



# The HSC National Conference 2008

Delta Prince Edward Hotel, Charlottetown PEI  
October 30–November 2, 2008  
Hosted by the HSC Prince Edward Island Chapter

## Why Attend?

Join us in Charlottetown at the Delta Prince Edward for an inspiring, energizing and information-packed three days. It promises to be the best HD conference in North America this year!

Our Saturday program features not just one keynote address, but an entire day of world-renowned HD speakers. Get the most up-to-date information on drug developments and research discoveries, the latest insights into maximizing quality of life, and a personal, impassioned view of what it means to live with HD. Browse through the speaker biographies—we guarantee you'll be impressed!

On Thursday night we feature some fascinating discussions of particular interest to those at risk for HD and those who want to create a legacy for the next generation. On Friday you'll develop strategies for teaming up with other community groups in a hands-on workshop that will invigorate your local HD initiatives and kick-start our climb to the summit.

Plus, of course, the HSC National Conference offers an unparalleled

opportunity to connect with researchers, healthcare professionals, caregivers, those at risk and HD family members from across the country.

Register now! We're looking forward to seeing you.

## The Theme: Reach for the Summit

At our 2006 national conference we celebrated reaching base camp, the highest point, so far, in our journey toward our own Mount Everest: a world free of Huntington disease.

When we first started, who could have imagined that we would find a way to stop the progression of the disease in mice, develop ways to improve quality of life for people with HD, establish a flourishing organization that offers information and support across the country, and launch clinical trials for potential drugs designed specifically for HD.

Now we're leaving base camp. As a team—families, scientists, service professionals and donors—we're tackling the climb to the summit. While the task is challenging,

we've laid the groundwork for success by taking care of families, enhancing services for today, working to find treatments for tomorrow and convincing more people than ever to help us reach the top. It will take vision, determination and persistence to keep going in the face of the setbacks that inevitably lie ahead, but we have done it before and we can do it again.

At the 2008 National Conference, we'll be celebrating our achievements, measuring the distance left, and mapping out a route to the summit. It's a breath-taking view.

## Thursday, October 30, 2008

Preparing for the Climb

7:30 – 8:30pm

**Reception & Dinner**

**Welcome and Introductions**

**My Dad and Huntington's Disease**  
**Katie DeLargie**

"You might feel bad for me, but don't," says grade seven student Katie DeLargie, who's father has HD. "By the time I am around 40, I know there will be a cure." Come and be inspired by Katie's vision.



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**8:40pm - 10:00pm**  
**Informal HD Dialogues**

Pull up a chair and join one of the stimulating post-dinner conversations on tap. Your hosts will start things off with a brief presentation and then open the floor to questions and discussion.

**HD Research and the Genetic Testing Decision**

**Jeffrey Carroll & Dr. Ray Truant**

If you're at risk for HD, the future offers both hope and threats. Dr. Ray Truant and Jeffrey Carroll will lead an informal dialogue on topics of interest, including the promise of current research as well as the personal issues involved in genetic testing.

**Creating a Legacy for the Next Generation**

**Ariel Walker & Paul Evered**

Ariel Walker and Paul Evered invite you to share in lively dialogue about their progress on one of HSC's newest projects, The Ralph and Ariel Walker Summit Society. It's a great way to leave an enduring legacy in the fight against HD. Don't forget to bring your questions!

**Friday, October 31, 2008**  
**Assembling the Climbing Team**

**7:30 – 8:45am**  
**Breakfast**

**9:00 am 9:15 am**  
**Welcome and Introductory Remarks**

**9:15am -9:40am**  
**The Huntington Society of Canada Annual General Meeting**

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**9:40am - 4:00pm\***  
**Expanding and Engaging Our Climbing Team**

**John Lord**

Success in reaching the summit depends upon our ability to engage others in our community and mobilize their strengths to achieve more for our families and our chapters. Yet, many of us are isolated in our communities and we are increasingly stretched for time. You will leave this interactive workshop with renewed energy and techniques that will transform how you and your chapter relate to your community. You will learn how to identify strengths and connections in your community, expand your personal networks, and understand the power of asking. Those already using aspects of this approach report great results. During the workshop we will make time to have fun, connect with others and learn from our successes.

\* Includes breaks and lunch

**6:00 – 10:00pm**  
**PEI Kitchen Party Reception and Dinner**

**Hosted by HSC PEI Chapter**

Come and experience Prince Edward Island culture and hospitality in an evening of great food, music, storytelling and fun.

**Saturday, November 1, 2008**  
**Preparing for the Initial Ascent**

**7:00 – 8:15am**  
**Breakfast**

**8:30 – 8:45am**  
**Welcome and Introductions**  
**The Hon. Barbara A. Hagerman,**  
**Lieutenant-Governor of PEI**

**8:45 – 10:00am**  
**Where We've Come From and Where We're Going**  
**Dr. Jim Gusella**

As one of the initial discoverers of the HD gene and now a leading researcher into the modifier genes that influence it, Dr. Jim Gusella brings a valuable perspective on

how far we've come on our journey, the prospects that lie ahead and the best path to take in the future.

**10:00 – 10:20am**  
**Break**

**10:20 – 11:35am**  
**Brain and Behaviour in HD**  
**Dr. Jane Paulsen**

HD leads to disruptions in the normal functioning of the brain. HD also leads to several disturbances in behavior, including low mood, cognitive dysfunction, and functional dependence. To what degree are these related? The current presentation will review both changes in the brain and behavior in HD, examine how they are related to one another, and how they are becoming targets of intervention in the treatment of HD.

**11:35am – 1:15pm**  
**Lunch**

**1:15 – 2:30pm**  
**The Most Promising Treatments in the Works**  
**Dr. Robert Pacifici**

A dynamic and exciting speaker, Dr. Robert Pacifici knows as much about which

# New This Year!

Take a break during the conference to check out the **HSC National Conference Hub** - a meeting place where you'll find information about PEI, HD Roster, HD clinical trials, etc.



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potential HD therapies are likely to bear fruit as anyone in the world. Find out about top drug candidates and new developments in the drug discovery process itself.

2:30 – 2:50pm  
**Break**

2:50 – 4:05pm  
**Thinking About Thinking with HD**  
*Jim Pollard*

How might it feel to think with HD? This hands-on session will explore how the cognitive features of HD complicate even the simplest daily interactions. Come and learn some practical ways to improve the experience of living with HD.

4:05 – 4:30pm  
**Wrap-Up**

*John Stainsby & Don Lamont*

Join HSC's Executive Director and our Board Chairperson to reflect on the day's proceedings.

6:30 – 10:00pm  
**Reception, Dinner & Post-Dinner Presentations**

**Fear, Hope and Dignity**  
*Charles Sabine*

NBC news correspondent Charles Sabine provides a powerful personal account of the toll HD took on his family, the terror of testing positive and the glimmer of hope he sees on the horizon.

## Conference Registration

Registration forms for the conference are available on the HSC website [www.huntingtonsociety.ca](http://www.huntingtonsociety.ca) or by calling Shirley Barnes at 1-800-998-7398.

Registration for the conference and hotel must be arranged through the HSC National Office before September 29<sup>th</sup>. After that date space cannot be guaranteed.

(Chapter Delegates need to register by August 29<sup>th</sup>. Please contact Shirley Barnes or Wayne Greenway.)

## Conference Fees

**Full conference, Thursday evening to Sunday morning**

**\$250.00**

Includes all events, presentations, meals, refreshment breaks, conference supplies and materials.

**Saturday only including Closing Dinner**

**\$80.00**

**Saturday only not including Closing Dinner**

**\$60.00**

**Saturday Evening Closing Dinner**

**\$40.00**

## Accommodations

Delta Prince Edward  
18 Queen Street  
Charlottetown, PEI  
C1A 8B9  
902.566.2222  
[www.deltahotels.com](http://www.deltahotels.com)

## Rates

\$102 per night (single/double), plus taxes.

This special rate is extended for 2 days before and 2 days after conference

## Contact

The Huntington Society of Canada  
151 Frederick St, Suite 400  
Kitchener, ON N2H 2M2  
1-800-998-7398  
[info@huntingtonsociety.ca](mailto:info@huntingtonsociety.ca)  
[www.huntingtonsociety.ca](http://www.huntingtonsociety.ca)





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## Speaker Biographies

### Jeffrey Carroll

*Ph.D. Student, Centre for Molecular Medicine and Therapeutics, UBC*

A graduate student in Dr. Michael Hayden's lab and gene positive himself, Jeff is well known to the Huntington community thanks to a Globe & Mail article last fall about him and his family. He is part of a team working on caspase inhibition, following up on CMMT's landmark discovery of a way to prevent HD in mice.

### Katie DeLargie

*St. Thomas, ON*

Katie caught the attention of the Huntington Society of Canada with her award-winning speech *My Dad and Huntington's Disease*, which she wrote when she was only 10 years old and in Grade 5. Katie's speech was the basis of the HSC 2007 direct mail piece. Katie lives in St. Thomas, ON with her parents and two brothers.

### Paul Evered

*Director of Major Gifts, Huntington Society of Canada*

Paul is a new member of the staff at HSC. His passion for making a difference in the lives of people living with HD comes from years of experience in fundraising, counselling and pastoral care.

### Dr. Jim Gusella, Ph.D.

*Director, Center for Human Genetic Research and Molecular Neurogenetics Unit, Massachusetts General Hospital*

*Bullard Professor of Neurogenetics, Harvard Medical School*

When the history of HD research is

written, Jim will have a prominent place in the book. The geneticist was part of the team that isolated the Huntington's gene in record time. Now doing landmark work on HD modifier genes, he is an insightful commentator on HD research as well as a leading scientist.

### John Lord

*Community Researcher, Social Innovator and Author*

John is a founder of the Centre for Community-Based Research in Kitchener, Ontario and a partner with the Facilitation Leadership Group. He recently co-authored *Pathways to Inclusion: Building a New Story with People and Communities*. A sought-after speaker, he regularly consults across Canada with governments and community groups.

### Robert Pacifici, Ph.D.

*Chief Scientific Officer, Drug Discovery and Development, CHDI Inc.*

As Chief Scientific Officer of CHDI (Cure Huntington Disease Initiative), a biotech company dedicated exclusively to developing HD drugs, Robert has his fingers on the pulse of every aspect of HD research. Before joining CHDI, he held senior positions at leading drug discovery companies including Eli Lilly, Xencor and Amgen.

### Jane Paulsen, Ph.D.

*Director of the HD Clinic, University of Iowa Hospitals and Clinics*

*Professor of Psychiatry, Neurology, Psychology and Neurosciences, University of Iowa Carver College of Medicine*

A founding member of the Huntington Study Group, Jane is a world-renown researcher, speaker and writer on behaviour in Huntington disease. She is currently the principal investigator of the Huntington's Disease Society of America HD Center of Excellence at the University of Iowa.

### James J. Pollard, M.A.

*Program Director, Huntington's Disease Treatment Program, Laurel Lake Center*

Jim has worked with people with HD for 18 years and offers tremendous insight into how they think and how to interact with them more effectively. Jim is the editor of *A Caregiver's Handbook for the Advanced Stages of Huntington's Disease* and has taught graduate-level courses in special education, behaviour analysis and child development.

### Charles Sabine

*NBC News Correspondent*

Emmy-award-winning Charles Sabine has been based in London, England with NBC News for a quarter of a century. A familiar sight on TV screens in North America, he has reported on conflicts and disasters around the world, from war-torn Iraq to tsunami-devastated Thailand. He is also gene-positive. Recently, he made the decision to come out of the "Huntington's closet."

### Dr. Ray Truant, Ph.D.

*Associate Professor, Biochemistry and Biomedical Sciences, McMaster University*

Ray is an up-and-coming scientist in the international HD movement. He has authored several high-level reviews of HD research and has uncovered a promising new treatment strategy involving kinase inhibitors, drugs that have proven effective for other diseases. He currently chairs the Huntington Society of Canada's Research Council.

### Ariel Walker

*Co-Founder, Huntington Society of Canada*

Ariel co-founded the Huntington Society of Canada in 1973 together with her late husband, Ralph. From those initial meetings at their kitchen table, she has helped the Society grow to an internationally recognized and respected organization.