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RESEARCH

Dr. Hayden Speaking in Toronto

Dr. Michael Hayden, named Canada's "researcher of the year" for 2008 by the Canadian Institutes for Health Research, will be in Toronto on Jan. 18, speaking on "Personalized Medicine: Hype or Hope, Canadian Perspectives", an issue currently at the forefront of not only the medical community, but the minds of many Canadians.

Considered one of the world's most renowned geneticists, Dr. Hayden is a charismatic speaker who is best known for his groundbreaking research into Huntington disease (HD).



This free public lecture is being co-sponsored by the Royal Canadian Institute for the Advancement of Science (www.royalcanadianinstitute.org) and the Gairdner Foundation (www.gairdner.org). The event will be held at the MacLeod Auditorium, Medical Sciences Building, University of Toronto, 1 King's College Circle at 3 p.m. with doors opening at 2:15 p.m. After his presentation the Huntington Society of Canada will be hosting a reception to celebrate Dr. Hayden's accomplishments from 4:30-6pm at the Collaboration Centre "café" at the MaRs Centre, 101 College Street.

New Research Project



The Huntington Society of Canada is working with the Ontario Cancer Biomarker Network and Dr. Mark Guttman to conduct research on the development of a Functional Rating Scale for Individuals with Pre-Huntington Disease. This research will help with assisting physicians to diagnosis and treat HD EARLIER than ever before, as well aid in targeting clinical trials. Early in 2009, we will be conducting separate focus groups for individuals living in the Toronto area who are pre-Huntington disease, early Huntington Disease and caregivers. The

purpose of these groups will be to openly discuss which signs and symptoms of HD are worrisome, bothersome or interfere with daily activities. If you are interested in participating in these groups please contact Jo Anne Watton at 1-800-998-7398, ext 32.

New HD Clinical Trial

The Huntington Study Group (HSG) is conducting a study of the research medication ACR16 in persons 30 years of age and older who have clinical features of Huntington Disease (HD). HART is designed to determine the general safety and tolerability and an effective dose of ACR16 as well as the effect of ACR16 on motor (movement) and cognitive (thinking) abilities in subjects with HD.

[Click here](#) to see the list of participating research sites

To read the press release [click here](#)

Juvenile HD Study

Sheffield Children's Hospital in the UK is undertaking a pioneering study that will look at the treatment

options available for Juvenile Huntington's Disease (JHD) - an inherited neurodegenerative condition that causes abnormal movements and emotional and cognitive problems JHD refers to anyone who develops signs or symptoms of Huntington's Disease before they are 20 years old. The study will survey up to 35 parents and guardians of children with JHD about the effectiveness and associated side effects of pharmacological treatments, before cross-referencing the survey findings with GP information.

To read the full article please see:

<http://www.medicalnewstoday.com/articles/133765.php>

Gene Disease Recreated in Lab

US researchers say they can now watch genetic diseases unfolding in the laboratory after finding a way to make large numbers of affected cells. The advance, reported in the journal *Nature*, used skin cells from a child with a devastating genetic condition. These were turned first into stem cells - the body's master cells - and then into nerve cells, which started to die as the gene fault took hold. The team said the earliest stages of the disease could now be identified. In theory, SMA is not the only genetic disease which could be studied using this method - the researchers say disorders such as Huntington's disease could be investigated this way.

To read the full articles please see:

<http://news.bbc.co.uk/1/hi/health/7791283.stm>

http://www.google.com/url?sa=X&q=http://www.madison.com/ws/topstories/324873&ct=ga&cd=TIImKLFoPvQk&usg=AFQjCNH_0_H3wKnNPY_O5BM1wM9QpedA7g

NATIONAL OFFICE

COMING SOON

Watch for details about an exciting campaign that will get you thinking about your hopes and dreams for 2009! Coming to an inbox near you in the coming weeks!

Youth for HD Program



The Huntington Society of Canada (HSC) is excited to announce that it will pioneer a new national program called *Youth for HD*, which will reach out to children and youth living with Huntington disease (HD). Over the next two years experts in the fields of child psychology, health and development will be consulted as we build a comprehensive program to help young people stay strong through HD.

This two-year national program will begin in Calgary Alberta, focusing on youth 14-16 and 17-18 years of age. The program will be a great way for youth in the HD community to meet others living with HD, have fun, learn more about the disease and help create a world free from HD.

"Each program will be designed according to what participants would like to see created", says Wayne Greenway, a *Youth for HD* organizer. "That why this pilot in Alberta is so important - this group will help us create the program for all other centres."

Building upon each success, the plan involves establishing *Youth for HD* in major centres in Western Canada with the intent of developing a model that can be shared with other HD organizations on a worldwide basis.

Based on the feedback received from the youth and the success of this program, the pilot has the potential of being utilized to pioneer different developmentally appropriate programming for younger children. The intention is to harness the power of web based strategies to support face-to-face programming.

Youth For HD Activity Day

Saturday February 2, 2009

Exshaw, Alberta

10:00 am -5:00pm

Are you:

- 14-16 years of age?
- Living within a 2 hour drive from Calgary?
- Close to someone who lives with or is at risk for Huntington disease?

Do you want to:

- Have a day of great activities, leadership development and fun?
- Learn more about HD?
- Meet people your own age from the HD community?
- Gain new leadership skills?
- Help create a world free from HD?

A unique program will be planned for each age group.

Free transportation can be arranged

A brief coffee time will be available for parents upon arrival

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Youth For HD Activity Day

Saturday February 28, 2009 – Camp Chief Hector YMCA
Exshaw, Alberta – 10:00 am -5:00pm

FREE TRANSPORTATION CAN BE ARRANGED
A brief coffee time will be available for parents upon arrival

A unique programme will be planned for each age group

Register by Feb. 16 - Space is limited

Great Activities, Leadership Development, Fun, Friendship, Learn more about HD

For more information call Wayne Greenway at 1800 998 7398 or wgreenway@huntingtonsociety.ca

Create a World Free from HD

Register now - Space is limited

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Great Activities, Leadership development, Fun, Friendship, Learn more about HD and Create a World Free from HD

Amaryllis



Big, blooming thanks to everyone who was involved in our Amaryllis Campaign for 2008! Remember that every Amaryllis blooming in someone's home or office is another boost to our programs in research, services and education; and every Amaryllis tells the story of our fight against HD and our hope for a world free from HD! Thank you for raising vital funds for our programs, raising the spirits of people who purchased them and raising awareness of our cause.

We are urging all volunteers still holding on to funds from the Campaign to please send it to us **as soon as you can**. We can't share our final results, get funds working in communities or close the chapter on 2008 and look ahead with energy to 2009 until we receive outstanding payments. Please email amaryllis@huntingtonsociety.ca or call us at 1-800-998-7398 if you wish to talk about your payments.

Thanks again!
Kelly and Jen

Casino Royale



Mark your calendars for Casino Royale on Saturday, February 21, 2009 at the Liberty Grand in Toronto, ON.

Get ready for an evening of blackjack, roulette, poker, and craps with play money.

To purchase your tickets please [click here](#)

Family Day 2009

Save the Date- June 6 and June 13, 2009. Don't miss out on this great opportunity. We are working to set up Family Day in a city near you.

Each day will be tailored to the needs of the Chapter and families in the region. Options include: videoconference presentation by an international HD expert, local events and workshops, practical or fundraising events, and tips and tricks for engaging your local community.

For more information please contact Wayne Greenway at wgreenway@huntingtonsociety.ca or 1-800-998-7398, ext. 33



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VOLUNTEER DEVELOPMENT

Town Hall Meetings

British Columbia Area Reps and Chapters

MON 19 JAN 2009

9:15 PM Eastern Time

Central Canada (Alberta, Sask, and Manitoba) Area Reps and Chapters)

TUES 20 JAN 2009

8:30 PM Eastern Time

Ontario Area Reps and Chapters

WEDS 21 JAN 2009

7:30PM Eastern Time

Atlantic Area Reps and Chapters

THURS 22 JAN 2009

5:00 PM Eastern Time

A reminder- all Town Hall meetings will be done by Skype. For more information or for any technical questions please contact Devin Bonner at dbonner@huntingtonsociety.ca or 1-800-998-7398 ext. 33

Event Section of HSC website

Are organizing events for the Huntington Society of Canada?



Educational Social and fund raising events can be posted on the Events section of the HSC website

As soon as you have your event confirmed

Send the information to Devin Bonner dbonner@huntingtonsociety.ca with the text you want to put on the events page.

Online pledging – We also have fantastic new system for on line pledging. Contact us early so we can get you set up for online pledging and make it as easy as we can on anyone wishing to sponsor your event participants.

After your event

To celebrate and recognize your volunteers and sponsors send your pictures and a short write up about your event. Remember that you need permission for any faces that are recognizable in your pictures

Staying Connected

Interested in finding out about the latest research news from around the world, or what is happening in your local HD community or for caring for a person with HD?

Please visit our [website](#) and fill out our confidential contact information form to receive email communications from HSC. According to your preferences, we'll communicate with you in confidence by email about research findings, clinical trials, best practices of care, local and national events and happenings, volunteer opportunities, etc.

Pass on the message to your family, friends and other chapter members to visit our website and fill out the contact form. [Click here to fill out the contact form.](#)

E-Blast Name	Main Focus	Distribution
Discovery Pipeline	Profiling the latest research news, research partners, programs, etc.	6 week rotation
Strength and Knowledge	Practical help and assistance; highlighting the IFS department – care, how they can help; who to connect with; advocacy. Articles of interest such as talking to children about HD.	6 week rotation
In The Know	Brief overview highlighting what is going on in the HD Community.	Twice monthly
Horizon	A comprehensive look at all areas of the HD community.	Three times per year (Fall, Winter, Spring)
Volunteers In Touch	Chapter Development- tips and tricks, chapter issues, including fundraising assistance.	Once a month
Amaryllis	Keeping connected with our amaryllis sellers.	Every two to three weeks during the campaign
Chapters In Touch	Keeping the community informed of upcoming events, news, etc on behalf of our chapters.	As requested/ four times per year

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