



# *Believe*

*Transforming  
Tomorrow  
Together*

**2016**  
Conference  
Program

Halifax, NS  
November 4-5

Huntington Society of Canada  
**HUNTINGTON**  
Société Huntington du Canada

The **Huntington Society of Canada**  
is delighted to welcome **you**  
and looks forward to ***transforming, tomorrow, together!***

## HOURS OF OPERATION

Thursday, November 3rd

7:30 a.m. to 10:00 a.m. and 3:30 p.m. to 6 p.m.

Friday, November 4th

8:00 a.m. to 3:30 p.m.

Saturday, November 5th

8:00 a.m. to 3:30 p.m.

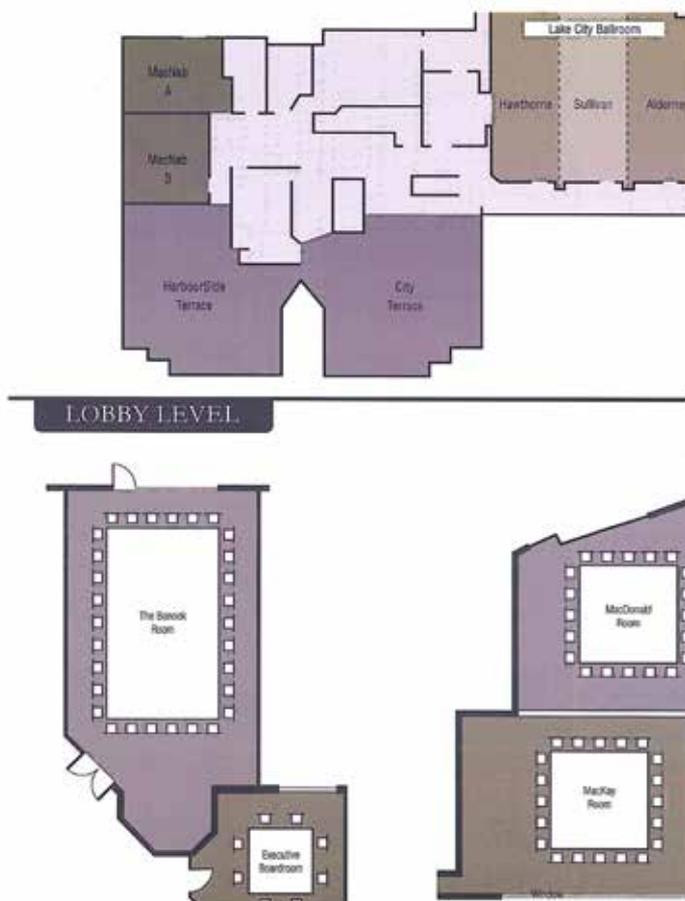
## SPECIAL THINGS TO NOTE

**Meals:** Your conference registration includes Friday breakfast, lunch and dinner with two coffee breaks and Saturday breakfast, lunch and dinner with two coffee breaks.

**Internet service:** Available free of charge to all guests. Wireless and wired internet is available in guest rooms, business centre and public areas.

VISIT THE FRONT DESK  
FOR A LOCAL MAP OF  
HALIFAX AND THE  
SURROUNDING AREA.

## VENUE MAP



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# Welcome to the HSC National Conference

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For more information about Huntington disease or support services in Canada, please visit the Huntington Society website at [www.huntingtonsociety.ca](http://www.huntingtonsociety.ca) or call us at 1-800-998-7398.

Remember to share your photos with

**#HSCHalifax**

and follow the action on:



/HuntingtonSC

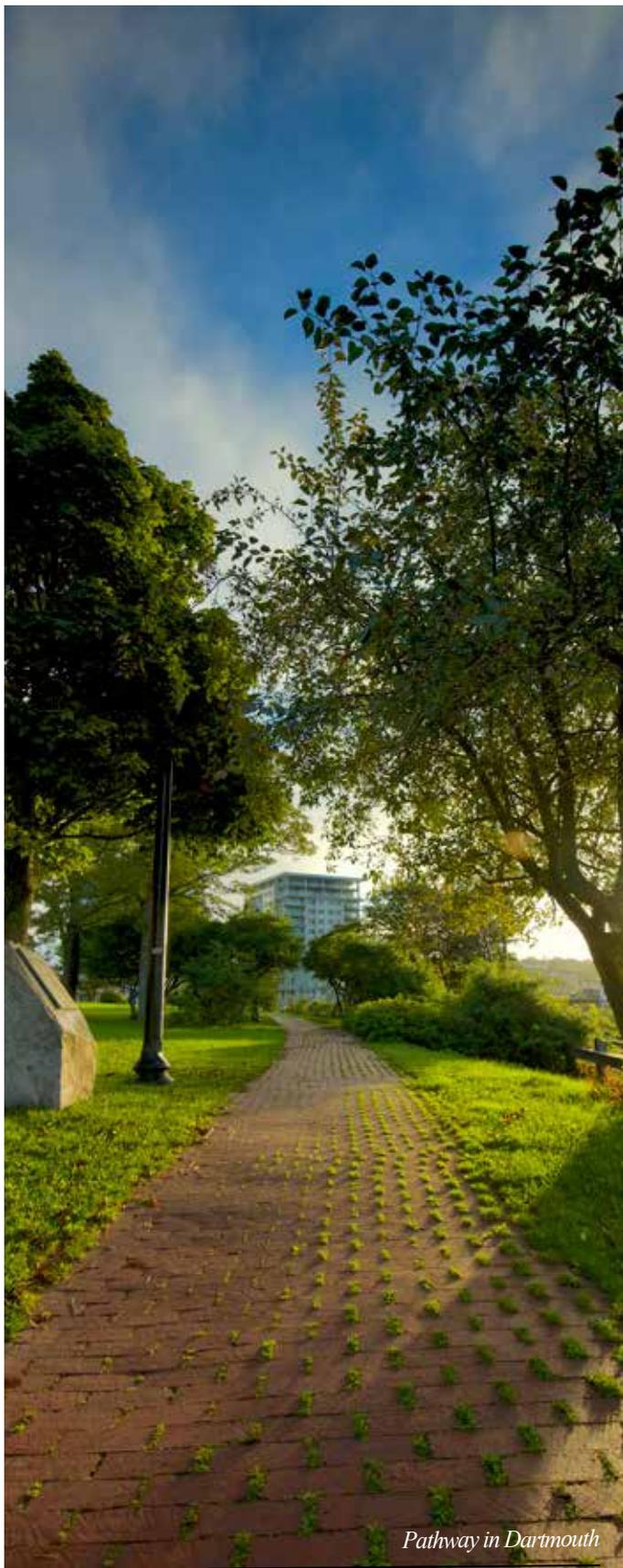


@HuntingtonSC



@HuntingtonSocietyCanada

# W E L C O M E from the CONFERENCE HOSTS



*Pathway in Dartmouth*

Dear HSC Halifax Conference Attendee,

Welcome to Halifax, Nova Scotia - Canada's ocean playground!

Your Organizing Committee is hoping to make this Conference one that you will always remember.

The Conference will enable you to learn more about Huntington disease, meet others who are also dealing with this horrible disease, and give you hope that a treatment or cure is coming. It will be emotional, uplifting and tiring. At the end, you will be glad you came!

There are a wide variety of speakers, sessions and activities planned for you. You will be busy.

On Friday night, we have planned a traditional Nova Scotia kitchen party with a lobster dinner right across the street from the Holiday Inn Halifax Harbourview at the Dartmouth Sportsplex. Dress to get messy! For those not interested in lobster, there will be other choices on the menu.

There is lots to see and do in Halifax and Nova Scotia and we hope you will get a chance to see some of it. After all, Halifax has been ranked as the "Happiest City in Canada." I strongly suggest you go to [www.destinationhalifax.com](http://www.destinationhalifax.com) for lots of information on Halifax and Nova Scotia.

Your Organizing Committee recommends:

- Taking a ride on the Halifax-Dartmouth Ferry
- Strolling through Halifax's Historic Properties on the waterfront
- Visiting Peggy's Cove
- Driving on Marine Drive with lots of sandy beaches and cafes

Please get in touch with me if you require further information during your visit.

Jim Russell  
President, Halifax Chapter  
Huntington Society of Canada

**November 4-5**

**2016**

On behalf of the Huntington Society of Canada, a warm maritime welcome to the 2016 HSC National Conference in Halifax, Nova Scotia! We hope you take full advantage of this wonderful location which is home to both the famous waterfront boardwalk that follows the water's edge alongside the world's second largest ice-free harbour and to Alexander Keith's original 1820 brewery.

Our theme "Believe: Transforming Tomorrow Together" could not have a more suitable backdrop for our time together. We are looking forward to forging new relationships, strengthening existing ties, robust learning, and recognizing individuals who have contributed to our success over 43 years.

The 2016 HSC National Conference is being hosted by the Halifax Chapter at the Holiday Inn Halifax Harbourview. Volunteers have been hard at work spending considerable time and effort in planning your visit. They are excited to host the conference and are prepared to make this a rewarding and memorable experience for each of you. The Halifax Chapter will also host a traditional Nova Scotia Kitchen Party complete with a lobster dinner, a not to miss event!

Throughout the two days there will be rich programming and an abundance of networking opportunities. The numerous workshop sessions will encompass topics that focus on stepping into a new era for Huntington disease. Since 2015 we have seen significant change with the introduction of five clinical trials. We anticipate that change to accelerate with the Brain Canada and HSC collaboration, the HD Consortium partnership and a host of initiatives to bring services to families across Canada.

The 2016 HSC National Conference is a catalyst for growth and opportunity for our entire HD community. This event underscores our belief that we can, and will, transform tomorrow together. It fuels our collective mission of finding meaningful treatments for Huntington disease and advancing those treatments to the HD Community.

Your presence here in Halifax is a true testament of how a small but mighty group of individuals can join forces and succeed together. Thank you for making time to be here and for being part of the movement to transform the horizon of HD for a brighter tomorrow! Our collective strength lies in sharing our understanding of, and experience with, Huntington disease. We sincerely thank the HSC Halifax Chapter, our many volunteers, sponsors and our impressive lineup of speakers, in making this conference possible.

Sincerely,



Susan Wright  
Chair, HSC National Board of Directors



Bev Heim-Myers  
Chief Executive Officer

## Friday, November 4



**Terry Kelly**  
Singer  
Songwriter  
Entertainer  
& Paralympian

### Celebrate Life

Life offers everyone gifts disguised as challenges. Dr. Terry Kelly's keynote will inspire you to embrace your talents and abilities with gratitude. Terry's commitment to celebrate life as a person who has been totally blind since age two will inspire you to remember that everyone has a purpose. Using personal anecdotes peppered with humour, songs, and audience participation, Terry will encourage you to develop your own strategies for living and working happily and healthily, relative to where Huntington disease (HD) is in your life.



**Dr. Ray Truant**  
PhD  
McMaster University



**Dr. Tamara Maiuri**  
PhD  
McMaster University

### The Start of a New Era in HD Research

What is so special about the number 36? For years, HD researchers have known that if you have 36 or more CAG repeats, you will develop HD. We now know why. Not only does this breakthrough solve a longstanding mystery, it will also dramatically speed up the hunt for treatments.

## Saturday, November 5



**Jay Ingram**  
Science Broadcaster  
& Writer

### The Real Scientific Influencer: Powerful Personage

Jay's keynote will explore the influence of Nancy Wexler, well-known in the HD community for her involvement with a study group in Venezuela that discovered the location of the gene that causes HD. Using Nancy's story as the foundation, Jay will discuss how a powerful personage, such as Nancy, can influence the course of science.



**Dr. Ed Wild**  
MRCP, UCL Institute of Technology



**Dr. Jeff Carroll**  
Western Washington University

### The Best Time to Plant a Tree

In this interactive session, the creator-editor team of HDBuzz share what's new in the research world and ways to keep up with the latest HD research. From clinical trials to new lab discoveries, they will help us understand the most promising research findings into Huntington disease and how to interpret the latest science news stories. The goal is understanding; which can lead to empowerment, hope and positive action.

# Thursday, November 3, 2016

## YPAHD DAY

8 - 9 AM	YPAHD: Breakfast & Registration	City Terrace
9 - 9:30 AM	YPAHD: Welcome	Hawthorne
9:30 - 10 AM	HD and YPAHD 101 with Katie DeLargie YPAHD Research Update with Dr. Ed Wild	Hawthorne Sullivan
10 - 10:30 AM	Youth Mentorship with Erin Stephen and Corey Janke Life After YPAHD with Brynne Stainsby, Mack Erno, and Annie Vanexem	Hawthorne Sullivan
10:30 - 10:45 AM	Break	
10:45 - 11:45 A	YPAHD Grief and Loss with Barb Horner	Hawthorne
11:45 - 12:45 PM	YPAHD: Lunch	
12:45 - 1:15 PM	Fundraising and Event Planning with Adriana Van Oostveen	Hawthorne
1:15 - 2:15 PM	Genetic Testing for YPAHD with Jill Beis Family Planning for YPAHD with Michelle Lane	Hawthorne Sullivan
2:15 - 2:30 PM	Break	
2:30 - 3:30 PM	Round Table Discussions with Senior YPAHD Executive Members	Hawthorne
3:30 - 4:30 PM	YPAHD Fundraising Dragon's Den with Annie Vanexem, Bev Heim-Myers and Dr. Ed Wild	Hawthorne
6 - 9 PM	Community Development Workshop for HSC Chapter Representatives	MacNab A

# Friday, November 4, 2016

7 - 7:45 AM	Yoga with Natalie Marnica	MacNab A
8 - 9 AM	Breakfast & Registration	Harbourside
9 AM	CHILL ZONE OPENS <i>until 5PM</i>	Macdonald
9 - 11 AM	Welcome and Opening Ceremonies Keynote with Terry Kelly	Lake City Ballroom
11 - 11:20 AM	Break	
11:30 - 12:30 PM	1A: Living the Life of Leisure: the Therapeutic Benefits of Recreation and Play with Bev Farrell	MacNab A
	1B: HD 101 with Dr. Kerrie Schoffer	Alderney
	1C: HSC Youth Mentorship Program with Erin Stephen and Corey Janke	MacNab B
	1D: HDClarity: A New International Study of Spinal Fluid in HD with Dr. Ed Wild	Hawthorne & Sullivan
12:30 - 1:30 PM	Lunch	
1:45 - 2:45 PM	2A: Yoga As Therapy: Essential Tools for Living Well with Natalie Marnica	MacNab A
	2B: No Right Or Wrong Answers: Considerations in Genetic Testing and Family Planning with Jill Beis & Michelle Lane	Alderney
	2C: Genetic Discrimination with Bev Heim-Myers & Richard Sturk	MacNab B
	2D: New Pathways in HD Research Made Possible by HSC Research Funding with Dr. Jeff Carroll	Hawthorne & Sullivan
2:45 - 3:15 PM	Break	
3:30 - 5 PM	Keynote with Dr. Ray Truant and Dr. Tamara Maiuri	Lake City Ballroom
6:30 PM	Welcome Lobster Social <i>hosted by the Halifax Chapter</i>	Dartmouth Sportsplex

# Saturday, November 5, 2016

7 - 7:45 AM	Yoga with Natalie Marnica	MacNab A
8 - 9 AM	Breakfast & Registration	Harbourside Terrace
9 AM	CHILL ZONE OPENS <i>until 5PM</i>	Macdonald
9 - 11 AM	Keynote with Jay Ingram	Lake City Ballroom
11 - 11:20 AM	Break	
11:30 - 12:30 PM	3A: Hypnosis Therapy with Margot Schelew	MacNab A
	3B: CHDI Foundation and Enroll-HD Clinical Research Towards Drug Development with Simon Noble	Hawthorne & Sullivan
	3C: Responsive Behaviours with Angele Benard and the HSC Family Services team	Alderney
	3D: Huntington Society of Canada Annual General Meeting	MacNab B
12:30 - 1:30 PM	Lunch	
1:45 - 2:45 PM	4A: Cannabinoids in the Context of HD with Eileen Denovan-Wright	MacNab A
	4B: Medical Aid in Dying Panel hosted by Julie Lawson-Timmer with Senator Cowan, Rob Laycock, Marlene Teske	Hawthorne & Sullivan
	4C: Huntington's Disguise with Jim Pollard	Alderney
	4D: Youth Opportunities and Support with HDYO and YPAHD Representatives	MacNab B
2:45 - 3:15 PM	Break	
3:30 - 5 PM	Keynote With Dr. Ed Wild and Dr. Jeff Carroll	Lake City Ballroom
7 PM	Closing Banquet and Awards Ceremony	Lake City Ballroom

# Workshop Descriptions

## 1A. Living the Life of Leisure: The Therapeutic Benefits of Recreation and Play

Research indicates that engaging in leisure pursuits from exercise, socializing, to games can improve the brain's neuroplasticity. Learn about the benefits of leisure, the impact on our "grey matter" and recommended activities for people with HD. Caregivers can also learn how to take care of themselves through their own leisure pursuits.

## 1B. HD101

Join local neurologist, Dr. Kerrie Schoffer in an overview of what we know about Huntington disease, the basic science and genetics, symptoms, and inheritance. This session will provide you with an introduction to Huntington disease.

## 1C. HSC Youth Mentorship Program

Since 2013, HSC's Youth Mentorship Program has matched youth mentees with young adult volunteers from families affected by HD across Canada. Join the Youth Mentorship Coordinator, Mentorship Coach and a youth mentor as we discuss the program's successes and challenges to date, and how the program may be able to serve you or your child.

## 1D. HDClarity: A New International Study of Spinal Fluid in HD

In this workshop, Ed will explain what cerebrospinal fluid (CSF) is and why it's so important for Huntington disease research. Ed will introduce his brand new study, HDClarity, that aims to produce the biggest collection of CSF ever, from volunteers around the world.

## 2A. Yoga As Therapy: Essential Tools for Living Well

This workshop will explore Yoga as therapy and the essential tools for living well. Experience and learn the benefits of conscious breathing, mindful movement, and meditation that promote health, longevity and peace. We will also explore the biology of stress, dealing with uncertainty, and the holistic approach to healing.

## 2B. No Right or Wrong Answers: Considerations in Genetic Testing and Family Planning

Learn about predictive and diagnostic genetic testing for Huntington disease, from basic science to making the decision to be tested. The workshop will also review options for family planning such as egg or sperm donation, preimplantation genetic diagnosis, prenatal diagnosis, etc.

## 2C. Genetic Discrimination

Bev will explore Genetic Discrimination in Canada and its impact on individuals with genetic diseases. Learn about the history of the Canadian Coalition for Genetic Fairness (CCGF) and what we have yet to do to protect genetic test information in Canada including updates on Bill S201 – a Genetic Non-discrimination act. Bev will be joined by Richard Sturk, who will share strategies for getting insurance when genetic test information is not protected.

## 2D. New Pathways in HD Research

Join this session to learn about new work being done this year by Dr. Jeff Carroll and his team at Western Washington University, supported through funding from the Huntington Society of Canada. We will discuss current research on the role that is played by the Huntingtin protein in 'somatic instability' in mouse models.

## 3A. Hypnosis and the Power of Positive Thinking

Learn the difference between your conscious and unconscious mind, what hypnosis is, how it works and how it can help reduce stress in your life by shifting your brain to focus on positive outcomes. The presentation will also include a group hypnosis session with suggestions to improve your overall sense of well-being.

## 3B. CHDI Foundation and Enroll-HD Clinical Research Towards Drug Development with Simon Noble

CHDI Foundation is a privately funded nonprofit biomedical research organization that is devoted to developing drugs that will improve the lives of HD patients. As part of that mission, CHDI runs Enroll-HD, a worldwide clinical research platform and observational study for HD families. This workshop will introduce both CHDI Foundation and Enroll-HD, and describe how they are working to accelerate the pace of HD drug development.

## 3C. Responsive Behaviours and Strategies for Caregivers

Responsive behaviours appear as HD progresses, and as losses are experienced in the person's abilities and relationships. Sadly, they tend to be directed mostly towards people living and caring for the person with HD. The HSC Family Services team will be discussing common responsive behaviours and discussing possible strategies for caregivers.

## 4A. Cannabinoids in the Context of HD

Cannabinoids are actively being investigated as drugs for many conditions including Huntington disease (HD). Are cannabinoids, including THC, effective and safe for HD patients? This seminar will highlight some of the current research on the positive and negative effects of different cannabinoid-based drugs in relation to models of Huntington disease.

#### ■ 4B. Medical Assistance in Dying Panel

Join our discussion panel exploring the different viewpoints and considerations in Medical Assistance in Dying. Our panel includes Senator Cowan, who will speak to the considerations in putting forth Bill C-14, as well as community members who support medical assistance in dying, and those who have concerns. There will also be discussions of other end-of-life options.

#### ■ 4C: Huntington's Disguise

As HD progresses, it often places a mask on the person that you love. He/She is the same person, but it's often difficult to see him/her behind the disguise. But understanding some of the more subtle physical and cognitive aspects of HD can help you see through this "Huntington's Disguise." He/She may very well not be bored, disinterested, angry or unwilling although it may appear that way to some. Underneath he/she is the very same person you have known, loved and cared for through the years.

#### ■ 4D: Youth Engagement

Join members of YPAHD (Young People Affected by Huntington Disease) and HDYO (Huntington's Disease Youth Organization) to learn about the start of these organizations, their roles in Canada and abroad, and how they support youth. Learn how you, or the young person in your life, can be involved in the HD community.



**YOUTH  
MENTORSHIP  
PROGRAM**

For more information, visit:  
[www.huntingtonsociety.ca](http://www.huntingtonsociety.ca)

## AGM Notice



Notice is hereby given of the 2016 Annual General Meeting of the Huntington Society of Canada.

**Date:** Saturday, November 5, 2016

**Time:** 11:30 AM

**Place:** Holiday Inn Harbourview, MacNab B

Please visit [www.huntingtonsociety.ca](http://www.huntingtonsociety.ca)  
or contact us at [info@huntingtonsociety.ca](mailto:info@huntingtonsociety.ca)  
or 1-800-998-7398 for further details.



*Lake Banook*

## WHO WE ARE

The Huntington Society of Canada is a not-for-profit charitable organization which raises funds to deliver individual and group counselling services to support individuals and families living with Huntington disease (HD) and to fund medical research to delay or stop the progression of the disease. The Society also works with health and social services professionals to enable them to better serve people living with Huntington disease.

## WHAT WE DO

The Huntington Society of Canada aspires to a world free from Huntington disease. The Society maximizes the quality of life of people living with HD by:

- Delivering services;
- Enabling others to understand the disease; and
- Furthering research to slow and prevent Huntington disease.



We provide a community and support network for young people affected by Huntington disease.



## Getting Around

### MAJOR ATTRACTIONS & UNIQUE VENUES

1. Alexander Keith's NS Brewery
2. Art Gallery of Nova Scotia
3. Bishop's Landing
4. Canadian Museum of Immigration at Pier 21
5. Casino Nova Scotia
6. City Hall
7. Cunard Centre
- 8a. Discovery Centre
- 8b. Discovery Centre 2014
9. Ferry Terminal
10. Government House
11. Halifax Citadel National Historic Site
12. Halifax Seaport Farmers' Market
13. Historic Properties
14. Maritime Museum of the Atlantic
15. Murphy's the Cable Wharf
16. Museum of Natural History, (Nova Scotia Museum)
17. Neptune Theatre
18. NS Sport Hall of Fame
19. Old Town Clock
20. Province House
21. St. Paul's Anglican Church
22. VIA Rail Station
23. World Trade & Convention Centre
24. Convention Centre 2016

### ACCOMMODATIONS

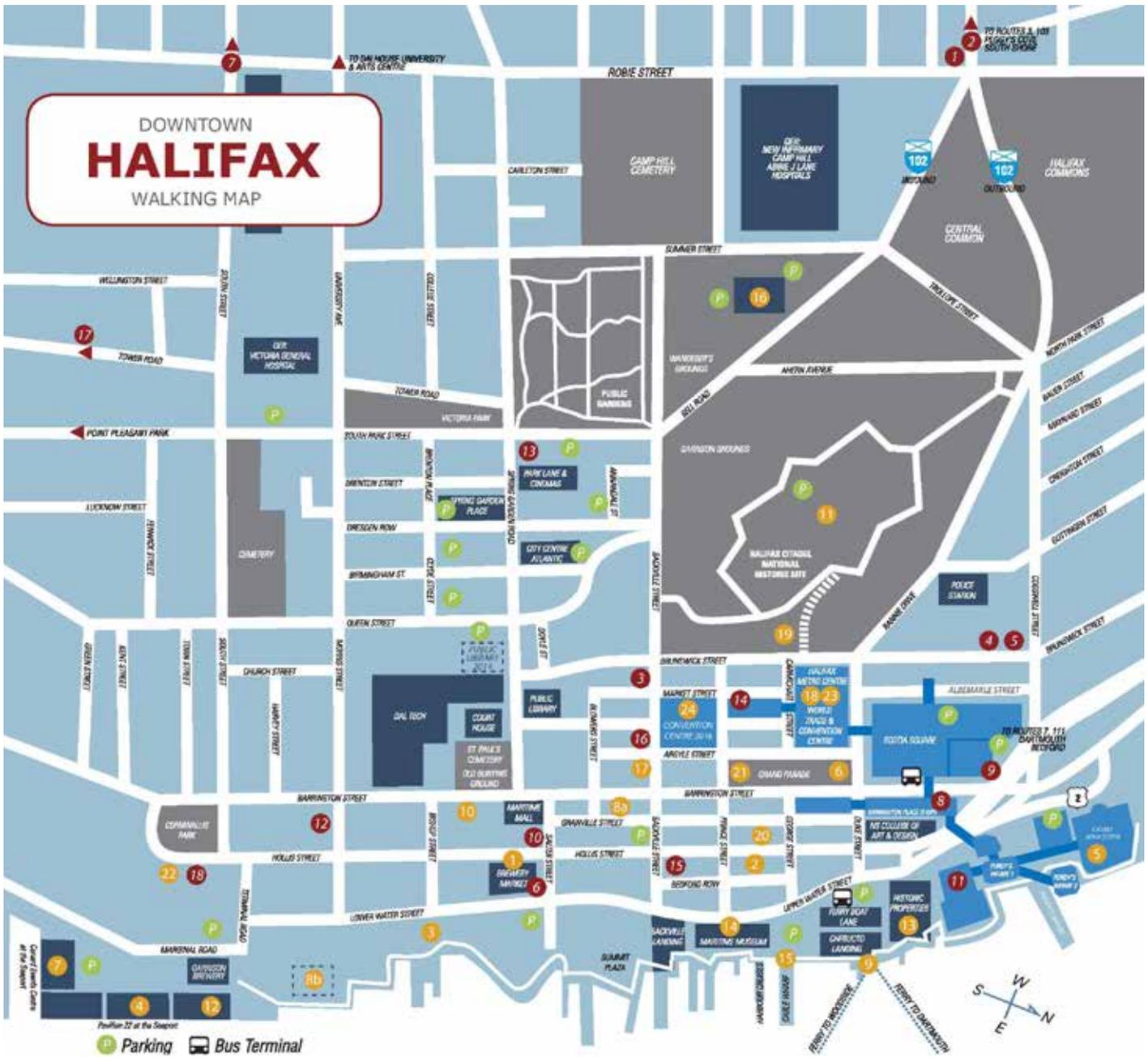
1. Atlantica Hotel Halifax
2. Best Western Plus Chocolate Lake Hotel
3. Cambridge Suites Hotel
4. Hampton Inn by Hilton (2014)
5. Homewood Suites by Hilton (2014)
6. Courtyard by Marriott Halifax Downtown
7. Dalhousie University
8. Delta Barrington
9. Delta Halifax
10. Four Points by Sheraton Halifax
11. Halifax Marriott Harbourfront Hotel
12. Haliburton, The
13. Lord Nelson Hotel & Suites
14. Prince George Hotel, The
15. Radisson Suite Hotel Halifax
16. Residence Inn Halifax Downtown
17. Saint Mary's University
18. Westin Nova Scotian, The



# Exploring Halifax

## Welcome to the East Coast!

There is lots to see during your stay in Dartmouth. Use the maps to explore, including some of the local gardens and shops in Dartmouth, or take the ferry to Halifax and visit the Citadel, historic Halifax, or the Canadian Museum of Immigration at Pier 21. For more ideas, just ask one of our local volunteers!



For travel guides, hidden gems and more information, visit [DestinationHalifax.com](http://DestinationHalifax.com).  
ph: 902-422-9334 toll free: 1-877-422-9334 [info@destinationhalifax.com](mailto:info@destinationhalifax.com)

# Proud Sponsors of the 2016 HSC National Conference

A sincere thank you to Kindred Home Care, Clearwater Seafoods, and the Municipal Group of Companies.



**MUNICIPAL GROUP OF COMPANIES**



DEXTER CONSTRUCTION COMPANY LIMITED



## SPECIAL THANKS to the Host Chapter Conference Committee

for welcoming us to their region for the 2016 National Conference! Chapter volunteers were an integral part of making this Conference so special, including planning assistance, support in securing local sponsorships, planning the Friday night welcome dinner, and recruiting volunteers for Conference activities. **THANK YOU!**



*View from Dartmouth*









# Believe

*Transforming, Tomorrow, Together*

Every child, adult and family deserves a safe place to land.

## \$3 million is needed over the next 2 years:

- \$1.5 million is needed to invest in discovery research, leading to treatments for Huntington disease;
- \$1.5 million is needed to increase services to families, individuals and youth.

We invite you to be a leader in the evolution towards a future where Huntington disease no longer ravages the mind and body by investing in these two key areas, where our goals are simple but the impact is profound.

More research funding is required to facilitate discoveries and the resources available for HD scientists. We need to strategically invest now in research that leads to a better understanding or treatments for Huntington disease, and to expand capacity for clinical trials to keep the momentum going.

Every child, individual and family deserves a safe place to land. To make this happen, we need to increase accessibility to support and services to include everyone affected by Huntington disease, including those in rural and diverse communities.

## Research

### Investing in Impactful Research to Expedite Discovery and Build Capacity

The Huntington Society of Canada's research program focuses on building critical mass in Huntington disease research. Only projects that meet our standard of excellence, as rated by our experts through a peer review process, are eligible to receive funding. Annually, the number of excellent research projects that show promise in ending or slowing down the process of HD put forward by the research peer review committee as fundable, exceed the funding available.

## Accessibility to Services

### Going Forward Together

Youth under 25 make up 29% of the Canadian population. They represent the future. You can make a difference for youth affected by Huntington disease by ensuring they are supported and investing in youth specific programs.

**1 in 5500** Canadians have Huntington disease.

**1 in 1000** Canadian are at-risk for, affected or touched by HD.

Based on these statistics, we are currently only reaching about **11%** of Canadians affected by HD.

There are people impacted by HD not yet being reached. **They need your help.** Those affected by HD in rural areas are isolated, forced to deal with HD on their own. **Services, clinical trials and treatments need to be accessible to everyone.** It is also necessary to connect with more people to expedite discovery and clinical trials.



**THANK YOU  
FOR ATTENDING  
#HSCHALIFAX**

151 Frederick St  
Suite 400

Kitchener, ON, N2H 2M2

Ph: (519) 749-7063

Toll Free: (800) 998-7398

Fax: (519) 749-8965

Email: [info@huntingtonsociety.ca](mailto:info@huntingtonsociety.ca)

[www.huntingtonsociety.ca](http://www.huntingtonsociety.ca)

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