Huntington Society of Canada

HORIZON

Société Huntington du Canada

RESEARCH - SERVICE - EDUCATION

The Akt pathway … trail to a treatment?

A new study published in the June 2002 issue of *Developmental Cell* unveiled a new discovery in the process of cell death in Huntington disease (HD), and another potential strategy for the development of a treatment.

Researchers from the Curie Institute in France, as well as the Harvard Medical School and the Gladstone Institute for Neurological Disorders at the University of California, have identified important chemical interactions at the cellular level that are able to inhibit the process of programmed cell death (apoptosis) that is created by mutant huntingtin.

This new study demonstrates that it is possible to slow apoptosis by interacting with something called the Akt pathway, another important player in the process of apoptosis. The Akt pathway functions as a transmitter, sending signals that call into action other players in the process of apoptosis, such as caspases. Researchers showed that by introducing a chemical called insulin growth factor 1 (or IGF-1), it is possible to "turn on" the Akt pathway, which then modifies mutant huntingtin and stalls the ability of the cell to self-destruct through apoptosis.

In addition to its ability to block the process of apoptosis, the introduction of IGF-1 also led to a reduction in the formation of protein aggregates (or protein balls) formed by mutant huntingtin in the cell. It is these protein aggregates made up of the mutant or toxic huntingtin that ultimately cause brain cells to trigger the process of apoptosis – the cell's self-destruct system – in the first place.

According to the research team, further study of the nature of the IGF-1/Akt pathway and its ability to stall apoptosis, and consequently protect brain cells, would be valuable –possibly identifying new options for treating HD. – SM

Think Back

Apoptosis is the self-destruct sequence for a cell. Previous articles of *Horizon* have provided details on the importance of *caspase inhibition* as a way of slowing down the process of apoptosis in a brain affected by HD. When a cell becomes too old, or is unable to function properly, it initiates apoptosis so that it can be destroyed. Caspases are molecules that play an important part in this self-destruct sequence, but they are not the only player in the process.

Can you translate that for me?

Apoptosis is a process that cells use to self-destruct if they are damaged or can no longer work properly. In the brain of a person with HD, mutant huntingtin (produced by the mutant gene that causes HD) creates toxic lumps of the mutant huntingtin protein in the brain cells, and causes the cells to start the process of apoptosis – the cell's self-destruct sequence.

In this study, researchers observed that a chemical called *insulin growth factor 1* (IGF-1) activates or "turns on" a key player in apoptosis called the *Akt protein*. The Akt protein works like a transmitter, sending signals to key parts of the cell to inhibit or "stall" apoptosis. When IGF-1 turns on Akt, mutant huntingtin is one of several proteins that is modified or altered by Akt. This alteration of the mutant huntingtin helps to delay the self-destruct sequence (apoptosis) and extend the life of the cell.

The researchers in this study see this result as another possible approach for the development of a treatment for HD.

INSIDE

No. 106
FALL 2002

Bile acid inhibits cell death in Huntington's disease

MINNEAPOLIS / ST. PAUL (July 24, 2002) — University of Minnesota researchers have found that a non-toxic bile acid produced in the body prevents apoptosis, or programmed cell death, in mice with Huntington's disease. This finding, published July 29 in the Proceedings of the National Academy of Sciences USA (PNAS), may eventually lead to a treatment for Huntington disease (HD) in humans.

In the study, led by Walter Low, Ph.D., professor of neurosurgery in the university's Medical School, a dose of tauroursodeoxycholic acid (TUDCA) was administered under the skin once every third day for six weeks in mice with the HD gene. Researchers found TUDCA was able to cross the blood/brain barrier, something many molecules are unable to do. This resulted in a decrease in apoptosis in the section of the brain affected by HD, improving the neurological cell function in the mice.

"We're extremely encouraged by the neuroprotective function of TUDCA in Huntington disease and will be examining its potential in future studies," said Low.

The bile acid's anti-apoptotic qualities were originally discovered in the laboratory of Clifford Steer, M.D., co-author of the article and director of the university's molecular gastroenterology program.

"We determined that this bile acid was unique in its ability to maintain the integrity of mitochondria [the power generators of a cell], which is so important for normal cell function," said Steer. "By so doing, the TUDCA was able to significantly reduce brain cell death in a variety of conditions, including acute stroke, in rats. We were interested to see if this would be the case in Huntington disease as well. What's exciting about TUDCA, in addition to its remarkable anti-apoptotic quality, is that it's made in our own bodies and causes virtually no side effects when given as a drug. TUDCA may even have potential for treating other chronic neurodegenerative conditions, such as Parkinson's, Alzheimer's and amyotrophic lateral sclerosis (ALS or Lou Gehrig's disease)."

Orally administered ursodeoxycholic acid, the parent molecule, is already FDA-approved for the treatment of primary biliary cirrhosis.

Other authors of the study include C. Dirk Keene, Cecilia M.P. Rodrigues, Tacjana Eich, and Manik S. Chhabra.

Can you translate that for me?

Apoptosis is a process that cells use to self-destruct if they are damaged or can no longer work properly. In the brain of a person with HD, mutant huntingtin (produced by the mutant gene that causes HD) creates toxic lumps of the mutant huntingtin protein in brain cells, and causes the cells to start the process of apoptosis – the cell's self-destruct sequence.

In this study, researchers gave HD mice a chemical – tauroursodeoxycholic acid (TUDCA) – that could successfully enter the brain and slow down the process of apoptosis that is started by the mutant huntingtin. By slowing down apoptosis – the brain cell's self-destruct sequence – researchers were able to extend the lives of mice with HD.

This is an extremely positive finding since TUDCA is already produced by the human body. If it is eventually shown to be effective in other models (including humans), there would be almost no side-effects for a person taking the chemical as a drug. —SM

Huntington Society of Canada
HORIZON
Société Huntington du Canada

ISSN 0827-7605

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:

Huntington Society of Canada
151 Frederick St., Suite 400
Kitchener, ON N2H 2M2

Tel: (519) 749-7063 • Fax: (519) 749-8965
Email: info@hsc-ca.org • Web site: www.hsc-ca.org

Charitable Registration #: 11896 5516 RR0001

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

NAVIGATOR

Founding Partner:
The Geoffrey H. Wood Foundation

Leadership Partners: AGF Group of Funds; George Weston Ltd.; McKeil Marine Ltd.; The Joseph S. Stuaffer Company; TELUS Community Connections

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

Groping for perspective

By Shawn Mitchell, Director of Communications and Volunteer Development

In early June, newspapers across North America carried the story of a 63-year-old woman in the state of Georgia who shot and killed her two sons as they lay in bed in a local nursing home. Both sons (42 and 41 years-of-age) were in the advanced stages of Huntington disease. After the shooting, the woman sat and waited to be arrested. The rest of her family is trying to move on, including her youngest son (38 years old) who is in the early stages of HD.

I left the names out on purpose. When people in the Huntington's community read about this story, some are likely placing themselves in the shoes of the people in the story, making the names, for just a moment, totally irrelevant.

The caregiver and other family members are maybe thinking, "What if I become overwhelmed like that, too?"

The person affected with HD is maybe thinking, "I'm going to be that helpless one day … what will happen to me if the people I rely on turn on me the same way?"

And the person at risk for the disease is maybe thinking, "I'm terrified that, one day, I might have to face all of this."

Throw in an ever-present sense of guilt, continuous fear and frustration, a vast amount of empathy, and then a dash of hopelessness at not being able to do anything about any of this, and the impact of this kind of incident on our community can begin to be understood.

This was a tragic event, and one that should never have happened. It is tragic because the pressure that was on a mother and caregiver caused her to do what she did. It is tragic because, in killing her sons, she took away the last of their rights as human beings. And it is tragic because of the emotional burden that the rest of her family, especially her other affected son, now must carry with them on top of everything else.

But the whole situation could have unfolded differently. This family lived in a state where, in order to obtain adequate care for her husband, this woman was forced to divorce her spouse with HD so that he could be eligible for government health benefits that they could not otherwise afford. The two sons were later placed in a nursing home that had been cited for poor patient care. And lastly, in all the reports of this story, nowhere does it talk about anyone advocating on behalf of the family to address any of these problems. This family appears to have slipped through the cracks.

For the staff at the Huntington Society of Canada, this kind of story is one of the reasons we go to work every day. It is one of the reasons that more than 40% of the Society's budget is spent on providing services to individuals and families who need help in coping with the realities they face every day. It is one of the reasons why our social workers go the extra distance on behalf of clients, and it is why nursing homes, hospitals and other care facilities turn to us to help them provide better care. It is why, if you are having a hard time sorting through your feelings about this incident, or others like it, you can and should call on us.

The mother's name was Carol. Her sons were Randy and Andy. Together we mourn their loss … together we can avoid having something like this happen again.

FYI!

If you recall, in the Spring 2002 *Horizon* (#104) the lead article featured the Winnipeg Chapter's successful *Rally the Sleds for HD*. As of press time for this issue, Brett Mitchell and Vern Barrett report that things are well under way for next year's event. Thanks to the many volunteers who contributed to the February 2002 record-breaking effort – including Brent Wall who came up with the idea for the event in the first place; Chapter volunteers who helped with the organization of the day; all the snowmobile riders who raised pledges and rode their sleds; and many others – everything is set for another incredible rally. Keep looking to *Horizon* for updates and news about this exciting new event, as well as for formal confirmation from the *Guinness Book of World Records* that *Rally the Sleds for HD* has the new world record for the longest continuous line of moving snowmobiles! – SM

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.:

I have had HD for a few years. I have a wife and two teenage children. Not that long ago I had to leave work. I do almost everything for myself. I can't work, but I'm not disabled when it comes to being a husband. I love my wife and want to have a normal sex life. During the last year, she has been refusing to have sex with me. She says that I'm too pushy and demanding and not treating her as a "whole person." I don't understand it! I feel like I'm losing everything.

Angry

Dear Angry:

You sound like you are going through a hard time. Huntington disease and the effects of HD can place a strain on a marriage. You also sound as though you have already experienced a great deal of loss – first your job, and now your sense of normalcy within your marriage.

Sexual intimacy within a relationship is indeed a very special thing. Often, however, when serious problems arise – be they physical, emotional or financial – intimacy can be affected. Similarly, HD can place added strain on a sexual relationship. Sometimes, for instance, the physical symptoms of HD (fatigue, chorea, mood swings) can alter an individual's sexual drive, as well as the ability to respond naturally to his or her partner. Medication can also be a culprit, as it can decrease an individual's sexual desire or degree of responsiveness. In contrast, some people with HD may experience increased libido. Regardless of what the changes are, the effects can be upsetting for both partners. My guess is that there have been changes over the past few years in your lives that have had an impact on your sexual relationship.

I understand your angry feelings, but I am sure you want to express your love for your wife in the most positive way possible. Start by respecting her wish for no intimacy at this time. A good sexual relationship, even if it is not always mutually satisfying, should always involve mutual consent.

Given the fact that you have both struggled with this problem for over a year, I would suggest that you talk to a third party (i.e., a doctor or counsellor) about your wife's and your concerns.

Many sexual difficulties result from miscommunication and/or problems outside the marital bed. There is the chance, however, that you may not be able to resurrect your sexual relationship. Many couples living with HD have continued to have a caring, loving relationship while foregoing the sexual aspect of their relationship. For a variety of reasons, these couples found that the sexual expression of their love toward each other was no longer mutually satisfying, but they loved each other enough to stay together.

Try and remember that your wife is also going through this experience with you. Neither of you is to blame for what has befallen you. Now is the time to find out what each of you needs and whether or not there is a middle ground that will work for the both of you.

S.W.

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

Elaine Taylor — a Great Humanitarian

Elaine Taylor: Past-Chair, National Board of Directors, Huntington Society of Canada and recent recipient of the Paul Mulvihill/ NABS Humanitarian Award

Long-time Huntington Society volunteer Elaine Taylor was recently honoured with a very special award for her volunteer efforts.

Elaine, whose mother died with Huntington disease, has been a volunteer of the Huntington Society for 14 years. She has been deeply involved in fundraising— most notably, she spearheaded the Toronto Monte Carlo event, which raised over a quarter of a million dollars over the course of its 11-year history. She continues to be an active member of the Society's corporate fundraising team.

Elaine has also been instrumental in the creation of several of the Society's public awareness campaigns. With the support of her employer and several of her colleagues at OgilvyOne worldwide, Elaine was a driving force behind the creation of the Society's TV and radio public service announcements, print advertisements and posters. She has also been interviewed several times by the media about Huntington disease, and her family's struggle with it, in order to raise awareness.

In 1994, Elaine joined the national Board of Directors of the Huntington Society, and served as Chair from 1999 – 2001. Currently, she serves on the Board as Past Chair.

The Society was proud to nominate Elaine for the Paul Mulvihill/ NABS Humanitarian Award, presented to an individual who works in the advertising or communications industry and demonstrates commitment to improving the lives of people in their own community and/or across Canada. The award was presented at a gala event hosted by the National Advertising Benevolent Society (NABS) in Toronto on May 10, 2002.

In accepting the award, which included a $5,000 cheque to the winner's charity of choice (the Huntington Society) and a beautiful, specially-designed crystal statue, Elaine said, "I got involved with an organization that I was totally passionate about, and I simply committed the time. But, an amazing thing happened *around* me over the past 14 years. As I have traipsed along doing what I could do, I have not been alone. In fact, I have been overwhelmed by the generosity of people I have encountered. Thank you to everyone who [helped me in my efforts]. And thank you to the Huntington Society of Canada for making volunteering fun and rewarding." Elaine dedicated the award to her mother's memory.

This special award was named after broadcaster Paul Mulvihill, a founder of the Broadcast Executives Society and the Canadian Association of Broadcast Representatives. Mr. Mulvihill was well-known for his many humanitarian gestures. —IH

Volunteers Who Have Truly Made A Difference

By Sandra Funk, Director, Manitoba Huntington Disease Resource Centre

Katherine Doerksen and Sheila Sampson are two very special women, who have significantly enriched the lives of several individuals with Huntington disease through their volunteer work with the Activity Group for Individuals with HD in Winnipeg.

Katherine Doerksen began her work with the Manitoba HD Resource Centre in November, 1985 as a volunteer visitor, with weekly visits to a personal care home to provide companionship to a lady with HD. In 1987, she began helping out with the Activity Group and she has remained with the group to this day.

Sheila Sampson began by accompanying a man with HD to the Activity Group from 1990 to 1993. She returned to help out with the group in 1995 and has remained until now.

Both ladies brought a background in nursing and so much more. Their gentle and caring natures grew into a genuine affection and compassion for the participants of the group. Both were always willing to lend a hand, whether it involved pushing a wheelchair, assisting in feeding an individual or helping someone to participate in a fun activity. Many times, they would extend their caring beyond the group by bringing favourite foods and special gifts to participants.

There are few words that can express the appreciation for the contributions made by these two very special women. Together they have given numerous hours of their time to bring fun, joy and genuine empathy into the lives of people with HD. It has been over a period of 16 years for Katherine and over a 10-year period for Sheila. We could not run the group program without their help.

The Huntington Society, Manitoba HD Resource Centre, and participants of the Winnipeg HD Activity Group offer a heartfelt thank you to Katherine and Sheila. You both have made an enormous difference in the lives of those individuals with HD whom you have touched.

Sheila Sampson (left) and Katherine Doerksen (right) — volunteers who have truly made a difference.

Running for HD

By Norma Stevens, President, BC Chapter and Shawn Mitchell, Director of Communications and Volunteer Development

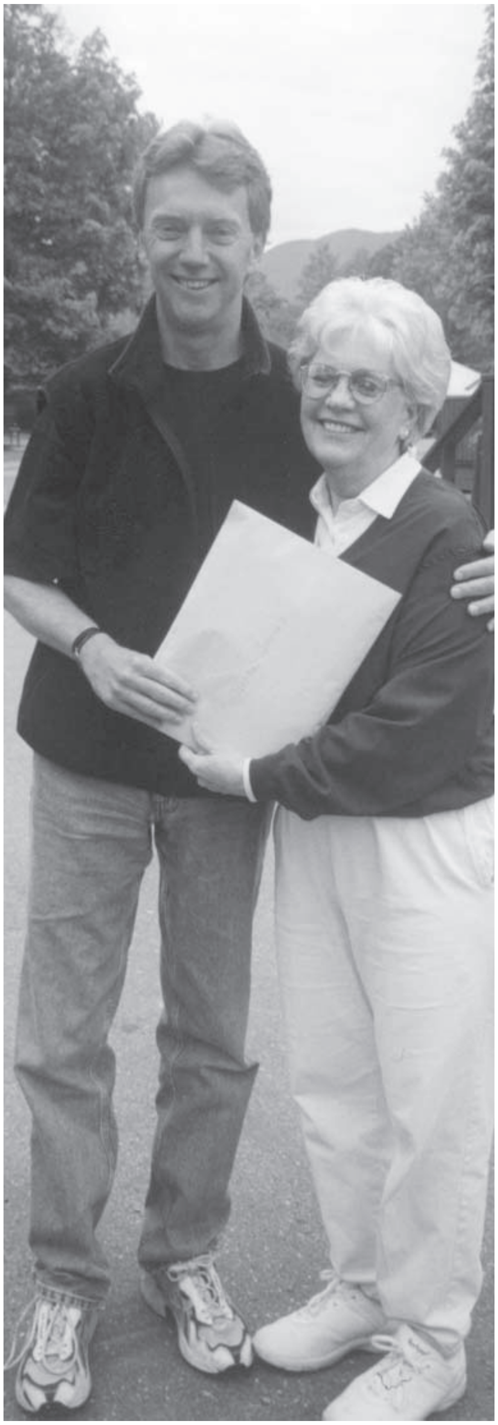
Eighteen years ago, Dean Crain started running every Sunday morning with the Brockton Point Running Club at Stanley Park, in Vancouver, British Columbia. An investment broker with RBC Dominion Securities, he would quite often enter in marathon events.

Dean is now symptomatic with Huntington disease. He has had to quit his job because of HD, but he is working hard as a volunteer for the Huntington Society. Even though the symptoms of HD now make it more of a challenge for him to run, he has continued to train with Brockton Point Running Club on a regular basis.

This year he has put a tremendous effort into his fitness program, preparing for the Adidas Vancouver International half-marathon (13.2 miles) in May. Dean told the 30 to 40 members of his Running Club that he was going to run in this race to raise funds and awareness for Huntington Disease. As a result, Brockton Point Running Club was a very strong supporter of his cause and collectively contributed a substantial amount of money, as did his friends and relatives.

But more specifically, two of the club members, who had never run marathon distances before, decided to work with Dean. He called them his guardian angels!

Dean also used to be a Rotarian, so he asked if he could speak to the Richmond Club's morning breakfast meeting. He had to catch the 4:30 am bus from his home (he has had to quit driving because of HD) to get there for the 7:00 am meeting. On his own, he prepared a speech talking about HD and how it has affected his life.


Dean Crain presenting Norma Stevens, BC Chapter President, with a cheque for proceeds from his half-marathon run.

He told them he was raising funds not for himself, but for his children (ages eight and ten) who are at risk.

Finally, Dean went back to RBC Dominion, where he used to work, and he made a presentation to the office staff telling them of his plans to raise funds and awareness for Huntington's. RBC Dominion Securities offered to match each employee's donations with 50 cents on each dollar pledged.

Overall, Dean raised more than $12,000 in pledges for his run!

So, on May 5th, 2002, 10,000 participants started the marathon, with 4,500 of those running the half-marathon – including one very special runner with HD. Dean and one of his "angels" were able to cross the finish line in two hours and 22 minutes. As Dean said, "I only fell once … not bad for a guy with HD!"

Since the race, Dean has attended our Chapter meetings and this year enjoyed his first year as a participant of Camp Squamish Huntington's Camp. He has also started volunteering for the BC Chapter's weekly Bingos, and has recruited a friend to come out and help as well. This same friend put notes in his apartment's mailboxes telling of Dean's run. Thanks to this effort, he was able to give Dean a cheque for over $300.00 raised from people living in his building.

People who know Dean Crain would describe him as a very humble person, one who sets high goals for himself and works hard to reach them. The way that his friends and acquaintances rallied around and supported him in this race speaks highly of how Dean is respected by admired by those around him. Dean Crain … another one of the Society's special volunteers making a difference.

Preparing for the Future

Huntington Society plays role in guiding the future of predictive genetic testing in Ontario

By Dana Hofstetter, Communications and Volunteer Development Coordinator

Looking back on the developments in genetic testing for HD, 1993 was a year of profound change. That year marked the discovery of the gene that causes Huntington disease and led to the current availability of genetic testing for those at risk of developing the disease. Genetic testing has been both a blessing and a curse for people in the Huntington's community. The decision to have, or not to have the test is a difficult one to make. But while people in the HD community have had much experience at grappling with these and other related issues, in general the science of genetics is not widely known or understood, or even regulated by the government.

Almost two years ago, the Ontario government struck a Provincial Advisory Committee to develop recommendations to help the province understand how it should regulate predictive genetic testing and how it should react to future advances in the field of genetics. The government has recently published the results of the work of the Committee in a report called, *Genetic Services in Ontario: Mapping the Future*.

The Provincial Advisory Committee was made up of a broad sample of medical professionals in the genetics discipline and representatives from health related non-profit organizations, including the Huntington Society of Canada. The committee's mandate was to develop a framework of policies to introduce new genetic predictive testing and services into Ontario's health care system. The committee also developed guidelines, criteria, principles, and advice on how new genetic services should be introduced.

Several sub-committees supported the advisory committee in the areas of education, clinical, practice, psychosocial issues, laboratory practices, and legal and ethical issues. These sub-committees were developed to look at certain issues at hand, and present recommendations to the Advisory Committee on which issues should be investigated and developed.

The Huntington Society was represented by Elaine Taylor, currently the past-Chair of the national Board of Directors; Francine Robert, Director, National Board of Director and a genetics nurse with the North Bay District Health Unit; and Nancy Webb, Toronto HD Resource Centre Director.

While the report made many recommendations on a number of different levels, there are four broad strategic thrusts proposed by the committee that are significant. First, the committee recommended that a permanent advisory committee be struck to assist the Ontario government with predictive genetic testing issues. The government has already begun the process of forming this committee. Elaine, Francine and Nancy each see this as an important first step. With a working committee always present, new advances can be evaluated efficiently, and support can always be given.

Second, a need for evaluation and re-evaluation is recommended, so that all new predictive genetic tests that are introduced could be evaluated on pre-defined criteria. For example, in having only the most accurate genetic tests available, the Ontario government is able to be more cost-efficient, and ensure that patients are receiving results that they can rely upon.

Third, a recommendation was made to increase the recruitment and training capacity provided for genetic service health care providers. Many health care providers are not provided with adequate information on many genetic diseases. Consequently, they are not able to effectively support their patients in providing the kind of information and counselling that each person might need. By increasing the training provided, patients are able to receive the proper care they deserve as part of the predictive testing process.

Finally, several recommendations were made with respect to ethical and legal issues arising from the availability of genetic information. According to the report, the Ontario government needs to ensure the privacy and confidentiality of all genetic testing patients, and to protect patients from the discrimination and stigmatization that may arise from the outcomes of genetic tests. In addition, several recommendations were made with an eye to abolishing the discrimination that currently exists in the insurance industry with respect to genetic diseases, such as HD.

Since the Government of Ontario has presented this report to other provinces, the response has been extremely positive, and there is hope that it will spark a national campaign on regulating and protecting patient's rights as they relate to predictive genetic tests.

In reflecting on their work in this process, all three women are extremely positive about the value of the final report. According to Francine Robert, "All of the recommendations made were in the best interests of all the patients involved." Nancy Webb agrees, adding that, "This will affect all kinds of people outside of just the lab."

For Elaine Taylor, "This report only means positive things for the HD community. It goes beyond regulating genetic testing – it establishes the need for human rights of every individual affected by a genetic disease."

If you would like to learn more about this report, and review the full range of recommendations contained in it, visit the Web site of the Ontario Ministry of Health and Long-Term Care at <http://www.gov.on.ca/health>, or call the Ministry's infoline at 1-800-268-1154.

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

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 $165,000 was donated to the Society as a result of our direct mail campaigns. That amount represents 55% 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 if you 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, the acquisition mailings have grossed almost $12,000, and added 430 new donors (who likely have no direct connection to the Huntington's cause) to our database. Almost one quarter of these donors have continued to support the Huntington's cause through our regular mailings in May and November – representing a total so far of about $15,000. These are very good numbers, considering we have only used traded lists for two acquisition mailings, in February and November of 2001.

The traded lists also led to eleven gifts of $100 or more, which is considered high for a first-time donation. As well, the Society receives more than $600 per year from monthly donors who came to us as a result of an acquisition mailing.

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 mailed appeals to over 20,000 additional people who might not otherwise know about HD or the great strides we're making in research. As well, almost 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.

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.* —HHP/jl

Communications and Volunteer Development at the Huntington Society of Canada

Dana Hofstetter has recently joined the Huntington Society of Canada at its Kitchener, Ontario office as the new Communications and Volunteer Development Coordinator.

Dana comes to the Society with a B.A. in Communications Studies, a Post-Graduate Certificate in Public Relations, as well as work experience with the Heart and Stroke Foundation of Ontario, Niagara Falls Tourism and the Canadian National Institute for the Blind.

She is filling a newly created position that has been a part of the Society's ongoing effort to expand its volunteer development function. Communications and Volunteer Development have been combined into one department, made up of Shawn Mitchell (Director), Dana (Coordinator) and Shirley Barnes (Assistant). The department will continue to be responsible for such things as *Horizon*, the Society's Web site, public and media relations, as well as structuring and maintaining the Society's volunteer management activities, and providing training and direct program support to HSC volunteers right across Canada.

Through the hiring process, interviews with Dana and her references revealed her to be an extremely personable, hard-working, team player. The Society is very excited to have her as a new member of the Society's staff. Dana can be reached at 1-800-998-7398, ext. 33, or by email at <dhofstetter@hsc-ca.org>. —SM

New Support Worker for Southern Ontario

As of August 1, 2002, we have a new support worker in the Kitchener/Waterloo/Cambridge/Guelph area. **Barb Shannon** will be taking over the area in place of Sheryl Millson, who recently stepped down from the role.

The role of support worker is to provide information and support to HD families and health professionals, as well as crisis intervention, advocacy, counseling and referral to community resources. The support worker is also available to facilitate support/ discussion groups for HD families.

Based in Cambridge, Barb has a Master's degree in Social Work and many years of experience working in the mental health field. We are very pleased to welcome her as new member of the Individual and Family Services team at the Huntington Society of Canada. She is available on an on-call basis, and is looking forward to hearing from families as well as professionals in the community who work with people dealing with HD. She can be reached at (519) 653-1396 – please leave a message on the voice mail and she will return your call as soon as possible.

Lastly, on behalf of the Huntington Society of Canada and the many families and health professionals that she worked with for the past three years, I'd like to thank Sheryl Millson for her dedicated contribution and service to the Huntington's community. We all wish her the best of luck in her future endeavours. —SDR

Racing for a cure

Sunday, September 8th, 2002 is ***Indy*** day and as of press time our volunteer organizers across Canada are tearing up their tracks pulling together the final details. Check the next issue of *Horizon* for the results. It's shaping up to be another tremendous year, thanks to the dedication of our volunteer organizers. Special thanks to our organizers for their leadership. With your energy, your time and your hard, hard work, our race for a cure will soon be won. Thank you! —JL

Our Shining Stars

Huntington Society of Canada Unveils New Tribute Wall

By Holly H. Paulin, Development Coordinator

This summer, there is a new addition to the walls of the Society's national office. In July, we unveiled our new Tribute Wall, filled with "Our Shining Stars" —the names (engraved on stars) and, in some cases, photographs of people close to the heart of the Huntington's cause.

The Tribute Wall as it hangs in the Society's office in Kitchener, Ontario.

The Tribute Wall program was developed as a lasting way for friends and family members to honour the people in their lives who have been touched by HD. Some stars recognize people who are living with Huntington disease today, while others recognize people who do not have a personal fight with HD, but have been touched by it in some way. Many of the stars are remembrances of loved ones who are no longer with us. These remind us especially of the courage shown by so many individuals, and inspire us to continue working together in the fight against HD.

The tribute wall depicts a twilit sky, filled with golden stars. At the base of the wall, outlined groups of figures, or families, look up together at the night sky. As the figures look up into the sky, they see shining stars filled with names of people whose lives have been touched by HD, as well as the names of those who have made great contributions to the Huntington Society of Canada. By portraying families at the base, the wall captures the genetic and family aspects of Huntington disease, as well as a sense of hope that is shared by everyone involved with the work of the Society. As we look at the stars in honour of these remarkable people, we can't help but look at the past and have hope for all of the future stars in our lives.

The wall was created by Cheryl McKay, a Graphic Design student at Conestoga College in Kitchener, Ontario. The Society is grateful for Cheryl's work, as she volunteered countless hours of her time in designing and painting the Tribute Wall. Each star is actually a laser engraving on a brass-like material, the shape of which was also designed by Cheryl to complement the overall style of the piece. As the accompanying photographs show, the result is wonderfully touching.

The shining stars are a poignant and enduring way to pay tribute to loved ones whose fight with HD has ended, and to those who are fighting the battle, shining with courage. To date, there are almost thirty stars on the wall, and we anticipate displaying more than 200 over time. Stars engraved with a loved one's name or personal message, and accompanied by an optional personal photograph, are available for a donation of $250 or more. If you are interested in the "Our Shining Stars" Tribute Program, please contact the Society's office for more information.

***Editor's Note**: The completion of the Tribute Wall, and the quality of the finished product, is due in no small part to Holly Paulin's efforts in overseeing the project from the hiring of the artist through to the official hanging in the Society's office.*

2002 Amaryllis Campaign:

Growing A Brighter Future!

We're "growing" towards another successful year of Amaryllis sales, thanks to all of our volunteers who have placed their Amaryllis orders for 2002. Our goal is to sell 23,000 plants this year, and so far over 18,000 have been ordered!

Volunteers all across Canada take part in our Amaryllis campaign to raise funds for the Society's services, education and research programs. By ordering a case of 12 Amaryllis kits to sell to your family, friends, and colleagues, you can help grow a brighter future too! Each kit sells for $11, and the bulbs produce beautiful orange blooms just in time for the holidays.

There is still time to order your Amaryllis kits. If you haven't already placed your order, or have any questions about our Amaryllis campaign, please 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

CASINO • NIAGARA
INTERNATIONAL
MARATHON

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

RETURN FORM

245

☐ 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:

____

____

____

____

Effective :____________

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

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

2002 Annual Conference – *Inspired by Memories, Ignited by Hope*

The Huntington's community will gather in Niagara Falls for our Annual General Meeting and Conference November 8th and 9th, 2002. Hosted by our vibrant Niagara Chapter at the Brock Plaza Hotel overlooking the glorious falls, this year's Conference theme is "Inspired by Memories, Ignited by Hope".

Saturday, November 9th will be our *Family Day*, and we invite you to join us. Features of *Family Day* include:

- "Families in Focus Forum," an opportunity to share thoughts and insights into Huntington disease;
- Science and Research Forum, featuring up-to-the-minute research news, the activity of the Huntington Society of Canada's Research Council and the perspective of a researcher funded by the Society;
- a tribute to Ralph Walker, co-founder of the Huntington Society of Canada;
- our annual banquet on Saturday night.

This year, *Family Day* will also feature something brand new. Instead of running support groups on *Family Day*, the Society's Services team will be offering a series of one-hour information workshops on a range of practical topics that will be of interest to individuals with HD, individuals at risk for HD, other family members and caregivers. The schedule for the day will allow for everyone to attend two different workshops of their choice.

Confirmed topics include: Coping with Grief and Loss; Caring for the Caregiver: Practical Tips; HD Primer: An Introductory Session; Managing Mid-stage Symptoms of HD. Other topics currently being considered include: HD Family: Helping Parents Talk to Kids about HD; After the Diagnosis: Managing Early HD; and Community Care Alternatives: When and How to Make the Decision about Alternative Placement. We look forward to launching this new program initiative.

To register, please fill in the enclosed form and send it back to the Society. For more information about the Conference, or if you have any questions, please call us at 1-800-998-7398. —JL

If undeliverable, return to:

Huntington Society of Canada
HUNTINGTON
Société Huntington du Canada

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

CANADA POST POSTES CANADA
Postage paid Port payé
Publications Mail Poste-publications
40010858