Building Healthy Homes

Ontario Rett Syndrome Association

APRIL 27-29, 2012 - MISSISSAUGA, ON

Helping families & individuals with Rett Syndrome for 20 years

Delta Meadowvale Hotel

Ontario Rett Syndrome Association

CONFERENCE 2012

Ontario Rett Syndrome Association

Building Healthy Tomorrows
MESSAGE FROM

The 2012 Ontario Rett Syndrome Association's Building Healthy Homes Conference is going to be a very informative and exciting event. The Building Healthy Homes Conference offers exceptional speakers that will be engaging for all those who support an individual with Rett Syndrome. This includes family members, caregivers, friends, educators, therapists, support staff and medical professionals. It has been a goal to bring the leading experts in the field of Rett Syndrome to the 2012 conference as presenters.
Dr. Alan Percy is known throughout the world for his knowledge and expertise of Rett Syndrome (RTT). He has published 120 papers on RTT and has established two RTT Clinics among other significant achievements; it is an honour to have Dr. Percy as a presenter. Jane Lane, RN has spoken internationally about care and management for those living with RTT and will share her knowledge on care, as well as speak about issues related to women with RTT; this is a new topic being presented at an O.R.S.A. conference. Dr. Walter Kaufmann is another leading RTT expert. His recent involvement on the working committee for the Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition (DSM-V) is recognized for its importance. His presentation will be of interest to all. Judy Lariviere, M.ED., OTR/L has exceptional knowledge regarding assistive technology, communication and literacy approaches to assist those who have RTT. Bob Topping is a Canadian architect who will be sharing his knowledge on making a home accessible. We are proud of the Canadian RTT experts and researchers who are members of O.R.S.A.’s Medical Advisory Council. We are fortunate to have them presenting at the Building Healthy Homes conference.

A unique event at the 2012 conference is the vendor fair that will be available to all attendees. Exhibitors will include businesses and companies that provide special needs equipment, home renovations, RTT information and more.

O.R.S.A. will commemorate its twentieth year anniversary during the Saturday evening banquet. This will be a time to rejoice and to reflect on the growth of this grassroots organization. A time to show appreciation and give thanks to all those that supported O.R.S.A. over the years. The celebration dinner will be a memorable one. The 2012 Building Healthy Homes Conference will provide tools for those who support an individual with Rett Syndrome. Knowledge on home accessibility, care and management strategies, communication programs, recent developments in understanding Rett Syndrome and research will allow for attendees to be further educated on this challenging disorder. Join us at O.R.S.A.’s 2012 Building Healthy Homes conference.

Terry Boyd
Conference Chair
President
April 27
Friday
 Clinics: By Appointment Only
 Hudson Bay Hospitality Suite
 1:30–4:30 p.m.
 Arrive 30 minutes prior to appointment
 Physicians: Dr. MacLeod,
 Dr. Humphreys, Dr. Percy
 Guest: Physicians from the GTA region.
 Welcome Reception & Registration
 South Studio 2
 6:30–8:00 p.m. Welcome Reception,
 Registration & Resource Centre
 7:00–7:45 p.m. Kids Treasure Hunt
 8:00–9:30 p.m. Discussion Groups

April 28
Saturday Morning
 7:30 a.m. Conference Registration Opens
 Hazel McCallion Foyer
 8:30 -4:30 p.m. Information Fair:
 Resource Centre, Vendors, O.R.S.A.
 & Outreach Committee Tables
 Hazel McCallion A
 8:00–9:00 a.m. Breakfast
 Hazel McCallion BCD
 8:45 a.m. Welcome & Announcements
 Hazel McCallion BCD
 9:00–10:00 a.m. Natural History of Rett
 Syndrome: Current Understanding – Dr. Percy
 10:00–10:15 a.m. Break
 10:15–11:15 a.m. Research News
 – Dr. Eubanks/Dr. Greer
 11:15–12-15 a.m. The Maturing Woman
 with Rett Syndrome: From Puberty
 to Menopause – Jane Lane, RN
 12:15–1:15 p.m. Lunch
AGENDA

April 28
Saturday Afternoon

1:15–1:40 p.m. DSM 5: What does it mean to Rett Syndrome? – Dr. Kaufmann

1:40–2:15 p.m. Medical Panel – Dr. Percy, Dr. Humphreys, Dr. MacLeod, Jane Lane, RN

2:15–2:30 p.m. Break

2:30–3:15 p.m. Accessible Homes – Bob Topping, B.Arch., M.R.A.I.C., O.A.A. Architect

3:15–4:30 p.m. Enhancing Communication: Regulating Sensory Input and Supporting Ease of Access – Judy Lariviere, M.ED., OTR/L

4:30–5:30 p.m. Free time

April 28
Saturday Evening

5:30 p.m. Reception & Cocktails
Hazel McCallion Foyer

6:00 p.m. 20th Anniversary Celebration Dinner
Hazel McCallion BCD

7:15 p.m. 20 Years of Memories Tribute

8:00 p.m. Dance

11:00 p.m. Closing

April 29
Sunday Morning

8:00 –9:00 a.m. Breakfast
Hazel McCallion BCD

8:50 a.m. Opening Remarks
Hazel McCallion BCD

9:00 –9:45 a.m. Pediatric and Adult Preventive Care in Rett Syndrome and MECP2 Mutations – Jane Lane, RN

9:45–10:30 a.m. Canadian Rett Syndrome Scientific Symposium Reflections – Dr. MacLeod

10:30–10:45 a.m. Break

10:45–12:00 p.m. Leap into Literacy: Strategies for Teaching Emergent and Conventional Literacy to Girls and Young Women with Rett Syndrome – Judy Lariviere, M.ED., OTR/L

12:00 noon Lunch

12:30 p.m. Farewell Comments
**DR. ALAN PERCY** is a pediatric neurologist at the University of Alabama. In 1983, Dr. Percy, along with Dr. Vanja Holm and Dr. Mary Coleman, were the first physicians to recognize Rett Syndrome in the United States.

In 1984, Dr. Hugo Moser, Dr. Holm, and Dr. Percy attended the Rett Syndrome conference in Vienna organized by Dr. Rett. Since that time, Dr. Percy has actively pursued clinical and laboratory studies on this unique neurodevelopmental disorder, establishing Rett centers at Baylor College of Medicine and later at the University of Alabama at Birmingham, where he is the principal investigator of the Angelman, Rett, and Prader-Willi Syndrome Rare Disease Clinical Research Consortium.

He was responsible for recruiting Dr. Huda Zoghbi in studies leading to identification of mutations in MeCP2. Since 1983, he has authored more than 120 scientific papers on Rett Syndrome and is a co-author of The Rett Syndrome Handbook.

Dr. Percy has occupied prominent leadership positions in numerous academic neurological societies, including Past President of the Child Neurology Society and the Child Neurology Foundation, as well as Director of the American Board of Psychiatry and Neurology, and is a Fellow in both the American Academy of Pediatrics and American Academy of Neurology. He currently serves as Professor of Pediatrics, Neurology, Neurobiology and Genetics at UAB, and is Associate Director of the Civitan International Research Center and UAB Intellectual and Developmental Disability Research Center Principal Investigator.

Photo: The Rett Syndrome Project
BIOGRAPHIES

JANE LANE, RN has more than sixteen years experience as a Research Coordinator and Manager in child neurology at the Civitan International Research Center at the University of Alabama at Birmingham, specifically relating to the study of epilepsy in neonates and movement disorders including Tourette Syndrome, Huntington disease, and Rett Syndrome.

Jane Lane received a BS in Microbiology from Mississippi University for Women and a BS in Nursing from the University of Alabama. During the past six years, she has worked exclusively with Rett Syndrome, serving as Project Manager for the Angelman, Rett, and Prader-Willi Syndromes consortium of the Rare Disease Clinical Research Network.

The Natural History study of Rett Syndrome and MeCP2 mutations alone has enrolled nearly 700 individuals with the disorder. She has co-authored over 25 publications; most pertaining to Rett Syndrome.

In addition to her position at UAB, Jane is Family Support Program Manager with the International Rett Syndrome Foundation, where she provides support to families who have questions regarding medical issues. She also serves as a member of the RettSearch Study Group, an international collaboration related to the organization of clinical trials for Rett Syndrome. She serves on the board of the Southeastern Rett Syndrome Alliance as a professional advisor. Jane has spoken numerous times on the topic of medical issues in Rett Syndrome and on issues related to health maintenance and the maturing woman with Rett Syndrome.

Photo: The Rett Syndrome Project
**DR. WALTER KAUFMANN** directs the Fragile X Syndrome Clinic, as well as the Centre for Genetic Disorders of Cognition & Behavior at Kennedy Krieger Institute.

Dr. Kaufmann’s work encompasses research activities on Down Syndrome, Rett Syndrome, Fragile X Syndrome, ASD in metabolic disorders, and ASD in the general population. He is also a Professor of pathology, neurology, pediatrics, psychiatry and radiology at the Johns Hopkins University School of Medicine. Dr. Kaufmann is currently a member of the Psychiatric/General Medical Interface Study Group and the Neurodevelopmental Disorders Work Group for the Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition (DSM-V). He also serves as a member of the scientific review board and the medical advisory board for the International Rett Syndrome Foundation (IRSF), and as the coordinator of RettSearch, the international consortium of Rett Syndrome clinical researchers. Additionally, he serves as a member of several committees and boards in the Fragile X Syndrome field, including the Steering and Membership and Infrastructure (Chair) Committees of the Fragile X Clinic and Research Consortium of North America (FXCRC), the Scientific and Clinical Advisory Committee of the National Fragile X Foundation (NFXF) and the NIH-sponsored committee on Outcome Measures for clinical trials in Fragile X Syndrome.

**DR. JOHN J. GREER** is a Professor of Physiology at the University of Alberta. He is also the Research Lead in the School for Neuroscience and a Scientist of the Alberta Heritage Foundation for Medical Research.

His areas of expertise include studies of how the nervous system controls breathing and development of novel pharmacological therapies to overcome sleep apnea and depression of breathing in newborns and adults. Past awards have included the Parker B. Francis Fellowship and Stevenson Lectureship awarded by the Canadian Physiology Society. Dr. Greer was the recipient of the 2010 Ontario Rett Syndrome Association’s research grant for his project entitled “Investigation of Respiratory Dysfunction in a Mouse Model of Rett Syndrome”. The project intended to discover the root cause of the respiratory dysfunction common in RTT and to potentially develop a potential therapeutic intervention.
Dr. Eubanks started his lab at the Toronto Western Research Institute in 1994, where he initially studied aspects of stroke and epilepsy. In 1996, he became interested in how epigenetic factors influenced the sensitivity of the brain to these conditions, and started investigating MeCP2 as one potential neuromodulating factor.

When mutations of the MeCP2 gene were identified as primary causes of Rett Syndrome in 1999, his focus changed towards delineating how MeCP2 normally regulates brain development and function, and identifying how the absence of MeCP2 affects brain activity. By identifying deficits related to MeCP2, his work provides a framework for rationale drug development to treat Rett Syndrome. In addition, Dr. Eubanks’ group is one of five worldwide to have shown that the condition of Rett Syndrome mice can be improved by reintroducing functional MeCP2 to the brain, and is one of a select group of investigators testing whether reintroducing functional MeCP2 into small regions of the brain in these mice will improve their condition.

Dr. Eubanks is a Senior Scientist in the Genetics and Development Division at the Toronto Western Research Institute, and a Full Professor in the Department of Surgery at the University of Toronto.

His current laboratory staff includes two Research Associates, two Master’s students, two Doctoral students, and varying numbers of undergraduates interested in studying Rett Syndrome. Dr. Eubanks is a member of the Scientific Advisory Board for both the Ontario Rett Syndrome Association, and the International Rett Syndrome Foundation. His lab is currently funded by operating grants from the Canadian Institutes of Health Research, the International Rett Syndrome Foundation, and the Canadian Heart and Stroke Foundation.
Dr. PETER HUMPHREYS, M.D. is a professor at the Department of Pediatrics at the University of Ottawa. He is the former founding Head of the Neurology Division at the Children’s Hospital of Eastern Ontario (CHEO) in Ottawa, Ontario.

Dr. Humphreys has been responsible for many publications which includes co-authoring a book, chapters, abstracts and numerous medical articles that include topics on coma in childhood, Prader-Willi Syndrome, ketogenic diet in the treatment of refractory epilepsy in childhood, correlates of epilepsy in different patterns of cerebral palsy, brain malformations associated with fetal hydrocephalus and loss of MeCP2. Dr. Humphreys’ research project called CSF Folate Metabolism in Rett Syndrome is now complete.

Dr. Humphreys has been the neurologist and advocate for many girls and women with Rett Syndrome since the late 1980’s. In 1997, he assisted the Eastern Ontario Chapter of the Ontario Rett Syndrome Association and the Canadian Paediatric Society with the organization of a Medical Symposium on Rett Syndrome. In 2006 he established the first Rett Syndrome Clinic in Ontario at the Children’s Hospital of Eastern Ontario, where he has since seen over 50 women and girls with Rett Syndrome from across Canada. Dr. Humphreys is also a member of the Canadian Rett Syndrome Consortium and the O.R.S.A. Medical Advisory Council.

DR. PATRICK MACLEOD, is a clinical geneticist involved in the diagnosis, management and treatment of patients with uncommon disorders that have a genetic predisposition at Victoria General Hospital in British Columbia.

Dr. MacLeod’s interest in Rett Syndrome began in the 1980’s when he diagnosed his first female patient with the disorder, while working as Director of Medical Genetics at Queen’s University and Kingston General Hospital in Ontario.

Since then, Dr. MacLeod has been instrumental in the education and diagnosing of many females with RTT across Canada. He has been a member of the Medical Advisory Council for O.R.S.A. for 20 years. Dr. MacLeod organized the first meeting of the Canadian Rett Syndrome Consortium in the summer of 2005 that brought doctors and researchers together from across Canada. This was a monumental step towards heightened interest in research in Canada and the future establishment of Rett Syndrome clinics in Ontario.

Dr. MacLeod is the founder and administrator of the newly developed Canadian Rett Syndrome Registry. In 2004, Dr. MacLeod received the Award of Merit from the Ontario Rett Syndrome Association for his significant contribution to Rett Syndrome research in Ontario and across Canada.
JUDY LARIVIERE, M.ED., OTR/L is an Assistive Technology Specialist and a Pediatric Occupational Therapist who has worked in the field of Assistive Technology, including Augmentative and Alternative Communication (AAC), for the past 24 years.

Judy received both her BS in Occupational Therapy and her M.Ed. degree from The University of Western Ontario. Judy worked for eight years at Thames Valley Children’s Center in the Augmentative Communication Service and School Health Support Services. After relocating to the Bay Area in California, Judy worked at California Children Services’ Medical Therapy Unit in San Francisco and the Rehabilitation Technology Center at Lucile Packard Children’s Hospital, Stanford University Medical Center. For the past 11 years, Judy has worked with many girls with Rett Syndrome in her private practice and as the Communication Specialist at Katie’s Clinic for Rett Syndrome at Children’s Hospital & Research Center Oakland. She has focused on identifying the girls’ best means of access to technology for communication and learning, while implementing tools and strategies to support their educational progress; particularly in the area of literacy. Judy has conducted over 100 successful eye gaze trials with girls and young women with Rett Syndrome using her custom designed page set that she developed specifically for them.

Judy consults with families and school teams in North and South America and presents at international conferences on topics related to access to AAC, including eye tracking/eye gaze technology, and tools and strategies for supporting literacy learning in girls with Rett Syndrome. She also serves as a Professional Advisor for the International Rett Syndrome Foundation (IRSF). In addition to her work with girls with Rett Syndrome, Judy is a full-time tenured faculty member as an Assistive Technology Specialist at Skyline College, a Community College in San Bruno, California, where she teaches students with disabilities various assistive technology applications.

BOB TOPPING, B.Arch., M.R.A.I.C., O.A.A. is a Canadian architect and member of the Global Alliance on Accessible Technologies and Environments (GAATES).

Bob has focused his work on accessibility issues and universal design through his consulting company, DESIGNABLE ENVIRONMENTS Inc. for over 25 years.

He has worked as an accessibility specialist on many projects in Canada, including the Mississauga Bus Rapid Transit System, Air Canada Centre, Ricoh Coliseum, Windsor Casino and the Four Seasons Center for the Performing Arts. He has also worked on many accessible housing renovation projects and is the author of a number of the Canada Mortgage and Housing Corporation’s (CMHC) About Your House: Accessible by Design publications.
Registration
We have tried to make the registration fee as low as possible, but still make the Building Healthy Homes conference an informative and memorable event.

The Conference Registration Fee Includes:

- Welcome Reception
- Rett Clinics
- Meals and Breaks on Saturday and Sunday
- Conference Materials and Entertainment

Please note that there are additional meal costs for guests not attending the full conference; see details below. All individuals with Rett Syndrome are complimentary guests of O.R.S.A., room and hotel costs not part of the conference program are the attendees’ responsibility.

Registration for “Meals Only”
In order to provide accurate numbers for the hotel and to keep expenses in line with the O.R.S.A. budget, it is important that you register each member of your party who may be eating at the hotel. If the individual(s) are not attending the conference, the “meals only” category applies.

Meals for all children and adults with RTT are provided at no charge to the family, but they should be included in the numbers.

O.R.S.A.’s 20th Anniversary Celebration Banquet and Dance
The Saturday evening banquet is a celebration of O.R.S.A.’s 20th anniversary. This will be a very special event that will include a video tribute, surprise guests and so much more. You are welcome to invite friends and family who are not registered for the conference.

Additional tickets are available for $30.00 per person. Please be sure to order these tickets when you register and it is requested you do so by April 13th at the very latest.

Group Photo
An official group photo of all the children and adults with Rett Syndrome will take place at 5:40 p.m., location to be announced.
Rett Syndrome Clinic - Friday April 27

How to Register

On Friday afternoon, there is an opportunity for families/caregivers and the special female with RTT to spend 30 minutes privately with one of the following doctors: Dr. Percy, Dr. Humphreys or Dr. MacLeod. Families/caregivers can ask questions and receive feedback, recommendations and a possible diagnosis; if applicable. Those interested in obtaining a clinic time, should check off the clinic request on the registration form.

Each family/caregiver will be contacted by the Clinic Coordinator once the registration form has been received. Clinic spots will be allocated on a first-come, first-served, basis. The first 18 requests will be accommodated.

When to Arrive for Clinic Appointment

Registration for families attending the clinics begins at 1:00 p.m. on Friday. It is requested that each family register at least 30 minutes before their scheduled clinic time. Missed clinic appointments cannot be rescheduled.

All families requesting a clinic time must be registered for the conference and be a 2012 paid-up member of O.R.S.A.

Membership renewal can be done online at www.rett.ca or by filling in a membership form and returning it to O.R.S.A. before the conference.

Special Consideration For All Our Girls And Women With RTT Attending The Conference

The conference will deal with topics related to the challenges of caring for an individual with Rett Syndrome and the impact this has on those who give care. Detailed descriptions of medical conditions will take place. These discussions may have a negative impact and the presence of individuals with RTT may not allow for individuals to feel comfortable sharing their true feelings. The conference committee strongly suggests that you arrange for a caregiver during the conference sessions. Caregivers may decide to take the girls and women to the pool, travel to the mall or park, or spend some down time in a quiet hotel room. Please inquire at registration if you’d like to meet other caregivers to make plans together.
Welcome Reception
The Building Healthy Homes Conference officially begins with the Welcome Reception on Friday evening. This is a time to socialize, register for the conference, pick up your attendee bag and purchase merchandise at the Resource Centre. A new tradition is the Kids Treasure Hunt. It is a great family fun event! Refreshments will be served.

Discussion Groups
On Friday evening at 8:00 p.m., all conference attendees are encouraged to participate in these unique sharing sessions. It is a great way to meet other families, caregivers and professionals with similar issues and concerns.

Photos for Name Tags
When you register at the conference, your name tag will be ready for you. To help in getting to know one another, we encourage you to send a photo of the special female with RTT in advance, if applicable. This will be affixed to your name tag for handy bragging rights. Print photos should be mailed in with registration (one photo per name tag). Digital photos can be emailed to buildinghealthyhomes@rett.ca. In your email, please specify the names of those requiring the photo on their name tag. The deadline for submitting photos is April 13th.

Resource Centre
The Ontario Rett Syndrome Resource Centre will be set up at the conference throughout the weekend. New merchandise will be available with O.R.S.A.’s new logo. Rett Syndrome educational materials will also be available for sale. Stop by and see what’s new!

Dress
Dress is casual for the conference. Some may dress up for the 20th Anniversary Celebration Banquet. April weather in Mississauga is very unpredictable. Remember to pack a swimsuit.

Questions?
If you have any questions please call (519) 474-6877 or email buildinghealthyhomes@rett.ca
Hotel Information

Location
The Delta Meadowvale is a family friendly hotel with the Greater Toronto Area’s longest indoor hotel waterslide. The kids will have a blast splashing down the twists and turns of the 165° waterslide.

Delta Meadowvale Hotel
6750 Mississauga Road
Mississauga, Ontario L5N 2L3
Tel. 1-888-890-3222

Check-in 3:00 p.m.
Check-out 12:00 p.m.

Rooms and Reservations
The Delta Meadowvale Hotel has been newly renovated with numerous accessible rooms. Book your room before April 13th and you will be eligible for the conference room rate of $119.00, plus tax. Mini fridges and microwaves are available in limited numbers and best reserved when booking; please make your reservation quickly.

For reservations call: Toll Free: 1-800-422-8238 Phone: 905-542-4003.

Remember to state you are booking under the Ontario Rett Syndrome Association’s conference.

Hotel Parking
Parking at the Delta Meadowvale Hotel for the Building Healthy Homes conference is complimentary for guests staying at the hotel and for all other conference attendees.

Be sure to give your licence plate number to the front desk at check-in. Guests not staying at the hotel should give their licence plate number to the concierge upon arrival.

Conference Travel Agent
Winchester Tours and Travel Agency is the conference’s chosen travel agency. If you need help with travel arrangements, please feel free to phone or email the following agents:

Shannon - shannon@winchestertravel.ca or Joyce - joyce@winchestertravel.ca

Phone: (613) 445-1001 Toll free 1-877-946-8685

Please mention that you are attending the Ontario Rett Syndrome Conference.
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Mississauga, Ontario L5N 2L3
Tel. 1-888-890-3222

Check-in 3:00 p.m.
Check-out 12:00 p.m.

O.R.S.A.
P.O. BOX 50030
London Ontario, N6A 6H8
Tel. 519-474-6877
www.rett.ca