration, war, stroke, AIDS, torture, breast cancer, suicide, sexual abuse, terrorism, and Huntington disease.

"Lives Interrupted" is produced by Sleeping Giant Productions in association with Vision TV, WTN and Great North International. The series will first begin to air in the Fall of 2001, and a reminder will appear in the next issue of *Horizon*. — SM

2001
International Year
of Volunteers

International Year of Volunteers 2001 launched around the world

The United Nations' declaration of International Year of Volunteers (IYV) 2001 gives cause for celebration to over 7.5 million Canadian volunteers and 175,000 not-for-profit organizations. Launched in Canada on December 5, 2000, IYV 2001 promises to be a landmark year for Canadian volunteers and the voluntary sector.

"The International Year of Volunteers affords us all with a rare opportunity to put volunteers and volunteering in the forefront of our thinking," says Lila Goodspeed, president of the board of directors of Volunteer Canada, the lead charity for IYV 2001 planning in Canada.

The launch of IYV 2001 in Canada was marked with Volunteer Canada's release of the Canadian Code of Volunteer Involvement, a document that outlines the values and standards of volunteer involvement for organizations. The Code is the first in a series of resource materials to be released in 2001.

The IYV 2001 Canadian Web site, <www.iyvcanada.org>, is designed to keep Canadians up to date on events and activities for the year. Visitors are encouraged to add their IYV 2001 events to the national calendar, pledge their volunteer hours, and post their volunteer stories. The Web site also links to the Volunteer Opportunities Exchange at <www.voe-reb.org> where individuals can count themselves in as volunteers.

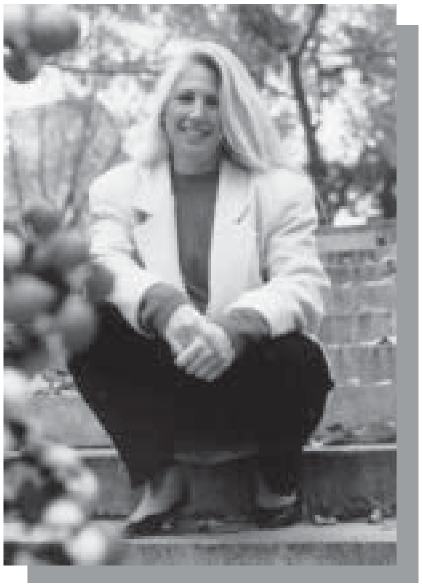
National planning for IYV 2001 in Canada is a joint initiative of Volunteer Canada, Canadian Heritage, and Human Resources and Development Canada.

Volunteer Canada is a registered charitable organization, a national leader whose mission is to promote volunteerism in Canada. For more information on IYV 2001 please call (telephone number and Web site) (800) 670-0401 or visit <www.iyvcanada.org>.

Just some of the Huntington Society's many, committed volunteers.

International Huntington Association: Spreading the word around the globe

By Ralph Walker, HSC Founder



"Individual people can make an impact, and when you're a group like this all across the country you make a bigger impact and when you're international, you make an even bigger impact. There is absolutely no question that the Huntington movement we're all part of is considered one of the most successful in the entire world. And what are we? Just individuals getting together and saying, "this disease cannot get me down, I'm going to conquer this thing. And we're going to do it soon. We're going to do it in the lifetime of ourselves and our children.'" — Dr. Nancy Wexler

1967

Five families meet with Marjorie Guthrie in New York to begin the first volunteer HD organization in the world.

1974

Mauveen Jones (UK) and Ralph Walker (CAN) attend annual meeting of the American HD organization to meet with Marjorie. They agree to start an international HD association.

1976

Marjorie Guthrie invited to Holland to visit Dutch scientists and meet with 200 family members, including Gerrit Dommerholt, who would later take up the international development cause.

1979

International Huntington Association (IHA) formally established, with Marjorie Guthrie as President. Member countries include: the United States, Canada, United Kingdom, Netherlands, Belgium, France, West Germany and New Zealand.

1981

Italy now represented at the IHA.

1983

Genetic marker for HD gene is found, and Canada hosts the IHA meeting in Niagara Falls. India now represented at IHA.

1985

Thirteen countries, now including Denmark, Ireland and Norway, meet in France for IHA meeting. Ralph Walker is elected President, and Predictive Test Committee is established to draft guidelines for when a predictive test is made available for those at risk for HD.

1987

Sweden, Israel, Finland and South Africa newly represented at the IHA.

1989

Canada hosts IHA meeting in Vancouver, welcoming for the first time a delegate from behind the Iron Curtain (East Germany).

1990

Political change in Eastern Europe makes it possible to make contact with HD families and physicians in countries such as the Czech Republic and Slovakia.

1991

IHA welcomes delegates from Austria and Scotland.

1993

Gerrit Dommerholt completes four-year term as IHA President, and agrees to become the International Development Officer, working part-time for the IHA without pay. IHA meeting in Boston welcomes delegates from Ecuador, Indonesia, Mexico, Northern Ireland and Russia.

1997

IHA now has representation from Hungary, Malta, Japan, Finland and Pakistan. An IHA Web site is established <www.huntington-assoc.com> with help from the Spanish HD association. Since June 1999, more than 13,000 people from 74 different countries have visited the Web site.

1998

With the help of the HD association in Spain, growing demand for information about HD in Spanish is answered. New members to IHA include Brazil, Portugal, Uruguay, Venezuela and Slovenia. As well, the European Federation of Neurological Societies begins to assist in the IHA's work.

1999

HD resource material is translated into French and distributed to Switzerland, France, Luxembourg and Belgium. In a joint meeting of the IHA and the scientific community, 160 scientists and physicians from around the world, and 85 IHA representatives from 26 countries share their combined knowledge and experiences.

2000

IHA develops contact with Greece, and delivers a lecture on HD at EXPO 2000 in Hanover, Germany. A representative from the Spanish HD association is a delegate to a conference of the Movement Disorder Society in Barcelona; a representative from the Danish HD association is a delegate at the conference of the European Federation of Neurological Societies in Copenhagen.

2001

IHA develops contacts in Cuba, building on recent successes in Peru, South Korea and Thailand.

BARC and the Huntington's Indy Go-Kart Challenge

Here we grow again …

The sponsors of our Toronto Indoor Huntington's Indy Go-Kart Challenge — the British Auto Racing Club (BARC) — are going back to the track. This time, BARC will be holding its own Indy on March 31st & April 1st at Indoor Formula Kartways in Brampton, Ontario. The group is running four sessions over two days, with participants from BARC and other businesses. The net proceeds from this event will be donated to the Huntington Society of Canada. BARC members will also be participating in our *Huntington's Indy Go-Kart Challenge* on Sunday, September 9, 2001.

Thanks so much to the folks at BARC for their amazing dedication and support, and special thanks to Judy Lang and Drene Prentice. – CL

Teff-Line Golf Tournament: Helping us find the green …

— Photo courtesy of Cindy Lewis.

On an unusually cold day last September, the owners of Teff-Line in Burlington, Ontario held a Charity Golf Tournament at the Beverly Golf and Country Club. Golfers braved the cold and were rewarded with a great dinner and prizes. Teff-Line donated the net proceeds of $5,500 to the work of the Huntington Society of Canada. Thank you to all the participants and sponsors of the tournament, and a very special thanks to Chris and the rest of the Hillsley family. – CL

RETURN FORM

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☐ Enclosed is my *Membership* payment ($25 per person)

☐ Enclosed is my *Lifetime Membership* payment ($250 per person)

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☐ Please remove my name from the *Horizon* mailing list.

New Publication

Copies of *A Personal Perspective on Estate Planning for HD Families* are now available from the Huntington Society of Canada's office.

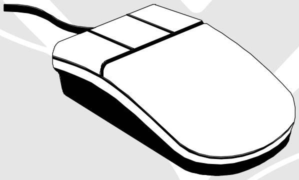
Written by PEI volunteer, Stephen Hurst, the booklet is a helpful guide to financial planning from the unique perspective of an HD family. "This brochure will tell you about our own family's planning process. Every family situation will be different, of course, but the need for appropriate estate planning is common to most of us. The exercise may be challenging and sometimes complicated, but it's worth it for the peace of mind which comes with knowing you've done everything you can to protect your loved ones."

The Huntington Society of Canada is grateful for the generous contribution of Equitable Life of Canada to the production of this brochure.

As of March 15, 2001, the brochure will also be available in electronic format at <www.hsc-ca.org>. – SM

HSC in Cyberspace

On January 15, 2001, the Huntington Society of Canada launched its new Web site at <www.hsc-ca.org>. Featuring streamlined site navigation tools, as well as fresh content and organization, the Web site has so far been a hit with users.



Here are just a few of the comments the Society has received:

> "Great website. Sooooo simple to print from the PDF, our own Jim Pollard's Caregiver Handbook and the JHD handbook! And, there are great links to the International Society, etc.. Very, very nice. Thank you very much."
>
> "… let me take this opportunity to say how much I like the newly designed Web site! The pages are well done and the donor information is very easy to find."

"The site is easy to read and navigate, very important especially for people with HD!"

Every month new information and material will be posted to the site, so be sure to visit often. To send along any comments or suggestions, contact Shawn Mitchell, Director of Communications, at <smitchell@hsc-ca.org>. – SM

If undeliverable, return to:

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