Huntington Society of Canada

HORIZON

Société Huntington du Canada

RESEARCH - SERVICE - EDUCATION

The Beginning of a New Era

By Vern Barrett
Chair, HSC Board of Directors

The Huntington Society of Canada is about to enter a new era in its development, and I'm pleased to provide this report, conveying some important news.

First, I'm delighted to report that the Board of Directors has appointed Isla Horvath as our Executive Director.

Isla is a leader in our organization, and she brings enormous strength to our activities and programs. She has worked very closely with our volunteer network for nearly 20 years on communications, fundraising and chapter development. Since being promoted to Director of Development in 1998, Isla has played an increasingly senior role in the Huntington Society and has taken on significantly enhanced responsibilities. Some of her major accomplishments have been in the areas of financial management, staff leadership, and cultivation/stewardship of major gifts and partnerships.

During the past three months as Acting Executive Director, Isla has demonstrated superior management ability and risen to the occasion without fail. She has brought a wealth of experience and insight to the Acting position, and has demonstrated that she is a very effective leader who is able to "build team" in the organization.

"I'm delighted to have an opportunity to work in this new role in the Huntington Society," says Isla. "I'm fortunate to have a chance to work in an environment that I love, with people I respect, for a cause about which I'm absolutely passionate. I look forward to the day when, together, we put an end to Huntington disease."

Isla will be working in our Kitchener office, and looks forward to hearing from volunteers, donors, members and friends of the Society. Feel free to contact her at 1-800-998-7398, or by email at <ihorvath@hsc-ca.org>.

Additional changes will soon take place in the Kitchener office, including the hiring of a new Director of Development, and some exciting new approaches to the work of the communications and volunteer development programs. Watch for details in future issues of *Horizon*.

I'm also happy to tell you that your Board of Directors has initiated a new strategic planning process. The plan we're currently working under comes to an end in the next year, so we're now developing our new strategic plan to take us from 2003 to 2006. It will be developed through broad consultation with board members, staff, volunteers and other HSC representatives. The Board is very excited about this new process. Watch future issues of *Horizon* for updates on our progress and opportunities for input into the process.

On a much different note, it was with great sadness that we learned of the premature death of our founder, Ralph Walker, on March 22, 2002. I knew Ralph personally for more than 20 years, and I considered him to be a very treasured friend. Ralph has also been a mentor and inspiration to many of us as we serve and work in the Huntington Society of Canada. Along with the thousands of people who were touched by his compassion, I will miss him terribly. Please see the inner pages of this newsletter for our tribute to him.

Ralph Walker's vision of a world without Huntington disease continues to be the driving force behind our organization. As our research program drives towards a treatment or cure, we continue to expand our excellent services for individuals and families, and develop outstanding educational materials. With new leadership in place, and the beginning phases of the strategic plan underway, the Board is confident that the Society is well-positioned for great achievements in the future. Thank you for your continued commitment and support. Together, we can make Ralph's dream a reality.

As always, we welcome feedback from all of our constituents, members and friends, and I encourage you to address any questions or comments to the Board, in care of the Society's office at 151 Frederick Street, Kitchener, ON, N2H 2M2. We value and appreciate your input.

INSIDE

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SUMMER 2002

Stem Cells and Huntington's Research:

Background

It is exactly one year ago that the Huntington Society of Canada featured an article on the front cover of *Horizon* (*Horizon*, #101, Summer 2001) about stem cells and Huntington disease. Written by Dr. Sam Weiss from the University of Calgary, a leading stem cell researcher and a member of the Society's Research Council, the article talked about the potential role that stem cells could play in the development of a treatment for Huntington disease.

Since that time, the media coverage about stem cells has grown, as has the research effort. Most recently the media has focussed on the regulation of stem cell research. Who is in charge? What role should government play in providing some level of control over the use of stem cells in research? What about the moral, legal and ethical implications of such research?

In the past year the United Kingdom and the United States have both passed legislation to provide rules for stem cell research in their respective countries. Canada is about to do the same thing.

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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.

Editor: Shawn Mitchell
Layout: Real World Graphic Design

Horizon welcomes your comments, ideas and suggestions for future articles. Please contact:

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But before a country passes such laws, what are researchers supposed to do? In response to the growing demand in the research community for direction on this point, the Canadian Institutes of Health Research (CIHR) put together a Working Group on Stem Cell Research.

After collaborating with expert researchers, lawyers, ethicists and lay-people, and after public consultation, the Working Group eventually drafted the document, *Human Pluripotent Stem Cell Research: Recommendations for CIHR-Funded Research.* These guidelines clarify what kinds of stem cell related research the CIHR will fund, and what it will not fund. While these guidelines do not restrict private research, the pending legislation by the Government of Canada will soon provide controls for research that is privately funded as well.

What are (some of) the issues?

For people in the Huntington's community, all of this still leaves some important questions unanswered. First, what makes stem cells so controversial? Second, what are the rules about this kind of research (i.e. what do the CIHR guidelines actually say)? Third, are stem cells important to Huntington's research? And finally, what does the Huntington Society of Canada have to say about all of this?

What makes stem cells so controversial?

Broadly speaking, a stem cell is an undifferentiated cell – meaning that it hasn't taken on an identity in the body yet, like being a skin cell, or a brain cell – that can renew itself and, with some limitations, become a more specialized type of cell.

But there are different types of stem cells, and different ways to get them, and this is where the controversy starts.

An embryonic stem cell is a stem cell that is taken from an embryo after the embryo is four or five days old. In Canada, the main source for such embryos are in vitro fertilization clinics. In such clinics, embryos which are grown from fertilized eggs are not all implanted as part of the reproductive process. These "extra" embryos can be donated to laboratories for research purposes.

These embryonic stem cells are called *pluripotent* because they can grow into any of the body's hundreds of different cell types. Because these cells have the potential to become just about any cell in the body, they are seen as being the most important to stem cell research efforts. They are also controversial for some people because they are taken from unused human embryos.

There are also adult stem cells. These are stem cells that can be found in different places in the human body, and are consequently less contentious. Because they are older cells than embryonic stem cells, and because they are found in specific parts of the body, these stem cells cannot become just any cell. Typically, they can become any specialized cell type associated with the tissue where they are found.

For example, there are adult stem cells in the human brain. These adult stem cells cannot become skin cells, but they can become specific cells in the brain. Recently there was a story in the news about a private laboratory in the United States that claimed to have successfully stimulated adult stem cells in the brain of a patient with Parkinson disease to replace specific cells damaged by the disease.

When you read or hear about stem cells, people don't often make the distinction between the different types of stem cells. But this distinction is important. It is the type of stem cell, and where it is obtained from, that makes embryonic stem cells – not all stem cells – controversial.

The other thing that makes stem cell research controversial is cloning. Ever since Dolly the sheep was created through cloning, the news is full of stories about the possibility of cloning a human being. There are two types of cloning (it's kind of like creating a genetic photocopy): cloning an embryo to create a new source of stem cells – this is known as therapeutic cloning; and cloning to produce an embryo from a single parent for implantation into a uterus to produce offspring – known as reproductive cloning.

Where we stand

By Dr. Harold Robertson, Chair, Research Council, Huntington Society of Canada and Shawn Mitchell, Director of Communications

While stem cell research has a great deal of potential, the most promising sources for stem cells are embryos and fetuses, because they are easy to identify, relatively easy to grow, and they are known to be able to become many different types of tissue. The use of stem cells from these two sources raises important legal and ethical concerns for everyone.

What are the rules in Canada on this type of research?

As was previously mentioned, the Government of Canada will have tabled relevant legislation by the time this issue of *Horizon* goes to print. This legislation, which will probably not become law until Fall 2002, will govern not only stem cell research funded by government (e.g. by the CIHR), but also research that is privately funded. In particular, it will focus on rules and regulations around the use of embryonic and fetal tissue associated with various reproductive technologies.

The CIHR guidelines were produced ahead of the legislation, and were done in consultation with legislators working on the development of the government's legislation. These guidelines are fairly long and complicated. If you'd like to review them in full, you can obtain them by contacting the CIHR at (613) 941-2672, or by going to the CIHR Web site at <www.cihr.ca>.

In a nutshell, CIHR will fund stem cell research under the following conditions:

- When using pre-existing human embryonic stem cell lines (Meaning: researchers already have stem cells in their labs for research purposes);
- When using embryos created for reproductive purposes which are no longer required (Meaning: a couple pursuing in vitro fertilization to have a child need to have many fertilized embryos created, and then implanted, before one finally develops into a pregnancy. A couple can then chose to keep the fertilized embryos that are left over in case they would like to try and have another child later, they can give the embryos to research, or they can have the embryos destroyed);
- Where the persons for whom the embryos were created have given free and informed consent for their use in research (Meaning: if a couple wants to give their embryos to research, they must be fully informed of the facts about what that means); and,
- When there were no commercial transactions involved in the creation and use of the embryos (Meaning: under no circumstances can money exchange hands regarding the use of the embryos. You cannot buy embryos from a couple; a couple cannot sell their embryos).

Among other things, the CIHR will **not** fund any research involving either therapeutic or reproductive cloning.

I think I understand all of that. But are stem cells important to Huntington's research?

In general, there are many aspects of research where using human stem cells, particularly embryonic stem cells, could be beneficial.

- The study of human development and the identification of the factors that control cellular specialization. This is particularly relevant to understanding how and why genes turn on and off during the process of human development. In the case of HD, how and why does the Huntington's gene do what it does, and can we somehow stop it?
- The development of alternative and potentially better methods for evaluating drugs. New drugs could be tested on certain human cells in a laboratory first, before being allowed to move on to further testing. In the case of HD, this could save already limited financial resources from being wasted on expensive drug trials for a drug that doesn't work.
- The development of cells and tissues for transplanting to patients who suffer from injuries to non-renewing tissues or who suffer from neurodegenerative diseases such as Huntington disease. In the case of HD, neural cell transplantation could prove to be an effective therapy for treating Huntington's.

In short, stem cell research could potentially have a significant impact on Huntington's research, which should give hope to everyone in the Huntington's community.

OK, so what does the Huntington Society of Canada have to say about stem cell research?

At the April 2002 meeting of the National Board of the Huntington Society of Canada, Board members deliberated for some time about the full range of issues associated with stem cell research, including what the official position of the Huntington Society should be. Based on briefing documents that they reviewed in advance of the meeting, as well as discussions led by Dr. Harold Robertson, Chair of the Society's Research Council, Board members unanimously decided that the Huntington Society of Canada should have a formal policy outlining its position in support of stem cell research.

The Board recognizes, however, that this policy may require some change in the future once the complete details of the new Canadian legislation are known.

Huntington Society of Canada Policy Statement : Stem Cell Research

One of the primary missions of the Huntington Society of Canada is to find treatments and, ultimately, a cure for Huntington disease. To accomplish this, the Society is committed to supporting the ethical and legal pursuit of research methodologies that have the greatest potential to achieve this mission. Consequently, the Society recognizes the importance of stem cells to the world-wide research effort in Huntington disease.

As a leading advocate and funder of HD research in Canada, the Huntington Society of Canada will only support stem cell research conducted in a manner that is consistent with the funding guidelines developed by the Canadian Institutes for

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Stem Cells Research cont'd. from p. 2…

Health Research (CIHR) and Canadian law, and has been approved under a relevant ethical review process.

The Huntington Society of Canada recognizes and is sensitive to the fact that members of the Huntington's community, as well as other individuals and organizations that support the Huntington's cause, have differing opinions about the use of stem cells in HD research, whether on religious, moral and/or ethical grounds. The Society respects ALL opinions on this issue.

The Society has always supported the ability of donors to direct their gifts to specific areas or initiatives. In keeping with this philosophy, we respect the right of donors to indicate that their donation is to NOT be used for stem cell related research.

Conclusion

The Huntington Society has a responsibility to ensure that all research options that have the potential to result in a treatment or a cure for HD – subject to Canadian law and ethical review – are being pursued. Stem cell research is no exception.

The Society – staff and Board – is always open to hearing perspectives from the Huntington's community on any issue. If you have any questions or concerns about the Society's new policy regarding stem cells, please do not hesitate to contact us at 1-800-998-7398, or at <info@hsc-ca.org>.

2002 Annual Conference

Planning has begun for our 2002 Annual Conference in Niagara Falls, Ontario. The Huntington's community will gather November 7th – 9th, 2002 at the Brock Plaza Hotel. The focus of the volunteer activities at the 2002 Conference will be strategic planning. We look forward to gathering our volunteer leaders from across Canada for an energizing and inspiring Conference.

The *Family Day* program for Saturday, November 9th, will include an update on the latest HD research, as well as several workshops on living with HD, and caring for those with the disease. We will be pleased to welcome the Walker family from during the afternoon for a special tribute to our founder, Ralph Walker. In short, *Family Day* will be of interest to everyone in the Huntington's community: HD family members, caregivers, donors and friends. Mark the date in your calendar and plan to attend. Watch for further details in the next issue of *Horizon*.

A special thank you goes to the outstanding Niagara Chapter planning committee made up of John Stainsby, Gail and Neil de Koning, Rene Landry and Diane Cranston. We look forward to your warm welcome! —JL

New Director Appointed for the Northern Ontario Huntington Disease Resource Centre

It is with pleasure that we announce the hiring of Julie Dénommé. As of April 8, 2002, Julie has taken over the responsibility of providing a variety of services including assessment, counselling and support services to individuals with HD, their families and health care professionals. She will also provide education and consultation to families and professionals regarding the nature and course of HD and care techniques, as well as function as a member of the multi-disciplinary Huntington Disease Clinic for Northern Ontario.

Julie has worked as a social worker for the past twelve years in different capacities, and brings with her a wealth of information from therapeutic interventions to program development. Julie has always been interested in creating environments which promote health and wellness, and her energy, combined with her positive way of looking at life, brings to her clients a sense of hope, respect and integrity. Julie is looking forward to meeting and working together with everyone in the Huntington's family.

Julie works full-time from her home office in Hanmer, part of the Greater City of Sudbury, and may be reached at:

Northern Ontario HD Resource Centre
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Hanmer, Ontario
P3P 1T2
Tel: 705-969-9771
Fax: 705-969-9772
Email: denommej@sympatico.ca

—SDR/JD

The Huntington Society of Canada's NAVIGATOR Coalition research programme is supported by the following funds:

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In Memoriam – Ralph McDougall Walker

January 14, 1939 – March 22, 2002

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.

"Working with Ralph for ten years was one of the richest and most important experiences of my life. He was an inspiring model, mentor, teacher and leader. He was a genius at making people feel valued. He loved to laugh. Whenever he saw a need, he stepped up. That's how he changed the world for HD families and that's also what made him an extraordinary friend. He leaves a powerful legacy – but I'll miss him terribly."

—Nancy Johnson, former Assistant Executive Director, Huntington Society of Canada

"It is said that there is no cure for Huntington disease – the end is inevitable in its cruelty. But in a way, Ralph Walker saved thousands of lives. By creating and ensuring public awareness, medical education, social programs and family support, Ralph enabled countless numbers to live for as long as they had with dignity and comradeship. He was a gentle gentleman that had a love for life that was infectious, and people loved him."

—Kim Hines, former Toronto Chapter President

"There are two traits that always stand out in my mind when I think of Ralph and that is his genuine concern for others and his ability to see things "outside the box." My best example of this would be the time I was hired. I was 7 months pregnant when Ralph interviewed me for the MB Resource Centre Director position. I was hired and worked for two months and then went on a four month maternity leave. He also arranged for me to work full-time for those first two months (in a position that was part-time) so as not to reduce my maternity benefits. I was so impressed that he agreed to this."

—Sandra Funk, Director, Manitoba HD Resource Centre

Dear Friends,

Thanks for the wonderful, loving support we received in response to Ralph's untimely death. The overwhelming number of letters, e-mails and kind words that have been sent to us and to the Huntington Society, have touched us deeply.

Thanks, too, for the generous donations made in Ralph's memory. He was a great supporter of the Huntington Society of Canada and of Huntington's communities throughout the world. Because of your support and donations, you have continued to support the work that he started. He would have been greatly touched by the out-pouring of love, as we have been.

Ralph loved his work, loved the people, and loved the caring feeling that was part of the whole movement. He loved to be a broker—connecting people all over the world—in the fight against Huntington disease. He especially loved the flow of ideas that resulted from these magical connections.

Every part of Ralph's life seemed to be connected with HD in some way. Our family vacations were camping holidays, an economical way to see the country. (Don't forget, McDougall was his middle name!) Whether it was a seaside trip down East, "sailing" across the Prairies, or a mountainous trek out West, Ralph always managed to work in some Society business. He would meet with Huntington's families or chapter leaders or scientists or even newspaper reporters to spread the word; he made every moment count.

Every spring, for ten years, friends and neighbours brought their "stuff"— potty chairs, jigsaw puzzles, fridges and stoves and freezers—to our front lawn and driveway for the annual HSC garage sale. Even though it was a lot of work and brought in a considerable amount of money for the Society, it was tremendous fun. It was only in the eleventh year, after we'd reseeded the lawn, that we finally had to move it off-site.

Our personal family life was so entwined with the Huntington's extended family's, that we feel very close to each and every one of you. Together we will continue to support the work of HSC. Lara and Tim, Matthew and Tori join with me in thanking all of you for caring so much.

Yours in friendship,

Ariel Walker

Ralph at a HSC staff party.

"We in New South Wales will always be indebted to Ralph for his professionalism, his friendship and support. We appreciate so much, and shall never forget, his willingness to share resources and ideas, his sound advice, and his wise counsel."

—Robyn Kapp, Executive Officer, Australian Huntington's Disease Association (NSW) Inc.

"I lost a friend and brother…I will miss him more than whatever. His warmth, enthusiasm, friendship, love. It was a very special relationship, which lucky people only experience once in life."

—Gerrit Dommerholt, International Huntington's Association

"Our community has lost a rare individual who touched many lives."

—Mr. Janko Peric, MP (Cambridge), excerpt from Member's statement in House of Commons, April 29, 2002.

Ralph at HD Summer Camp, 1993.

"My personal recollection is that Ralph was compassionate to me, a stranger, when my mother died and it was revealed that she had HD, putting me and my family in turmoil. I really needed professional advice, support and information, and Ralph put me in touch with medical experts who could help us. He treated me like a friend from the very beginning. I just feel so strongly that his contribution to Canadian health history should be acknowledged."

—Marcia Sweet, Burlington, ON

"When Huntington disease was first discovered in our family. I contacted Ralph and Ariel Walker (1976). This contact has been a memorable journey, and has changed my life forever. He was just a phone call away for support in what I was doing in Saskatchewan. He encouraged me to get more involved with the Society, eventually representing Saskatchewan at the National Board level. He loved to listen to new ideas on how to reach new families and educate the public about HD. It didn't matter where you lived, he believed you could make a difference. For myself it was on a farm, in a sparsely populated part of Saskatchewan. He took time to truly listen to the problems the families were having and come up with solutions for all families in Canada. He loved to laugh, tease and tell or hear a good joke. He cared deeply for what he believed in. Ralph was a true friend."

—Carol Ellis, National Board of Directors, Lafleche, SK

On June 26, 2002, at 12 noon (EDT), the Huntington Society of Canada would like to encourage all those who have been touched by the work of Ralph Walker to pause for a minute of silence in memory of a wonderful man who worked so hard for the Huntington's cause. It is our hope that for that one minute, everyone in the Huntington's community, regardless of time zone or location, will be united in reflecting on how far we have come since 1973, and how positive the future is, thanks in large part to the work of Ralph Walker.

In Canada, the minute of silence will be at the following times:

BC	9:00 am
AB/SK	10:00 am
MB	11:00 am
ON	12:00 pm
QC	12:00 pm
NB/NS/PEI	1:00 pm
NF	1:30 pm

For those overseas, the minute of silence will be at 5:00 pm (GMT).

With wife Ariel and long-time volunteer, Pearl Smith.

Hard at work.

"Working with Ralph in the Huntington's office every day was a wonderful experience. Ralph made the work environment feel more like family, because he truly cared about each of us. He inspired us with his dedication to the HD cause and his compassion for those touched by HD. His vision, values, creativity and caring will continue to be felt by the entire Huntington's community for many years to come."

—Isla Horvath, Executive Director,
Huntington Society of Canada

"I first met Ralph in Hamilton, Ontario in 1993, and never thought much about him until a few weeks later when he called me to see how [my husband] Norman was. It blew me away when he called us both by our first names and chatted with both of us. With everything on his mind that week-end he still remembered us. I knew then he was someone special. He always had time to stop and talk."

— Beatrice Langille, President,
Cumberland County Chapter

"In the nearly 30 years I knew Ralph, many positive things stood out about his style of people management. First and foremost was his superior skill of communicating with people. Thousands in Canada, and indeed throughout the world, will miss his handwritten, personal communiqués that we all received over the years."

—Bob Stevens, former Huntington Society
President, BC Chapter member

Making a presentation in Sudbury, 1995.

Ralph at a fundraiser dance in February 1989 with (left to right) Alice Dekleyn, Diane and Larry Ecker.

May 1989 visit with volunteers in the Ottawa area.

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

Dear Social Worker

Editor's Note: The following are examples of inquiries that have been sent to members of the Society's Individual and Family Services team, as well as the responses that were sent back. Details have been altered to protect the confidentiality of the people involved – "S.W." stands for "Social Worker."

Dear S.W.:

My nephew has HD. However, he doesn't think that he has it. I'm really worried about him. He's lost his job and is living in an apartment that is a mess. He doesn't have any money and won't let anybody help. He also smokes cigarettes and is constantly dropping them. We know that he is in denial, but we can't make him accept his HD. What can we do?

Worried

Dear Worried:

You are indeed in a difficult situation. You obviously care deeply about your nephew and want the best for him. Your nephew is also in a difficult place right now. He may or may not know that he is experiencing symptoms of HD.

You see, for individuals with HD there is often a psychological phenomenon present that makes them unaware of their symptoms. This is a result of neurological changes within their brain and is totally involuntary. This process is also different from the defense mechanism we call denial.

All of us deny things at one time or another. We (and this includes the person with HD) tend to do this when we are faced with thoughts or situations that are "too hot for us to handle." This response is normal. Usually, under the right conditions and/or with help from others, we can work through our resistance and face whatever it is we need to face. Unawareness, however, is not the same, and this might be why your interventions with you nephew don't seem to work.

Our job, therefore, is to start by accepting the person with HD as he is. If he is in denial, then we should of course try and help him by addressing his possible fears and anxieties. But if it's unawareness (or denial to the degree that counseling cannot penetrate), then it's best to just start by accepting his view. If he declares that he doesn't have HD, then fine … for now he doesn't have HD.

Instead of arguing the case, it is better if we try to offer support in an indirect way. Maybe your nephew could be encouraged to come to dinner once a week. (Be sure not to mention HD at dinner.) Or maybe he would accept a birthday gift – the gift could be a 'Molly Maid' type of service for one day. Whatever you choose, the goal is simple: to try to reconnect with him and to show him that you're not a threat to his independence and the way he wants to live his life. Hopefully, when he feels accepted, he will be more willing to accept help. This will be a slow process, and at times you may feel that there are many setbacks. Be patient and be sure to celebrate all of your successes. Eventually, most people with HD acknowledge that they need assistance.

One word of caution: if there comes a time when you are worried that he is a risk to himself or others (i.e., that he could burn his apartment building down), then family and friends will have to react differently. If he is in imminent danger to himself or to others, then you will need to involve the professionals in your community who deal with issues of capacity and competency. If in doubt, call your local HD Resource Centre and they will help you decide what to do next.

If you have any questions or concerns that you would like addressed by a Huntington Society social worker, feel free to send your question or concern to: ***Dear Social Worker*****, 151 Frederick St., Suite 400, Kitchener, ON, N2H 2M2**, and mark "Confidential" on the outside of the envelope. While you don't need to put a return address on the envelope, please be sure to include a return address in your letter so that we can send you a response. All letters will be answered, but not every letter will be included in *Horizon*.

The Huntington Society of Canada's Individual and Family Serivces programme is supported by the Jeffrey Laycock Trust and the Bloom Family Fund.

Our Success — Thanks To The Volunteers Who Make It Happen!

By Holly H. Paulin, Development Coordinator

Over the past three decades, the Huntington Society of Canada has grown to be a thriving, well-respected national organization dedicated to eradicating HD as well as improving the lives of people touched by the disease. Our successes are due largely to the efforts of the thousands of people across Canada who have donated their time and energy to the Huntington's cause.

A great example of a dedicated HSC volunteer is Lloyd Wilson. Lloyd, who lives in Kingston, Ontario, is gearing up for his third *Huntington's Indy Go-Kart Challenge*. As the Chair of the Kingston Indy, Lloyd oversees all aspects of the event, and is known for his innovative and exciting ways to make the Indy even more successful. In fact, he's busy now working on a transportable painted backdrop of a Go-Kart to promote the Kingston event throughout the community.

Although he might be the last to say it, Lloyd's involvement has had a huge impact on the Indy. In 2000, the Kingston crew planned their event to break even. "As long as we didn't lose money, we'd go home happy," Lloyd said, but the event raised a profit of over $6,000! The next year, Lloyd's group boldly set the goal to double the results of the 2000 event, and they successfully raised $13,000. This year, Lloyd is confident the 2002 Kingston Indy will continue to grow.

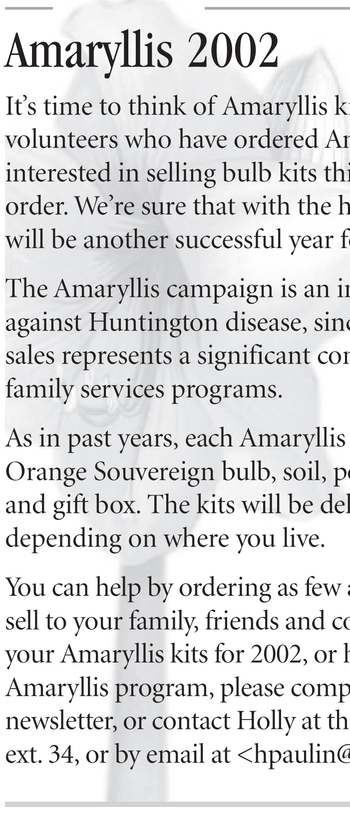
Lloyd's commitment to the Huntington's cause extends beyond raising money with the Indy. If there is ever an opportunity for an information booth to be set up in the Kingston area, you can be sure Lloyd is there. By representing the Huntington Society at numerous community events, he helps to increase both the public's understanding of HD, and their compassion for the people whose lives are changed by this disease.

Like Lloyd Wilson, Debbie Arsenault is devoted to increasing the awareness of Huntington disease. Debbie lives in Iroquois Falls, Ontario — a community of about 5,000 people northeast of Timmins — and says that, as a Huntington Society volunteer, she is determined to help other families in the Huntington's community.

Debbie has been very busy working on activities for HD Awareness Month throughout the month of May. She took the lead in promoting May 1st as "Huntington Disease Awareness Day" in Iroquois Falls, and encouraged almost all of the local restaurants to participate. The restaurants donated a portion of the day's sales to the Society, and they used placemats that offered guests information about Huntington disease. Visiting businesses, meeting with the owners, and coordinating the event were very labour-intensive, but Debbie's efforts really paid off: most of the restaurants have already signed on to participate again next year!

Also as part of May Awareness events, Debbie set up a display at the local hospital that included Huntington Society balloons, posters, brochures, and newsletters. She and her husband Rick (who has HD) recently enlisted the help of friends to help put up posters in and around town to educate people about the disease. Debbie is starting to look into other fundraising and awareness events for her area, such as barbeques and bingos. "I'm a talkative person," says Debbie. "I want to talk to people about Huntington disease everywhere I go."

Debbie and Lloyd are only two of our many dedicated volunteers whose individual efforts make a huge difference to the lives of everyone touched by Huntington's. Every volunteer's contribution, big or small, is incredibly important to the strength of our organization. With the support of volunteers like ours, the future is sure to bring continued success and hope.



Amaryllis 2002

It's time to think of Amaryllis kits again! Thanks to all of our volunteers who have ordered Amaryllis kits for 2002. If you are interested in selling bulb kits this Fall, there's still time to place your order. We're sure that with the help of our devoted volunteers, 2002 will be another successful year for our Amaryllis program.

The Amaryllis campaign is an important part of the Society's fight against Huntington disease, since money raised from Amaryllis sales represents a significant contribution to our research and family services programs.

As in past years, each Amaryllis kit sells for $11, and includes an Orange Souvereign bulb, soil, pot and saucer, growing instructions, and gift box. The kits will be delivered from October to November, depending on where you live.

You can help by ordering as few as one case of 12 Amaryllis kits to sell to your family, friends and colleagues. If you would like to order your Amaryllis kits for 2002, or have any questions about the Amaryllis program, please complete the return form included in this newsletter, or contact Holly at the Society's office at 1-800-998-7398 ext. 34, or by email at <hpaulin@hsc-ca.org>. —HHP

Casino Niagara International Marathon: Supporting the Huntington Society's Race for a Cure

On October 27, 2002, thousands of people from around the world will be running, walking, in-line skating and wheeling to raise money for charity – once again, one of those charities is the Huntington Society of Canada.

The Casino Niagara International Marathon is a qualifying event for the Boston Marathon, and draws participants from around the world. Runners who want to commit their raised pledges to the Huntington Society of Canada just need to tell event staff at registration time. If you'd like more information about this event, or would like pledge forms, call the Society's office and ask for Jen Love at 1-800-998-7398, or by email at <jlove@hsc-ca.org>. You can also contact Judy Koczula at (905) 354-5744. —SM

The Huntington Society's Marthe Gautreau, NB Support Worker, and Linda Geyer, NS and PEI Resource Centre Director, accept a cheque for $23,771.38 from Léonce Losier, President of Co-op Atlantic, at Co-op Atlantic's Annual General Meeting in March 2002. The Huntington Society is extremely grateful to Co-op Atlantic (and its member stores) for its continued partnership and support.

Huntington's Casual Day 2002

On May 3, workplaces right across Canada took part in *Huntington's Casual Day 2002*. This event, part of the Society's "May is HD Awareness Month" activities, helps create a sense of understanding and acceptance for those touched by HD in our communities. It is also a fundraising event — we're happy to say that at press time, proceeds from many workplace participants had already begun to come in to the office.

Many thanks to every participant who dressed down, distributed our brochures, and donated $2 at work. Special thanks are also extended to our volunteers for their efforts in coordinating Casual Day events with local businesses. Great job!

If you would like more information on holding a Casual Day event at your workplace, please contact Holly at 1-800-998-7398, extension 34. —HHP

RETURN FORM

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

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

☐ ENCLOSED IS MY DONATION of $ ____________ to further the fight against Huntington disease.

☐ Please send me information on how to include the Huntington Society in my *will or insurance policy*.

☐ Please send me ______ Annual Report(s).

Method of Payment: ☐ Cheque ☐ Money Order

☐ Visa ☐ Mastercard

Credit Card # : ________________________________

Expiry Date : ______________ Signature : ______________________

Name: ________________________________

Address: ________________________________

____

____

City : ____________________ Province: ____________________

Postal Code: ____________________ Phone #: ____________________

Please note my change of address:

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Effective :______________

☐ Please send me more information about getting involved in the Society's Amaryllis campaign.

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

Ready…Set…GO!!! Join our race for a cure!

Sunday, September 8, 2002 is the ***Huntington's Indy Go-Kart Challenge*** day. In 2002 we will have events in communities across Canada from Nova Scotia to Alberta. Thank you goes out to all our 2002 ***Indy*** organizers: Ken Bumstead, Ron Paterson, Lloyd Wilson, Ellen Foster, Linda Starr, Lara Hall, Terry Hanson-Lamb, Christie Kilgore, Vern Barrett, June Nichol, Gina Langager, Rachel Callister, Judy Lang, Sherri Reichert and Stephen Hurst. And a very special welcome to our new organizers, Christine Atwater in New Glasgow, Nova Scotia, Tanya Bickle in Oshawa, Ontario, and John Craenen in London, Ontario.

We have a number of ***Indy*** organizers who run spring events, so a huge thank you goes to Judy Lang and our volunteers from BARC (British Automobile Racing Club), Sherri Reichert and the volunteer team in Regina and Stephen Hurst and his volunteers in PEI for launching the 2002 ***Indy*** in style!

Our partnership with BARC continues to grow. The March 2002 ***BARC-Huntington's Indy Go-Kart Challenge*** raised almost $12,000, and BARC is set to host a two-day event in Brampton in September. Way to go!

If you are interested in participating in an ***Indy*** event or learning more about joining our race for a cure by hosting an ***Indy*** event in your community, call Jen Love at the Society's office at 1-800-998-7398, extension 30. Our volunteer teams across Canada are gaining momentum to shatter our record set in 2001 when the national ***Indy*** program raised over $125,000 to support the Society's programs. —JL

If undeliverable, return to:

Huntington Society of Canada
HUNTINGTON
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