

# FALL 2018



## DONOR REPORT

**A report to thank our incredible donors for their leadership and support to help families living with Huntington disease.**

**These highlights are possible because of your generosity.**

# RESEARCH



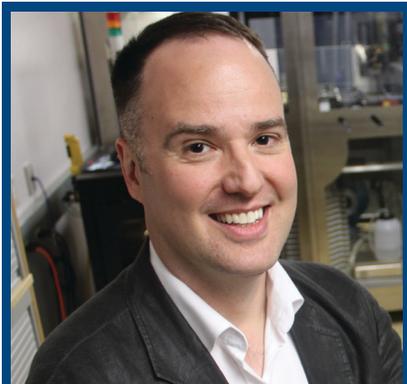
In 1993, scientists made headlines when they announced the discovery of the HD gene. Twenty-five years later, we're now seeing the fruits of that breakthrough. Instead of testing whether drugs developed for other diseases might help HD, investigators are now testing drugs specifically designed to address the root cause of Huntington disease.

The universal goal for international HD research is to find treatments that reverse, slow or prevent the progression of HD. The Huntington Society of Canada, HSC donors and HD Canadian researchers are a key part of this effort and the Society has a unique role to play.

The Huntington Society of Canada invests in excellent, peer-reviewed research into the most promising basic and clinical research, leading to viable treatments for HD.

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## EXCITING PROGRESS IN HD RESEARCH



Dr. Ray Truant, McMaster University

A multi-institutional, international study supported in part by donors like you has developed a new theory on Huntington disease (HD) which is showing promise and is opening new avenues of potential drug development.

"The concept was that if we applied the signalling molecule back in excess, even orally, this signalling can be restored in the Huntington disease mouse brain," said Laura Bowie, a PhD student in the Department of Biochemistry and Biomedical Sciences at McMaster University. "This resulted in the mutant huntingtin protein levels being restored to normal, leading to a correction of Huntington disease in mouse models."

This discovery was made using a robotic microscope and drug screening by artificial intelligence, coupled to state-of-the-art, super-resolution microscopy in a system developed by Bowie.

Ray Truant, senior author on the study, has focussed his career on Huntington disease research and how the mutation leads to Huntington disease. His lab was the first to show that normal huntingtin was involved in DNA repair.

"This is an important new lead and a new hypothesis, but it is important for people to know this is not a drug or cure," said Truant, professor in the Department of Biochemistry and Biomedical Sciences at McMaster. "These compounds also show promise in Parkinson disease models as there may be pathways in common for Huntington and Parkinson diseases."

## PROBING THE DETAILS OF HUNTINGTIN PROTEIN

Current huntingtin-lowering trials may hold plenty of potential, but we don't want to put all our eggs in one basket. That's why HSC continues to invest in other promising HD research with the support of our donors.

Earlier this year, we awarded a two-year, \$150,000 NAVIGATOR grant to Dr. Cheryl Arrowsmith, a professor of medical biophysics at the University of Toronto and a chief scientist at the Structural Genomics Consortium, who is developing a detailed 3D model of the huntingtin protein.



Dr. Cheryl Arrowsmith,  
University of Toronto

By figuring out its exact shape, right down to the level of atoms, she and post-doctoral researcher Rachel Harding can gain new insights into what the normal version of the protein does and what goes wrong in the mutant version.

It's challenging work. Because huntingtin is much bigger than most proteins in the human body, it forms a very complex three-dimensional shape. To examine it, they'll use cryo-electron microscopy, a revolutionary new technology for looking at large proteins. Once they've nailed down the bigger picture, they'll use high-resolution X-ray crystallography to zoom in on the details of key areas.

According to Dr. Arrowsmith, there's growing evidence that normal huntingtin might be involved in fixing the DNA damage that naturally occurs in our bodies over time. That's why she and Dr. Harding will also look at how huntingtin interacts with DNA and different repair molecules. "It will go a long way to try to help understand how this very elusive protein is behaving," she says.

What they learn, they'll share. Researchers typically don't reveal their data until they publish it in a scientific journal. However, Dr. Harding is taking the radical step of publishing all her experimental results in an online blog at [www.labscribbles.com](http://www.labscribbles.com). Once they've figured out the exact structure of huntingtin, they'll make it available in a public database.

Research is a long, slow, painstaking process, but this "open science" approach will speed up the pace of discovery. "By sharing the information sooner, it should accelerate science," says Dr. Arrowsmith. "Anything you can do to make things move more quickly will help."

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Thank you for continuing to believe in the power of research and generously funding these advances. Your support is helping us move closer to our vision of a world free from HD.

To learn more about the difference you are making as an HSC donor through ground-breaking HD research, visit [www.hdresearchnews.ca](http://www.hdresearchnews.ca).

# FAMILY SERVICES

The Family Services team annually supports over 15,000 individuals across Canada. This team delivers support, education and advocacy services from coast-to-coast. Through their work, they are ensuring that individuals, families and organizations have a better understanding of HD and how it impacts the whole family. This is made possible by the ongoing and continued support of our donors. For a complete list of Family Services team members, and to learn more about the support our Family Services team provides, please visit [www.huntingtonsociety.ca/family-services-program](http://www.huntingtonsociety.ca/family-services-program).



## NEW RESOURCE CENTRE OPENS IN HALTON/PEEL

Through the incredible support of our donors, HSC has opened a new Resource Centre in the Halton/Peel area of Ontario which will help to meet the increased need for support in that part of Ontario. Ekta Hattangady, RSW has been hired as the new Resource Centre Director.

Ekta brings experience with group facilitation, advocacy, program development and individual and group counselling to her new role. Most recently, Ekta has been certified as a Master

Trainer with the Living the Dementia Journey program – a program focusing on care partners and professionals supporting people living with dementia. Ekta is a strong advocate and group facilitator and looks forward to continuing her work with the families affected by HD in the Halton/Peel region.



## HD-COPE

HD-COPE is an international collaboration between the Huntington Society of Canada, the Huntington Disease Society of America (HDSA) and the European Huntington Association (EHA). HD-COPE was formed to replace the current ad hoc approach to incorporating the patient-voice in global therapeutic development efforts for HD. Over the last year, the group has shared the HD community's experiences and needs with regulators, industry and researchers. As more clinical trials become available, the voice of the HD community is of utmost importance! Your support has helped to lay the groundwork for HD-COPE and it is our hope that it will continue to grow over time to include more community members and other HD organizations from around the world!

Our HD-COPE team (pictured left to right): Rob, Suzy, Shaunacy and Jenna.



# CONNECTING OUR COMMUNITY

## 2018 NATIONAL CONFERENCE



Through donor support, we are able to meet and connect face-to-face with our community of individuals living with or at-risk for Huntington disease, including youth, caregivers, researchers and care professionals on a biennial basis at our HSC National Conference.

This year, Conference will be held in Kelowna, British Columbia on November 2 and 3. To join us and for more information, please visit [www.huntingtonsociety.ca/conference](http://www.huntingtonsociety.ca/conference).

## 2018 YOUNG PEOPLE AFFECTED BY HD DAY (YPAHD DAY)

As part of our Youth Program, and through the support of donors like you, HSC supports our virtual youth Chapter by holding Young People Affected by Huntington disease (YPAHD) Day annually. YPAHD Day will be hosted in Kelowna, BC this year on November 1, right before the Conference.



YPAHD Participants in Kelowna, British Columbia in 2017.

To date, more than 55 youth have registered for this educational event. Youth will be funded thanks to donor support, and over 60% are first time attendees. Visit [www.huntingtonsociety.ca/YPAHD](http://www.huntingtonsociety.ca/YPAHD) for more details.

## JIM POLLARD 2018 INFORMATION SESSION TOUR



Jim Pollard giving his engaging talk, Hurry Up and Wait.

Thanks to the generosity of our donors, HSC was able to conduct an information session tour in British Columbia with Jimmy Pollard, well-known HD presenter.

In April 2018, Jimmy visited multiple locations in BC giving two presentations: "Huntington's Disguise" which helps the audience to understand some of the subtle physical and cognitive aspects of HD, and "Hurry Up and Wait: Thinking about Thinking with HD" which includes a series of interactive exercises that simulates how thinking with HD challenges how we communicate with one another. Thanks to our donor's generous support, Canadian HD community members were able to benefit from Jim's insight.

# THANK YOU

On behalf of families living with HD, thank you for your continued generosity and partnership. Your donations make all the difference as we support families and youth from coast-to-coast, reach out to families who are not yet receiving much-needed support, invest in world-class research and play a leadership role in the international Huntington community.

With your help, we continue to improve the quality of life for people with HD, cultivate strength and resilience in the Huntington community and provide substantive reasons for hope.



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