Huntington Society of Canada

HORIZON

Société Huntington du Canada

RESEARCH - SERVICE - EDUCATION

Huntington Society Awards Research Grants

The Research Council of the Huntington Society of Canada approved six new research grants for funding through the fall 2003 research competition. The grants were awarded through three programs:

NAVIGATOR Research Awards:

Grant Amount: $50,000 per year for each of two years. These grants are awarded to senior investigators working in HD research. Grants were awarded through this program to Dr. Michael Hayden and to Dr. Janice Braun.

Laura's Hope Awards:

Grant amount: $50,000 per year for each of two years. Laura's Hope Grants are awarded to researchers who are working to advance the search for a treatment for HD, through clinical and pre-clinical research. The first Laura's Hope grants were awarded to Dr. Blair Leavitt and Dr. Eileen Denovan-Wright.

Landmark Graduate Awards:

Grant Amount: $20,000 per year for each of two years, with a possible third year renewal. These grants are awarded to doctoral and post-doctoral students working in HD research. Two grants were awarded: to Herman Fernandez and Haibei Hu.

More information about HSC's granting programs can be found on the Society's Web site at <www.hsc-ca.org>.

Summaries of the new research projects follow. –IH

Dr. Blair R. Leavitt University of British Columbia

Modulating huntingtin levels as a potential therapeutic approach for Huntington disease

People with HD have two kinds of huntingtin protein in their brain cells: the normal form of the protein, which is produced by the normal or "wild-type" HD gene that has anormal sized CAG repeat region, and the expanded or "mutant" form of the protein, which is produced by the copy of the HD gene that contains an expanded CAG repeat region. A lot of research into HD has focussed on the expanded form of huntingtin that ultimately causes cell death, but much less is known about the function of the normal protein.

Interestingly, the normal form of huntingtin seems to have the opposite effect — it protects brain cells from dying. What's even more interesting is that Dr. Leavitt has shown that increasing the amount of normal huntingtin in an HD cell can block some of the toxic effects of expanded huntingtin.

Dr. Leavitt plans to look more closely at how normal huntingtin works and whether it has the potential to be an effective treatment for HD. He'll examine the effects of increasing or decreasing the levels of normal huntingtin in brain cells, and try to pinpoint the specific part of the protein that prevents cell death.

Next, he'll use specially bred HD mice to see whether mice with high levels of normal huntingtin have fewer Huntington's symptoms than mice with low levels of normal huntingtin. The research will take several years to complete, but it could lead to important new approaches to treating Huntington disease.

Dr. Michael Hayden University of British Columbia

The Role of huntingtin phosphorylation on serine 421 (pS421) by Akt in the pathogenesis of HD

Like Dr. Leavitt, Dr. Hayden is interested in how the huntingtin protein helps cells to

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grow and survive. He believes that one of the keys is phosphorylation — the process where a protein is modified by adding a phosphate to it. Dr. Hayden has been studying the phosphorylation of huntingtin by a specific enzyme, Akt (also known as protein kinase B).

Dr. Hayden suspects that this phosphorylation process is important for proper functioning of the huntingtin protein. This leads to an important question: is the phosphorylation of huntingtin altered in the expanded form of huntingtin that is produced by the HD gene? If it is altered, this may be one reason why HD brain cells die.

There's lots we need to learn. Dr. Hayden will look at a number of the factors that might influence huntingtin phosphorylation, and he'll examine how this phosphorylation affects HD brain cells. For example, he'll look at HD mice to see whether the expanded form of huntingtin is less phosphorylated than normal huntingtin. He'll confirm whether phosphorylation is necessary to protect brain cells from dying, and he'll look at how phosphorylated huntingtin interacts with other proteins in the cell.

This research is still in the early stages, but it could be an exciting avenue for preventing brain cell death in HD.

Dr. Eileen Denovan-Wright Dalhousie University

Reduction of expanded huntingtin by anti-huntingtin ribozymes and siRNA in transgenic mice

It seems clear now that expanded huntingtin — the protein produced by the HD gene — is responsible for killing brain cells in people with Huntington's. So if we can find a way to prevent it from forming, we should be able to stop the disease in its tracks.

That's the thinking behind Dr. Denovan-Wright's research. She believes the solution may lie in blocking something called messenger RNA (mRNA), which uses the information coded in the HD gene to build expanded huntingtin.

Dr. Denovan-Wright and her colleagues have already developed two tools to do the job. One is a set of anti-huntingtin ribozymes — enzymes that specifically destroy the mRNA that produces expanded huntingtin. The other is an unusual molecule called small interfering RNA (siRNA) that can break down mRNA.

In these experiments, she'll be injecting a harmless virus containing ribozymes and siRNA into the brains of HD mice. The virus will infect each cell, delivering the anti-mRNA tools in the process. Then she'll monitor the mice for signs of HD. If the hypothesis is correct, this treatment will slow down the progression of HD. And, if this works in mice, ribozymes and siRNA might be able to treat Huntington's in humans.

Haibei Hu Dalhousie University

Ribozymes and siRNA for the treatment of Huntington's disease

Haibei Hu is a PhD student in Dr. Eileen Denovan-Wright's lab, and her research will also focus on ribozymes and siRNA. Although initial studies show that these molecules stop expanded huntingtin from forming by blocking the action of messenger RNA, there's still a lot we don't understand about this process. Hu hopes to fill in some of the details.

First of all, she will focus on the question of doses and times. She'll work with HD brain cells to see how much ribozyme and siRNA is required to block messenger RNA, and how much time is required for them to do the job. She'll also test different types of ribozymes and siRNA to find which are most effective.

In theory, blocking mRNA should prevent the next steps in the process of cell death, but it's important to see whether this really is the case. Hu will measure the level of

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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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NAVIGATOR

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various molecules in the cells that are affected by expanded huntingtin to make sure that ribozymes and siRNA have an impact downstream. Finally, if she gets good results at this stage, she'll repeat these experiments in an animal model — HD mice — using the ribozymes and siRNA that were most effective in the test tube.

Herman Fernandes University of British Columbia

Modulation of NMDA receptor and mitochondrial function by expanded huntingtin in a transgenic mouse model of Huntington disease

Herman Fernandes is a graduate student who is examining a receptor in brain cell membranes — the NMDA receptor — that helps to transmit messages within the brain.

Basically what happens is this: When a neighbouring brain cell is excited, it releases a messenger molecule called glutamate that binds to the NMDA receptor. The NMDA receptor responds by allowing calcium ions to flow into the cell. This generates a signal that directs the cell to perform many of its normal functions. In this way, calcium ions act as a messenger, telling the cell what to do in response to the messages that it receives.

If a brain cell is affected by Huntington disease (HD), however, expanded huntingtin makes NMDA receptors overly sensitive, which means too many calcium ions flow into the cell. This triggers a sequence of events that ultimately may cause the cell to die. Herman will conduct experiments to uncover some of the details of this process and perhaps identify ways to stop it from happening.

He'll compare normal cells with HD cells to see how expanded huntingtin affects the NMDA receptors, and he'll measure the changes in calcium levels inside the cell. He'll also look at how calcium levels affect mitochondria, which generate the energy necessary for cell survival.

Dr. Janice Braun University of Calgary

Association of N-type calcium channels with huntingtin^{exp} and huntingtin^{nonexp}

Not only is the huntingtin protein involved in receiving messages from neighbouring brain cells, as Herman Fernandes is investigating, it also seems to be involved in passing along the message to other cells in the brain.

Dr. Braun's lab has discovered that normal huntingtin binds to N-type calcium channels in the cell membrane. When an electric signal travels along a brain cell, these channels open, allowing calcium ions to flow into the cell. The calcium ions play an important role in helping the cell to release neurotransmitters, which relay the signal to nearby brain cells.

Dr. Braun believes that when huntingtin binds to N-type calcium channels, it regulates their function, and she wants to learn more about this. She'll use a number of molecular biology and biochemistry techniques to discover details like how huntingtin binds to the calcium channels and whether any other proteins are involved.

The next step will be to examine whether the expanded form of the huntingtin protein interferes with the normal function of N-type calcium channels. If it does, it might be possible to treat HD by developing a drug that prevents expanded huntingtin from binding to these calcium channels.

From Cloning the Gene to Finding a Cure

Dr. Susan Andrew's presentation at the 2003 Annual Conference

By Julie Stauffer

In the last issue of *Horizon* we reported on two of the presentations from 2003's Science and Research Panel. The final panelist was Dr. Susan Andrew, an assistant professor of medical genetics at the University of Alberta.

The Huntington Society of Canada began funding Dr. Andrew when she was a Ph.D. student in Dr. Michael Hayden's lab. Today HSC continues to fund the important work she's doing on DNA repair proteins and CAG repeats. Rather than talk about her own research, however, Dr. Andrew focused her presentation on the impressive advances in HD research that have occurred recently.

The first breakthrough she described was the development of a rat model of HD. Animal models are essential for studying the function of the HD protein and for testing potential treatments before we try them in humans. For example, we've tested the antibiotic minocycline in mice. The results were promising — minocycline delayed cell death and the onset of disease in these animals without any harmful effects — so now we've launched human drug trials, which are currently ongoing. Although we have many mouse models of HD, a rat model will be even more helpful in screening drugs to delay onset of Huntington's because we know much more about the rat brain and rat behaviour than we do about mice.

In 2003, we learned a lot more about how the HD protein affects brain cells. One of the keys to normal brain cell function are organelles called synaptic vesicles, which contain neurotransmitters that relay messages from one brain cell to another. New research revealed that HD brain cells have fewer synaptic vesicles than normal cells, and mutant HD protein prevents them from properly releasing their neurotransmitters.

We also learned more about the factors that influence the age of onset of HD. We knew that the more CAG repeats someone has, the earlier HD is likely to strike. However, this is only half the story. Studies have now identified three new chromosomal regions that play a role. The next step is to identify the culprit genes in those regions, which will hopefully provide clues to delaying or preventing the onset of disease. With data from the Human Genome Project, says Dr. Andrew, it will not be long before these key genes are identified.

A promising treatment for Huntington's was discovered accidentally when researchers realized that a scientific dye called "Congo Red" could prevent the HD protein from binding to itself and triggering cell death. More experiments showed that Congo Red helped HD mice to live longer with fewer symptoms. Researchers are now trying to alter the dye so it can cross the blood-brain barrier for studies in humans.

Finally, Dr. Andrew talked about RNA interference: an exciting new way to stop the expression of a specific gene. RNA is an intermediate between DNA and protein. Special RNA can be designed to bind to the HD RNA, preventing it from translating DNA into protein. This can shut down the mutant HD gene without silencing the normal HD gene, which we know is essential to brain cell survival.

Stopping HD is an uphill battle, she concluded, but we've come a long way in understanding the disease. When Dr. Andrew was born in 1965, 10 papers were published on HD. Today there are more than 5,000 peer-reviewed papers on Huntington disease.

Today researchers are focussing on the functions of the normal HD protein and which of these functions the mutant HD protein has lost. Another important question is why cell death only occurs in certain parts of the brain. Above all, scientists in laboratories around the world are working to discover what can be done to prevent or delay brain cell death in Huntington's.

"2003 was a year of successful landmark discoveries into HD, with further inroads on therapies actually shown to delay onset and/or reduce cell death," said Dr. Andrew. "I hope 2004 will bring even more momentous discoveries and a cure for this disorder."

Watch This Space for News About the 2004 *Huntington's Indy Go-Kart Challenge*!

We are gaining momentum and gearing up for the 2004 *Huntington's Indy Go-Kart Challenge*. The *Indy* is a terrific national fundraising event, and volunteers are its driving force.

Join our race for a cure in communities across Canada this spring and fall. If you are interested in organizing an event in your community, contact us! Fresh ideas will keep the *Indy* event vital and vibrant. For more information — or to request an information package — please contact Jen Love at 1-800-998-7398 or by email at <jlove@hsc-ca.org>. —JL

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 Social Worker

I've got a problem that I haven't been able to tell anybody about. My wife has HD. We've been together for almost 30 years. Most of that time has been good for us. During the last nine years, however, my wife has changed. Lately I can't handle her. I still love her, but I find I lose my temper a lot. She was so different before. Now I have to do everything, and she takes forever to do something as simple as getting dressed in the morning. Sometimes she won't talk to me at all. In the past year I have started to "snap." I find myself being rough when I help her change. Sometimes I push her, and last week I slapped her when she screamed at me. I know that what I am doing is wrong, but I can't help myself.

Losing It

Dear Losing It

I'm glad you had the courage to talk about what is happening between your wife and you. From the sound of it, you've been carrying around feelings that must make you feel awful inside. Guilt, anger, frustration and resentment are just a few of the emotions that can be triggered when someone is trying to be a full-time care partner.

While I can certainly appreciate your situation, I am still going to have to tell you that you need help immediately. Your anger and frustration are normal, **but** the way in which you are expressing these emotions can be dangerous for both you and your wife. Pushing, hitting, or aggressively restraining her will only place both of you at risk.

I know that what you are facing is difficult. I would imagine that you might also be feeling a great deal of sadness and loss with regard to what is happening to your wife, your marital relationship and your overall lifestyle. Nevertheless, regardless of how difficult things are, you should never lose sight of the fact that your wife is disabled, and thus vulnerable.

My first question is whether or not you have any help. If you are trying to care for your wife on your own, you might be "burned out." No one should be attempting to care for a loved one totally on his or her own. All care partners need time when they can think about their own needs, rather than those of their spouse.

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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 Services program is supported by the Jeffrey Laycock Trust and the Bloom Family Fund.

Dear Social Worker (continued)

As a start, I would suggest that you sit down with someone and talk about the times when you have "snapped." Take this time to really explore the events that led up to your snapping. Then ask yourself: "What could have helped in these situations to prevent me from snapping?" For instance, do you need alternative care approaches? Stress management techniques? Respite? Is your wife receiving the best medical treatment so that her moods are as stable as possible? Do you have some healthy ways of venting your frustration — for example, talking to someone, exercise, other outside interests, vacations?

In my experience, I have found that loving, caring people snap when they feel scared, helpless or incompetent. Most people who have ever cared for someone disabled will admit that the experience demanded skills and strengths that they didn't know they had. With help, you should notice that your strong feelings of frustration and/or anger will change dramatically. If, however, that is not the case, then it is probably time to find alternative living arrangements for you or your wife.

Talk to your wife. Don't assume that she wants to continue living this way either. I have known situations where the person with HD has wanted to leave the home situation because she or he knew that it was no longer safe to stay. It is possible that your wife is feeling just as stuck and upset about how you both are relating to each other. You need to act on this right away. It's time to put in place the supports that will stop you from hurting your wife and, in the end, hurting yourself.

Good luck!
S.W.

Fundraising Boot Camp

Thank you!

These two magic words go out to all the volunteers — community volunteers from across Canada and members of the Society's national Board of Directors — who joined us at Fundraising Boot Camp sessions this winter.

Our sessions were energetic, upbeat and interactive, thanks to the participation and enthusiasm of HSC volunteers. It was clear from our sessions that HSC volunteers are invigorated and excited about community fundraising — and that's fantastic news!

At each session, volunteers learned about new fundraising strategies and ways to put them into action in their communities. We also shared ideas and stories, and worked in small groups on activities and role-playing exercises.

If Fundraising Boot Camp is an early indication, we are off to a sensational start in the Huntington Society of Canada's Road to Triumph campaign. Our Road to Triumph goal — to double our revenues in 5 years — is ambitious! And with our network of volunteers inspired and ready to take on the new fundraising challenges ahead, it is achievable.

Our two magic words — thank you — also go out to Health Canada for providing the funding that made our Fundraising Boot Camp project possible. We are deeply grateful for Health Canada's tremendous support.

As part of our funding from Health Canada, we have created a new set of fundraising materials — the *Community Fundraising Toolkit*. The *Community Fundraising Toolkit* can give you helpful ideas and useful tips to develop, refresh and enhance your local fundraising activities. It includes strategies and theories as well as practical tools you can use right away. You can get your own copy of the *Community Fundraising Toolkit* by contacting the Society's fundraising team at 1-800-998-7398. —JL/HHP

Swimming with the Fishies for HD

By Dana Hofstetter, Senior Communications Coordinator

Innovative, imaginative, creative, and unique were some of the words that stuck in Derrick Best's mind after he left the Calgary Conference. Since becoming involved with the Society through his girlfriend Lynn Hahn, Derrick had wanted to do something that possessed those four words. And, he did just that!

Derrick is the Rescue Safety Diver at Water World Tours, which is located at the West Edmonton Mall in Alberta. Sea Trek provides tours of the underwater attractions at the mall by having tourists wear a 31.5 kilogram helmet that provides them with air underwater. Derrick combined his work, his skills, and the charity that is closest to his heart, and planned a 24 hour underwater event. One Sunday in December, Derrick went underwater at the Santa Maria in the West Edmonton Mall and came out of the water the next day to a large crowd and thunderous applause. The only times he emerged from the water were for 10 minutes every 8 hours for a snack and washroom break. He even had company while we was underwater; Jim Echino, owner of Water World Tours, joined Derrick and played a couple of games of chess with him.

"After going to the Conference, and even before the Conference I was touched by seeing Lynn's family's struggle with the disease. It is always in the back of Lynn's mind, and I wanted to help." Adds Derrick, "At the Conference everyone was talking about how they wanted to do unique and different events. It was so simple to me to think of my work."

Derrick had a lot of fun and support in planning this event. The administration staff at the West Edmonton Mall were so great in providing support that numerous media outlets came out on the day of the event. Newspaper articles were written, clips were shown on TV, and it couldn't have been done without the support from the mall.

"When I came out of the water the crowd of shoppers was phenomenal! They greeted me with applause and cheered me on. It was great to have something be such a success, since it was so easy to plan."

Derrick raised over $6,000 during his underwater marathon, and he is inspired to do it again. Derrick feels that if you put your mind to it, you are able to achieve anything. He hopes other people are inspired to organize unique events such as his. These events will help bring more awareness and more money to aid the search for a treatment, even a cure for Huntington disease.

If you have an interesting idea for a fundraising event or would like more information about planning a special event, please contact the Development department of the Huntington Society of Canada at 1-800-998-7398

Derrick Best (left) and fellow diver, Brian play a game of chess underwater – photo courtesy of Derrick Best

Doing A-OK! - photo courtesy of Derrick Best

LCBO Supports the Fight Against HD

We are very excited to announce that the Liquor Control Board of Ontario (LCBO) has selected the Huntington Society of Canada to participate in their province-wide Donation Box program!

Over 600 LCBO stores will be displaying HSC coin boxes at their cash registers during the month of May 2004. This is a terrific opportunity to increase public awareness and raise additional funds for the fight against Huntington disease.

The province-wide program collects donations from customers and employees at all stores in support of two designated registered charities each month. To be selected, charities must submit a written application and be reviewed by an inter-departmental committee at the LCBO.

If you live in Ontario, **you** can help make this initiative a success! Consider some of the following ideas:

- Ask your family, friends, neighbours and co-workers to drop their change in our coin boxes this May!
- Write a Letter to the Editor of your local newspaper to let everyone in your community know about this opportunity to support a cause that is important to you!
- Visit your local LCBO this May to tell the manager or staff that you are a Huntington Society volunteer, and how exciting it is to see our coin boxes in your local store!

For more information, contact Holly at the Society's office at 1-800-998-7398 ext. 34, or by email at <hpaulin@hsc-ca.org>. —HHP

Providing Hope for the Future: *Our Living Legacy* Planned Giving Program

Have you considered naming the Huntington Society of Canada in your will? Or making the Society the beneficiary of a new or existing life insurance policy or retirement fund?

Once your family is provided for, your planned gift will benefit the Huntington's community for years to come. You will help ensure that the Society can meet the ongoing needs of families through *Our Community of Caring* individual and family services program and provide hope for the future through our *NAVIGATOR* research program.

A planned gift is also an important part of your family's financial and estate planning, providing potential tax savings for your estate and family. Bequests in a will, gifts of life insurance, and other planned gifts are easily established — your financial advisor, lawyer, or insurance agent can help you arrange a gift according to your family's needs and wishes.

Please consider making plans now for a gift that will benefit the Society in the future. The Society's office can provide you with more information about *Our Living Legacy* planned giving program — simply fill out the return form at the back of this issue of *Horizon*. —HHP

Calling All Enthusiastic Campers

Another fun-filled season is planned for our camp programs offered in British Columbia, Ontario and Alberta.

Last year's participants enjoyed pool basketball, baseball, music therapy, massage, pool time, and a banquet night as part of their great camp experience. Approximately 55 individuals with Huntington disease attend the program each year. Camp provides a wonderful opportunity to make new friends, revisit old friends and be part of something very special.

For more information about the 2004 program, contact the Camp Director closest to you.

The British Columbia Camp will be held from May 25–30 at Camp Squamish. Susan Tolley, the Camp Director, may be reached at (604) 822-7195.

The Ontario Camp program will be held from June 7–11 at the CNIB Lake Joseph Centre near MacTier. Please contact the Co-Director nearest to you. Nancy Webb may be reached in Toronto at (416) 494-1221. Julie Dénommé may be reached in Northern Ontario at (705) 969-9771.

The Alberta Camp program will take place from September 20–24 at Camp Health, Hope and Happiness on the shores of Lake Isle, 90 km west of Edmonton. Please contact the Co-Director nearest you. Sally Vincent can be reached in the Edmonton office at (780) 434-3229, and Alice Gibson can be reached in Saskatchewan at (306) 373-3503.

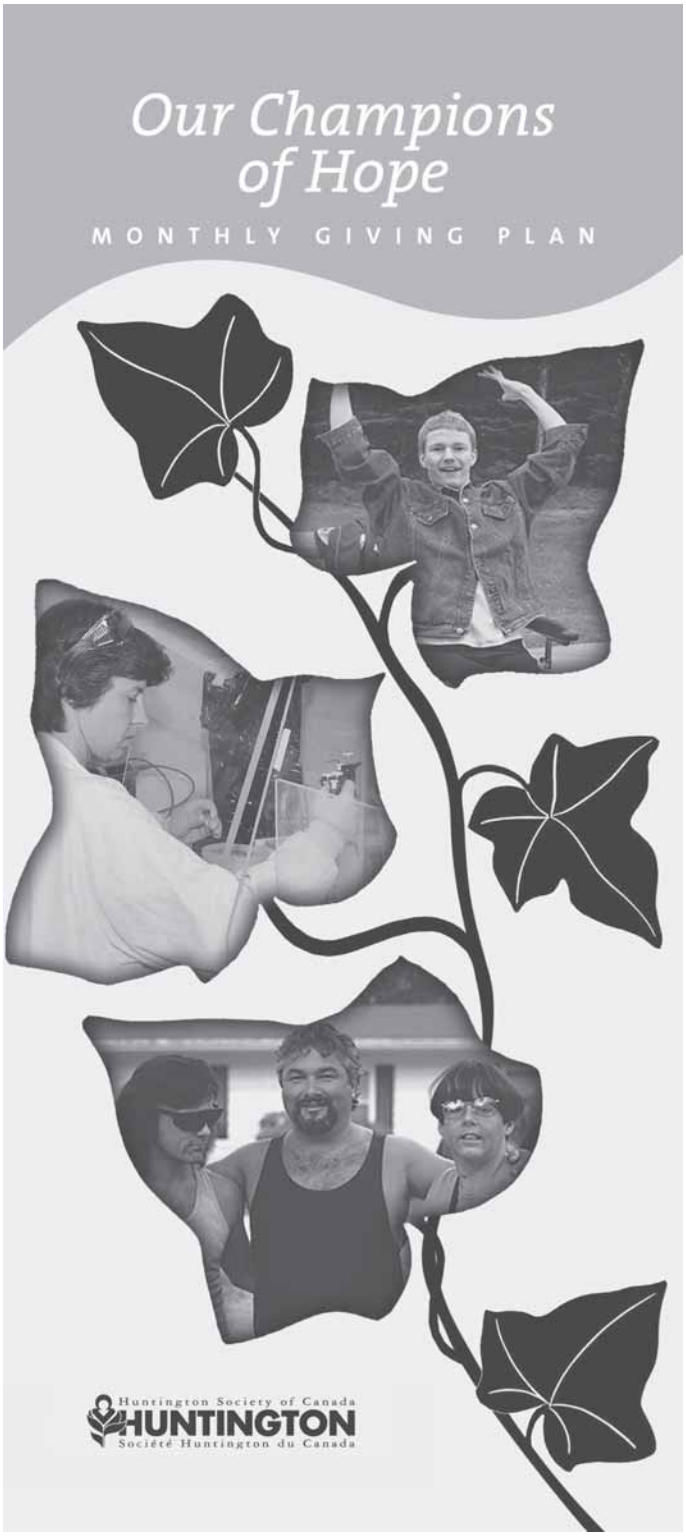
Campers enjoying the fun activities at Lake Joseph, Ontario – photo courtesy of Rob Laycock

If you have any questions about the camps through our Individual and Family Services program, please contact Rose Silvestro by phone at 1-800-998-7398 or by email at <rsilvestro@hsc-ca.org>. —RS

Barb Reichert: A Champion of Hope

By Jen Love, Senior Development Coordinator

Scanning her monthly credit card statement, Barb Reichert smiles. She smiles when she sees her gift in support of the fight against Huntington disease — her gift to the Huntington Society of Canada through *Our Champions of Hope* monthly giving plan.



"I am reminded every month that I am making a contribution to the fight against HD. I feel that I am making an impact every day — and that's a wonderful feeling," Barb says. Barb explains her reasons for joining as a monthly supporter. "This is how I keep up the fight on my Mom's behalf. She was always very interested in the research, as am I — this helps keep the money more consistent. I don't want her life-long struggle to be in vain."

Our Champions of Hope — friends like Barb — are loyal partners in our work who make an enduring commitment to building a bright future for the Huntington's community in Canada. *Our Champions of Hope* provide a vital and vibrant support network, and their gifts provide a stable funding base — funds we can count on to plan ahead and respond quickly to urgent needs.

Barb works as a sales manager at SaskTel. She joined *Our Champions of Hope* over a year ago, and has found that monthly giving is the best way for her to support the fight against HD.

"I have discovered that by making smaller monthly gifts, my total contribution to the Society in a year is much higher than I could give as a single gift. When I first started, I made sure that my gift fit within my monthly budget — but I soon realized that I hardly noticed it. In fact, less than a year after I joined, I was able to double the amount of my monthly gift!"

Our Champions of Hope is a fantastic way to support the fight against Huntington disease. Becoming one of *Our Champions of Hope* is simple and safe. You commit to making a gift to the Huntington Society of Canada each month. You specify the amount of your monthly gift and whether you prefer to make your gift on your credit card or directly from your bank account.

Joining *Our Champions of Hope* benefits you in many ways:

- It's simple, safe and confidential: your gift is automatically and securely transferred directly to the Society on or around the 15th of each month.
- It's flexible: you are in complete control of your giving and can change or cancel your monthly gift at any time by contacting us.
- It's convenient: a manageable monthly gift allows you to make a significant contribution, and you'll receive a single, annual tax receipt in January.
- It's rewarding: you will be supporting the fight against HD every day.

Joining *Our Champions of Hope* also makes a big difference to the Society:

- It provides an ongoing source of funding we can depend on for our planning.
- It allows us to process your donation more efficiently — our administrative, paper and mailing costs are kept down so more of your gift goes to work helping HD families in communities across Canada.

If you would like more information about joining *Our Champions of Hope*, please send back the *Horizon* return form or call Jen Love at the Society's office at 1-800-998-7398.

The Huntington Society of Canada extends warm thanks to Barb Reichert for her tremendous support through Our Champions of Hope — and for sharing her story.

Investing in our Future

Exchanging Our Donors' Names Helps Raise Money For The Huntington's Cause

The Huntington Society of Canada relies on donations from individuals to a great extent in order to provide HD services, research, and education. Individuals donate to our cause in a number of different ways, one of which is by sending in a donation in reply to our twice-yearly mail appeal. This method of fundraising is called our Direct Mail Program.

The Society's direct mail program is a vital part of our fundraising strategy. Last year, over $150,000 was donated to the Society as a result of our direct mail campaigns. That amount represents almost a third of our total revenue from individuals – our second largest source of income behind chapter fundraising.

A successful direct mail program is built upon a foundation of donors who renew their support every year, and, in many cases, also increase the size of their gift. However, there is no guarantee that every previous donor will give again (resulting in 'lost' donors), or that they will give a larger gift than last time (resulting in zero growth). Therefore, it is necessary to acquire new donors to 'replace' the donors who may be 'lost', and to provide new sources of income.

This process of replacing lapsed donors with new donors is called *donor acquisition*. Acquisition programs are essentially investments in the future of the Society, as we may not see a profit for a few years, until the new donors we've acquired continue to renew and increase their support. It may sound confusing, but fundamentally acquisition campaigns build the donor base of the Society, and ensure that we are able to increase the number of donors who will continue to give over time.

The main sources of new donors in an acquisition campaign are ***list rentals***, where we obtain another organization's list of donors for a fee; or ***list trades***, where we exchange our list of donors for another charity's list – for free. List trading is a fundraising technique that, although widely used by other charitable organizations, is relatively new to the Huntington Society of Canada. However in recent mailings, you will have noticed that we've asked your permission to exchange your name with other charities.

By allowing the Society to exchange your name and address with other organizations – no donation history or other information is ever disclosed – you are helping us to encourage more Canadians to support HD research, education, and care, in the most cost-effective way possible. There is no obligation to make a donation to another charity. Of course, we are primarily committed to respecting our donors' wishes, and will remove your name from the trade list at your request.

However, because many of our donors have agreed to have their names periodically traded, allowing us to acquire new names to approach for support, we have been able to make a significant investment in our direct mail fundraising program that will lead to increased support for critical HD research and services. We want to share the results of our list trades with you, to demonstrate the positive impact you're having on our direct mail program.

To date, our acquisition mailings have raised thousands of dollars, and added hundreds of new donors to our database – donors who likely have no direct connection to the Huntington's cause. Many of these donors have continued to support the fight against HD through our regular mailings in May and November.

But direct mail does more than raise funds for the fight against HD – it also is an effective way to let thousands of people know about the Society, and the important work we are doing to help improve the quality of life for people with HD and their families. Because of the names we've obtained by trading our mailing list, we have been able to mail letters to over 40,000 additional people who might not otherwise know about HD or the great strides we're making in research. As well, more than 200 people whose names we obtained from other charities' lists have asked to receive *Horizon* – a primary source of information on issues related to Huntington disease, new breakthroughs in research, and how the Society is helping people touched by HD.

So, thank you to the many donors who have agreed to let us trade their names with other registered charities. We are certain that this is an important step in building onto the already solid foundation of our fundraising program, to ensure the ongoing support for the fight against Huntington disease. —JL/HHP

The Huntington Society of Canada subscribes to the Canadian Centre for Philanthropy's Ethical Fundraising and Financial Accountability Code*, and is committed to respecting donors' rights to information and to privacy. We encourage you to contact the Society's office if you have any questions about list exchanges or our direct mail program.*

Workplace Giving

Did you know that you can support the work of the Huntington Society of Canada through your workplace?

Many businesses and organizations take part in United Way and Healthpartners campaigns, offering their employees an opportunity to support charities with payroll deductions. You can support the Huntington Society of Canada through either of these campaigns.

As well, some companies offer matching gift programs: for every dollar an employee donates, the company will match the gift to the employee's charity of choice. Some businesses make donations to charities for which their employees volunteer, too. Check with your employer to see if these programs are offered in your workplace.

For more information on workplace giving, please contact Holly Paulin at the Kitchener office. —IH

You Do Have a Say!

Do you have an idea or a suggestion on what you would like to read in *Horizon*? Now is your chance to tell us what you would like to read about. Send us your ideas on research, living with HD, caregiving, or your experience with volunteering for the Society. If you know someone in the Huntington's community you think has made a significant contribution, please forward their name to us. We always try to profile individuals who have made a difference!

Horizon is widely known as a newsletter that provides the latest information on Huntington's research, updates on our services program, information on the organization of the Society, and the hard working volunteers that make this Society what it is. We always try to provide you with an in-depth view of what affects the Huntington's community. If you have heard about something and you think we should write an article about it, please let us know!

We always welcome comments and suggestions. Contact Dana Hofstetter at 1-800-998-7398. We can't guarantee that we will write an article on every idea or suggestion, but we will certainly try. —DH

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 _____ Annual Report(s).

Please send me more information about getting involved in the Society's fundraising program:

- ❑ Amaryllis campaign
- ❑ *Indy Go-Kart Challenge*

Please send me more information on the following programs:

- ❑ Family Funds
- ❑ Planned Giving
- ❑ *Our Shining Stars* Tribute Wall
- ❑ Monthly Donations Program

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

Name: _____

Address: _____

_____

_____

City : _____ Province: _____

Postal Code: _____ Phone #: _____

Please note my change of address:

_____

_____

_____

_____

Effective :_____

Method of Payment: ❑ Cheque ❑ Money Order

❑ Visa ❑ Mastercard

Credit Card # : _____

Expiry Date : _____ Signature : _____

Huntington Society of Canada: Are You Sure You're a Member?

Members are important to us. There are an estimated 3,000 individuals with HD in Canada, and an additional 15,000 people at risk for the disease. Yet our paid up members total less than 2,000. Imagine what we could do if even half of the 18,000 people were HSC members. Here's how you can tell if you have a current membership with the Huntington Society of Canada:

Look at the back page of your copy of *Horizon*. At the bottom of the back page is your name and mailing address. There might also be a short code.

1. If all you see is your name and mailing address, but nothing else, then it means that you have never actually made an official membership donation to the Huntington Society. Now is your chance!
2. If you have had a membership before, but you are not sure when, your code will read the last year you bought a membership (ie. "99" for 1999), as well as the letter "M", "S", or "B".
   - The letter "M" means that the person whose name is on the mailing label had a membership.
   - The letter "S" means that the spouse of the person whose name is on the mailing label had a membership.
   - The letter "B" means that the person on the mailing label AND their spouse have both had paid memberships.

   So, unless the code on your mailing label reads "04M", "04S" or "04B" — "04" referring to the year 2004 — then you don't have anyone at your address with a current membership with the Society. Now is your chance!
3. If you have purchased a Lifetime membership to the Huntington Society, you should see a code that reads "LTM" (for "Lifetime") plus the letter "M", "S", or "B".
   - The letter "M" means the membership was purchased for the person whose name appears on the mailing label.
   - The letter "S" means that the membership was purchased for the spouse of the person whose name is on the mailing list.
   - The letter "B" means that the person on the mailing label AND their spouse have both purchased a Lifetime membership.

   So, if the code reads any of these, you are, from a membership perspective, set for life.

Some people may assume that if they have made a donation above the cost of a membership in a year ($25), they AUTOMATICALLY renew their membership to the Society. This is not the case. Under the law, the Society cannot make any part of your gift a membership donation without your express permission. If, in the future, you would like us to do this, just let us know.

If you have any questions about your membership status, or any other concerns, please feel free to call us at 1-800-998-7398.

If undeliverable, return to:

Huntington Society of Canada
HUNTINGTON
Société Huntington du Canada

151 Frederick St., Suite 400
Kitchener, Ontario
N2H 2M2

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