



The HSC National Conference 2010

Sutton Place Hotel, Edmonton AB

November 11–14, 2010

Hosted by the HSC Edmonton Chapter

Climbing Higher

If you're part of the Huntington's community, you'll want to be in Edmonton in November for the HSC National Conference 2010. The theme this year is all about building on our successes and fostering the teamwork that will be more important than ever as we continue our ascent towards the summit — a world free from HD.

Join us for two full days of world-class speakers and interactive workshops covering HD research, care and community building. Get the latest information on HD breakthroughs from the scientists who are making them happen. Find out how to reach out and engage our broader community to help us in our final climb. Build stronger families and get insights into the early stages of Huntington's with our special focus this year on *Family Life with HD—The Early Years*.

This year we are focusing more than ever on translating scientific research into a language that both families and professionals can readily understand.

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

Thursday, November 11, 2010

7:30 pm – 8:30 pm

Welcome Reception & Dinner

8:30 pm – 10:00 pm

"Fireside" Chats (concurrent – choose one)

We won't have any crackling logs, but we can promise stimulating post-dinner conversations. Pick one of the informal dialogues and pull up a chair. Your hosts will start things off with a brief presentation and then open the floor to questions and discussion.

FC1 Innovations in Drug Treatments – Drs. Wayne Martin & Ray Truant

Get a lab-bench perspective on recent progress in HD drug research. This workshop will review progress from the discovery of new drug pathways to the status of clinical trials for treatments designed to slow the progression of HD and reduce some of the motor and behaviour symptoms.

FC2 Genetic Discrimination – Dr. Yvonne Bombard & Jo Anne Watton

While the genetics revolution has brought many benefits to the HD

community, it has also created the potential for genetic discrimination. Learn about the latest research and our efforts to eliminate genetic discrimination through organizations like the Canadian Coalition for Genetic Fairness.

Friday, November 12, 2010 Assembling the Climbing Team

7:00 am – 8:15 am

Breakfast

8:30 am – 8:45 am

Welcome and Introductory Remarks

8:45 am – 9:30 am

Climbing Higher – Phil Callaway

Internationally renowned humorist Phil Callaway will tell us the story of his family's journey through Huntington disease. With gentle wit and wisdom, he will remind us how to engage all of our resources in coping with loss, strengthening our friendships, balancing stress, keeping our sense of humour in tough times and making a lasting difference. Don't forget to bring your funny bone!



The HSC National Conference 2010

continued from page 1

9:30 am – 10:00 am
Refreshment Break

10:00 am – 10:30 am
Workshops: Building Stronger Communities and Chapters

Our interactive workshops will give your chapter a huge boost — and help you raise more money for support and research. Discover innovative ways to reach out beyond the HD community for dollars, volunteers and valuable expertise.

Check the HSC site for workshop updates!

11:30 am – 1:30 pm
Lunch

1:30 pm – 2:30 pm
“Pre-symptomatic” HD: What Do We Know and What Should We Do? – Jeffrey Carroll

Historically, people who carry the Huntington Disease mutation have been referred to as “pre-symptomatic” until they show clear signs of the disease. However, long-term observational studies suggest that changes in brains and behaviour are happening years before formal onset of disease. What does research tell us about the early phases of HD? What can we, as pre-symptomatic people and their loved ones, do to actively engage this phase of HD?

2:30 pm – 3:00 pm
Refreshment Break

3:00 pm – 3:30 pm
Workshops: Frontiers of Research
(concurrent – choose one)

With several clinical trials underway and more drugs in the pipeline, this

in an exciting time in Huntington’s research. Get the scoop on new developments, as well as insight into the ethics of HD studies.

WS1 Stem Cells

Check the HSC site for workshop updates!

WS2 Participating in Clinical Trials – Dr. Wayne Martin

Clinical trials are a crucial part of developing treatments for Huntington disease, and patients and their families have an important role to play. Find out more about how new drugs are approved, as well as the pros and cons of participating in clinical trials.

WS3 Ethical Issues in Genetic Testing – Dr. Oksana Suchowersky

Genetics testing is now readily available for HD and a number of other disorders. Not only can physicians confirm a genetic diagnosis, they can determine if you are at risk for getting a hereditary disorder in the future. This session will examine the clinical and ethical issues related to undergoing genetic testing.

3:30 pm – 3:45 pm
Break

3:45 pm – 4:15 pm
Workshops: Frontiers of Research
(repeated — see descriptions above)

4:15 pm – 4:45 pm
Climbing Higher Wrap-Up

End the afternoon on a high note as we sum up the day’s learnings.

6:30 pm – 10:00 pm
Reception and Dinner

Experience hospitality Alberta-style with an evening of fine food and fun hosted by the Edmonton chapter. *Check our conference site for updates on what our host chapter has planned!*

Saturday, November 13, 2010
Preparing for the Initial Ascent

7:00 am – 8:15 am
Breakfast

8:30 am – 8:45 am
Welcome and Introductions

8:45 am – 9:30 am
Optimizing Life with HD – Dr. Edward Wild

Although research and clinical care in HD are constantly moving forward, without effective disease-slowing treatments it can easily feel like nothing is happening at all for those living at risk. Until that breakthrough arrives, there’s still plenty you can do. “Optimizing life” with HD means staying active, informed and involved. This talk will focus on good news from research into HD that can make a difference to you now, and making the most of the support available to maximize your independence.

9:30 am – 10:00 am
Refreshment Break

10:00 am – 10:30 am
Workshops: Staying Active, Informed and Involved
(concurrent – choose one)

Whether you’re living with the disease, at risk for HD or caring for someone with Huntington’s, you’ll find plenty of valuable information in these workshops to help you optimize life with HD.

WS1 Exercise and Brain Function – Dr. Shannon Johnson

How does exercise affect brain function — and what could it mean for people with HD? Dr. Johnson will discuss the latest human and animal studies and suggest ways to keep your brain working as well as possible.



continued from page 2

WS2 Pre-implantation Genetic Diagnosis: Benefits and Limitations – Dr. Benjamin Wong

Find out about the process of pre-implantation genetic diagnosis (PGD) and its benefits and limitations for couples at risk for having offspring with HD. Dr. Wong will describe the reproductive medical techniques that make PGD possible: in-vitro fertilization (IVF), intracytoplasmic sperm injection (ICSI) and embryo biopsy. He will also describe how couples who are unaware of their HD status can still have the option of undergoing PGD.

WS3 Intermediate Alleles – Alicia Semaka

Never heard of an intermediate allele? You're not alone. This unique type of HD gene has 27-35 CAG repeats. While someone with an intermediate allele will not develop HD, there is a small risk that the number of CAG repeats could expand when passed from parent to child, pushing it into the HD range. Find out what we currently know about intermediate alleles and the current research initiatives that will provide more insight.

10:30 am – 10:45 am
Break

Workshops: Staying Active, Informed and Involved

(repeated — see descriptions above)

11:30 am – Noon
Annual General Meeting

Noon – 1:30 pm
Lunch

The HSC National Conference 2010

1:30 pm – 4:15 pm **Optimizing the Healthy Development of Children and Youth**

How does having a parent with HD affect children and adolescents? These afternoon's interactive sessions will offer insights and as well as practical tools to encourage the healthy development of children facing the special challenges of Huntington's. (Includes a refreshment break.)
Check the HSC site for workshop updates!

4:15 pm – 4:45 pm **Wrap-Up**

End the afternoon on a high note as we sum up the day's learnings.

6:30 pm – 10:00 pm **Climbing Higher Awards Reception and Banquet**

Celebrate our experience over the past two days and pay tribute to the outstanding volunteers who have spearheaded our "climb to the summit".

Conference Registration

Registration forms are available at www.huntingtonsociety.ca/ or by calling 1-800-998-7398.

Please register before Friday, July 16. After that date, additional fees apply and space cannot be guaranteed.

Conference Fees

Full conference, including all events, presentations, meals and refreshment breaks from Thursday dinner to Sunday breakfast **\$250.00**

Saturday, including closing dinner **\$80.00**

Saturday, but *not* closing dinner **\$60.00**

Saturday, closing dinner only **\$40.00**

Accommodations

Sutton Place Hotel
10235 - 101 Street NW, Edmonton
Toll Free: 1-866-378-8866
Fax: 780-441-3098

\$109 per night (single/double) plus taxes.

Speaker Biographies

Yvonne Bombard, PhD

Postdoctoral Fellow, Department of Health Policy, Management and Evaluation, University of Toronto

Dr. Bombard received her doctorate in interdisciplinary studies at the University of British Columbia with Dr. Michael Hayden. She conducts research on the ethical and policy implications of genetic testing and population screening; her work has been published in human genetics, medical ethics and general medicine journals. Dr. Bombard is actively involved in policy development through the Ontario Ministry of Health's Medical Advisory Secretariat, Ontario's Citizen Reference Panel on Health Technologies and the Canadian Coalition for Genetic Fairness.

Phil Callaway

Bestselling Author and Speaker

Phil is an award-winning author and speaker, known worldwide for his humorous yet perceptive look at life. He is the bestselling author of 24 books including *Laughing Matter* and *Making Life Rich Without Any Money*. Phil's writing has been translated into a dozen languages, but he insists that his greatest achievement was convincing his high-school sweetheart to marry him. He lives in Alberta with Ramona and their three children.



The HSC National Conference 2010

continued from page 3

Jeffrey Carroll

PhD Student, Centre for Molecular Medicine and Therapeutics, University of British Columbia

Jeff is a researcher studying the basic mechanisms of HD in the lab of Dr. Michael Hayden in Vancouver, BC. Jeff comes from an HD family and carries the HD mutation himself.

Shannon Johnson, PhD

Assistant Professor, Psychology, Psychiatry, and Pediatrics, Dalhousie University

Dr. Johnson is a registered psychologist who has been involved in Huntington's research for more than 15 years. Her clinical and cognitive research lab at Dalhousie focuses on individuals with neurodevelopmental and neurodegenerative disorders. Dr. Johnson is also a team member of the multidisciplinary HD clinic in Halifax.

Wayne Martin, MD, FRCP

Professor, Neurology, University of Alberta, and Director, Movement Disorders Program, Glenrose Rehabilitation Hospital

Dr. Martin's research focuses on non-invasive studies of brain function and structure in people with neurodegenerative diseases, often using magnetic resonance imaging (MRI) and spectroscopy in collaboration with MRI researchers. His current work examines brain changes associated with changes in gait and balance in Parkinson's disease, as well as MRI studies in Huntington disease.

Alicia Semaka, MSC, CGC, CCGC

Doctoral Candidate, Centre for Molecular Medicine and Therapeutics, University of British Columbia

Alicia joined Dr. Michael Hayden's laboratory as a PhD student in medical genetics after completing a Master's degree in genetic counselling at UBC in 2005. For many years she has volunteered at the HSC Retreat for Individuals with HD in British Columbia and organized the annual HSC Laboratory Tour for Patients and Families.

Oksana Suchowersky, MD

Professor and Department Head, Medical Genetics, University of Calgary

Dr. Suchowersky has directed the Movement Disorders Program in Calgary since she first moved to the city in 1984. Her research interests lie in the management of movement disorders, neuroprotection in neurodegenerative disorders, and pre-symptomatic testing of adult-onset hereditary disorders. Dr. Suchowersky serves on the editorial board of *Natural Clinical Neurology* and the *Canadian Journal of Neurological Sciences*. She is the recipient of many awards, including the University of Calgary's Star Research Prize.

Ray Truant, PhD

Associate Professor, Biochemistry and Biomedical Sciences, McMaster University

A past winner of the Canadian Institutes of Health Research New Investigator Award, Dr. Truant has more than 40 research papers to his name. Currently he is investigating how kinase inhibitors can protect cells from the mutant huntingtin protein, as well as elucidating the biological role of huntingtin. Dr. Truant serves as chair of the Huntington Society of Canada's Scientific Advisory Board and is a member of the Cell Biology and Mechanisms of Disease Panel at the Canadian Institutes of Health Research.

Jo Anne Watton, BA, MSW

Director of Individual and Family Services, Huntington Society of Canada

Before joining HSC in 2007, Jo Anne held a variety of positions in government, not-for-profit, for-profit and research sectors, focusing on home care and support for people with disabilities. Currently, in addition to her role at HSC, Jo Anne has been active in Neurological Health Charities Canada and the Canadian Coalition for Genetic Fairness, advocating for legislation to outlaw genetic discrimination.

Edward Wild, PhD

Honorary Research Associate, University College London Institute of Neurology

Dr. Wild trained at Cambridge University and obtained his PhD from University College London's Institute of Neurology, where he studied biomarkers for Huntington disease with Prof. Sarah Tabrizi. He is currently working as a neurologist in Bristol, UK while continuing his research into HD.

Benjamin Wong, MD, FRCSC, FACOG (REI)

Clinical Assistant Professor, Reproductive Endocrinology & Infertility, Obstetrics and Gynaecology, University of Calgary

Dr. Wong developed a keen interest in reproductive endocrinology and infertility (REI) during his Ob/Gyn residency at the University of Calgary, following it up with further training in REI at the Jones Institute for Reproductive Medicine at the Eastern Virginia Medical School. Currently he serves as a staff reproductive endocrinology and infertility specialist at Calgary's Regional Fertility Program Inc. and as the physician coordinator of the pre-implantation genetic diagnosis program. He also teaches at the Faculty of Medicine, University of Calgary.