Conference Speakers and Sessions

Day One: Optimizing Neurodevelopment

Keynote Presentation: Supporting Positive Behaviour Through a Neurodevelopmental Lens

Dr. David Stein is the founder of New England Neurodevelopment, a pediatric psychology practice in the greater Boston area of Massachusetts. He is the author of the new book *Supporting Positive Behavior in Children and Teens with Down Syndrome: The Respond, but Don't React Method* published by Woodbine House in 2016. Dr. Stein has served as Co-Director of the Down Syndrome Program at Boston Children’s Hospital, a pediatric psychologist within the Division of Developmental Medicine at Boston Children’s, and an instructor at Harvard Medical School through 2016. Dr. Stein’s clinical work is focused on neuropsychological testing, behavior therapy, and parent training with children who have neurodevelopmental disorders.

Behavior problems impact 30% of children with Down syndrome. Left untreated, these same children often exhibit behavior problems as adults, limiting work and independent living opportunities. In order to address behavior problems in DS effectively, one must understand the brain-based reasons for these challenges and direct treatment appropriately. This workshop will present the basic neuroscience of Down syndrome and how this informs effective behavior management, with practical strategies provided for use in the home and school settings.

10:30 Breakout Sessions (choose one)

Q&A with Dr. David Stein

A Q&A following Dr. Stein’s keynote presentation on Supporting Positive Behaviour Through a Neurodevelopmental Lens.

Down Syndrome and Autism Spectrum Disorder

Lina Patel, PsyD is an Assistant Professor of Child and Adolescent Psychiatry at the University of Colorado School of Medicine, practicing at Children’s Hospital Colorado. Dr. Patel is the Director of Psychology for the Anna and John J. Sie Center for Down Syndrome, a multidisciplinary consultative clinic coordinating care for infants, children, teens and young adults with Down syndrome. Dr. Patel is responsible for management of all referrals for psychological treatment and evaluation. She provides consultation with schools, parent training regarding the management
of challenging or unsafe behaviors, evaluation for dual diagnoses (Down syndrome and Autism), toilet training, and desensitization to medical devices (such as hearing aids and CPAP) and procedure-related distress. Outside of her clinical work, she has presented to numerous organizations across the country with a focus on behavioral interventions with individuals with Down syndrome. She also conducts research on clinical issues impacting those with Down syndrome.

Dr. Patel received her bachelor degree in Psychology from the University of Oklahoma. She received her masters and doctorate in clinical psychology from the University of Denver’s Graduate School of Professional Psychology. She completed her internship training at Boston University Medical Center and her postdoctoral fellowship at Stanford University’s Lucile Packard Children’s Hospital.

This presentation will explore the characteristics of Down syndrome and autism and when the two overlap. Research will be presented to explain the methods for obtaining a differential diagnosis and the complex nature of a dual diagnosis. Implications for intervention will also be explored.

**Strengthening Goal-Directed Behavior for Adults with Down Syndrome in Post-Secondary Settings**

Dr. Deborah Fidler is a Professor in the Department of Human Development and Family Studies at CSU. Her research expertise is in the area of neurogenetic syndromes, with a specific focus on supporting outcomes for individuals with Down syndrome across the lifespan. Dr. Fidler currently serves as Editor of the American Journal on Intellectual and Developmental Disabilities and is Co-Editor of the International Review of Research in Developmental Disabilities. She has published over 60 articles and chapters on cognition and behavioral development in children with Down syndrome and other developmental disabilities.

This presentation will focus on ideas for supporting goal-directed behavior and planning skills in adults with Down syndrome. Ideas for continuing to strengthen these skills will be presented, as well as a pilot adult education program that emphasizes goal-directed behavior while focusing on areas of wellness (physical activity, nutrition, social engagement, decision making).

**Supporting Early Communication Skills in the Home and Classroom Settings**

Jillian Baldwin, M.Sc. RSLP is a speech and language pathologist at the Down Syndrome Research Foundation in Burnaby, BC. She completed her Master’s degree in Speech-Language Pathology at UBC and her Bachelor of Arts degree in Psychology at the University of Saskatchewan. Before joining DSRF, she provided speech, language, and swallowing support to children in schools and adults in a rehabilitation centre.

Jillian will review common communication profiles (strengths and challenges) seen in Down syndrome, including speech, social interaction, and language development. General strategies will then be discussed for parents and teachers to capitalize on common strengths and to develop areas of need for children in the early stages of communication development. This talk will be applicable to people who are using no words, single words, or just a few word combinations. Parents, teachers and SEAs will learn about supporting language comprehension and expression through a variety of modalities, including speech, signing, pictures, and technology.

**Navigating Transitions Through Circle Building and Networking for Young Adults with Down Syndrome and their Families**

Jan Burke-Gaffney has been an advocate for people with developmental disabilities for 26 years. She is a founder of the Hamilton Family Network, a parent-to-parent support group that seeks to implement innovative strategies to support and strengthen families to thrive in their local communities. Her most recent publication is a Guidebook for Parents, Building Circles of Support and
Friendship, a practical guide to help family members and especially parents, create a circle of support around their son or daughter. Jan has been an active member of Community Faculty at McMaster University in Hamilton, Ontario and involved with numerous projects and articles at CanChild Centre for Childhood Disability Research, including as co-investigator for the Keeping It Together KIT, Youth KIT, Parent Navigation project and transitions to adulthood for youth with disabilities. She holds a Professional Associate Appointment with the School of Rehabilitation Science, McMaster. Jan and her husband have four mischievous children, the youngest two who happen to have Down syndrome.

In this presentation we will discuss the importance of involving others to build a network of support and friendship around a person with a disability. We will consider how a circle and a not-for profit incorporated board can keep someone safe and connected. We will learn how to involve people to keep them excited to be a part of a community that stresses the contributions and benefits for both the focus person and themselves. We will also look at transition times and how to begin planning and building toward the future. Finally we will discuss the ways in which parent navigators can assist other parents to plan and travel through health, education and social systems.

1:00 Breakout Sessions (choose one)

**Supporting Early Goal-Directed Behavior in Young Children with Down Syndrome**

Dr. Deborah Fidler is a Professor in the Department of Human Development and Family Studies at CSU. Her research expertise is in the area of neurogenetic syndromes, with a specific focus on supporting outcomes for individuals with Down syndrome across the lifespan. Dr. Fidler currently serves as Editor of the American Journal on Intellectual and Developmental Disabilities and is Co-Editor of the International Review of Research in Developmental Disabilities. She has published over 60 articles and chapters on cognition and behavioral development in children with Down syndrome and other developmental disabilities.

This presentation will focus on the developmental foundations of goal-directed behavior in young children with Down syndrome. A specific emphasis will be placed on identifying early markers of planning and persistence in reaching goals, and practical strategies for supporting development in this critical area.

**Teaching Adherence to Use of Medical Equipment (CPAP, hearing aids, glasses)**

Lina Patel, PsyD is an Assistant Professor of Child and Adolescent Psychiatry at the University of Colorado School of Medicine, practicing at Children's Hospital Colorado. Dr. Patel is the Director of Psychology for the Anna and John J. Sie Center for Down Syndrome, a multidisciplinary consultative clinic coordinating care for infants, children, teens and young adults with Down syndrome. Dr. Patel is responsible for management of all referrals for psychological treatment and evaluation. She provides consultation with schools, parent training regarding the management of challenging or unsafe behaviors, evaluation for dual diagnoses (Down syndrome and Autism), toilet training, and desensitization to medical devices (such as hearing aids and CPAP) and procedure-related distress. Outside of her clinical work, she has presented to numerous organizations across the country with a focus on behavioral interventions with individuals with Down syndrome. She also conducts research on clinical issues impacting those with Down syndrome.

Dr. Patel received her bachelor degree in Psychology from the University of Oklahoma. She received her masters and doctorate in clinical psychology from the University of Denver's Graduate School of Professional Psychology. She completed her internship training at Boston University Medical Center and her postdoctoral fellowship at Stanford University's Lucile Packard Children's Hospital.
This presentation will begin by reviewing the frequency of diagnosis of hearing loss, vision impairment, and apnea and prescription of medical equipment. Benefits for use of medical equipment will then be explained. Factors impacting adherence (sensory, motivation, developmental stage, other family stressors, changes in medical status, and prioritization) will be discussed. A clear plan will be provided for steps towards desensitization. This will include creation of a schedule for practicing, identifying motivators, and troubleshooting of challenging behaviors. Participants will learn how to identify why a child may be struggling with practicing and then learn strategies to manage these behaviors.

**Early Reading: Building a Foundation**

Danielle McKinney, BEd is a BC-certified teacher who completed her Bachelor of Education in Elementary Education and a concentration in Language Arts, at the University of Victoria. She has been with the DSRF since 2011, and has supported the reading development of many children and young adults with Down syndrome.

The audience will be introduced to the fun, hands on methods for teaching high meaning sight words used in the DSRF’s Early Foundations one to one reading program for beginning readers. Danielle will explore how reading instruction can be beneficial for increasing cognitive engagement, expressive and receptive language and listening comprehension. She will also discuss how to develop phonological awareness in learners with strengths in visual processing and relative weaknesses in auditory processing and expressive language.

**Supporting Higher Level Communication Skills in Classroom, Community, and Home**

Jillian Baldwin, M.Sc. RSLP is a speech and language pathologist at the Down Syndrome Research Foundation in Burnaby, BC. She completed her Master’s degree in Speech-Language Pathology at UBC and her Bachelor of Arts degree in Psychology at the University of Saskatchewan. Before joining DSRF, she provided speech, language, and swallowing support to children in schools and adults in a rehabilitation centre.

Marla Folden, M.Sc. RSLP completed her Masters of Science at McGill University in Speech-Language Pathology. While attending McGill, she ran a research project about intensive speech treatment for teens with Down syndrome and childhood apraxia of speech. She enjoys working with individuals with developmental differences, and worked at the DSRF as a programs assistant and instructor prior to returning to school to study Speech Pathology.

Jillian and Marla will review common communication profiles (strengths and challenges) seen in Down syndrome, including speech, social interaction, and language development. General strategies will then be discussed for parents and teachers to capitalize on common strengths and to develop areas of need to support conversation and higher level language skills of children and adolescents. This talk will be applicable to people who are using sentences but may struggle with using their language for conversation, play, learning, or work.

**Do Our Genes Determine What We Should Eat?**

Dr. García-Bailo is Director of Research and Development at Nutrigenomix Inc. and Adjunct Professor at the University of Toronto. She received her PhD in Nutritional Sciences at the University of Toronto and completed a joint industrial/academic postdoctoral fellowship at General Mills and the University of Toronto, followed by an appointment as Senior Scientist at the Bell Institute of Health and Nutrition at General Mills. In addition to her work at the University of Toronto and General Mills, Dr. García-Bailo has conducted nutrigenomics and epidemiology research at Tufts University and the Public Health Agency of Canada. Her research interests focus
on the relationship between genetic and lifestyle variation, diet and health. She has published over 30 peer-reviewed articles and has given invited talks at scientific conferences, government agencies and research organizations worldwide. Dr. García-Bailo has received several awards for her research work, including the 2014 Canadian Nutrition Society PhD Dissertation Research Award and the 2012 American Society for Nutrition Nutritional Sciences Council Research Award.

There is increasing awareness among researchers, educators, healthcare professionals and consumers that the one-size-fits-all, population-based approach to nutritional guidance is inefficient and often ineffective. This awareness has created a growing market for personal genetic testing services. Recent advances in human genomics have uncovered extensive variations in genes affecting nutrient metabolism, but their full impact on nutrient requirements remains to be elucidated. Differences in the rates of absorption, distribution, uptake, utilization, biotransformation and excretion ultimately impact the concentration of a nutrient at a target site of interest. Key genes on chromosome 21 are associated with oxidative damage, mitochondrial dysfunction and beta amyloid over-production, with implications for development across the lifespan as well as premature aging, and may be targets for early preventative strategies including dietary intervention and supplements. Genetic polymorphisms associated with elevated maternal risk of trisomy 21 births may also be mitigated through primary prevention strategies involving nutrition and blood marker monitoring. Until recently, the effects of disclosing genetic information on consumer behaviors were not known. We conducted the first randomized controlled trial of genetic information on personalized nutrition and found that DNA-based dietary advice was superior to population-based recommendations at motivating changes in eating behaviors. Incorporating markers of genetic variation into studies of nutrition and health or performance aims to benefit those seeking personalized dietary advice, but should also improve public health recommendations by providing sound scientific evidence linking diet and health/performance.

3:00 Breakout Sessions (choose one)

Providing Positive Behaviour Support for Children with Down Syndrome

Susan Fawcett, M.Sc. RSLP has been a Speech-Language Pathologist at the Down Syndrome Research Foundation for 14 years. She is currently completing her PhD at the University of British Columbia where she is studying Family-Centered Positive Behaviour Support under Dr. Joe Lucyshyn.

Behavioural challenges in individuals with Down syndrome can negatively impact learning, social opportunities and relationship development. In this presentation Susan will discuss what we currently know about the overall characteristics and learning style associated with Down syndrome, and how we can apply this knowledge to reduce problem behaviour. Family-centered Positive Behaviour Support is a values-focused, evidence-based approach to problem behaviour that aims to improve not only child behaviour, but also child and family quality of life. Susan will share Positive Behaviour Support principles and strategies, tailored to children with DS, to help educators and families promote appropriate behaviour and interactions from an early age.

The Next Step: Developing Readers

Eleanor Stewart, M.Ed has worked at the Down Syndrome Research Foundation since 2008 and is the lead teacher. Eleanor is a BC certified teacher who has a Master’s degree in Educational Psychology, with a specialization in reading and exceptionality, from Simon Fraser University. She completed her Bachelor of Education at McGill University.

Eleanor will discuss creative and effective methods for teaching phonics, reading fluency, and comprehension. These methods will be demonstrated using videos and her favourite
learning materials. Adapting and modifying instruction will be addressed throughout the presentation to:

- Increase confidence and motivation in struggling readers
- Use the strengths of visual learners
- Support working memory and auditory processing

**Imagining Home Project: When Families are in Charge of Housing**

Janet Klees has been involved with families and issues of home and housing for the past 25 years and more. She spent over twenty years with a family group in Pickering, Ontario helping to ensure that life in a housing cooperative would become home and a good neighbourhood for all. For the past three years she has been the Executive Director of DAFRS in Oshawa, a family support and resource organization that partners in various ways with families to make sure that a good life in community is unfolding for and with their family member with a disability. They have focused on housing with family-led, community-based one person at a time thinking and a great amount of creative results have emerged despite very few dollars available.

Over the last few years, Marilyn Forster-Lo Turco and her daughter, Sara, have become very thoughtful about planning together for a good life in community including housing, home, purposeful roles, connection and belonging. Follow this family’s journey that includes relocating in order to increase family connections, moving from a day program to a real life in community which includes a number of valued and contributing roles based on the things that Sara is passionate about and interested in, changing current home in light of sharing with an adult daughter and planning for next steps. In addition, Marilyn and Sara’s housing journey has led them to be a part of a family-led corporation hoping to inspire and build diverse neighbourhoods with developers in Durham Region.

Despite severe affordable housing shortages everywhere in Canada, every day people still do use a combination of their own assets, local opportunities, new and emerging government programs and much creativity to figure out good housing for themselves. Believing that this should be no different for families with a member with a disability, families have been coming together in Durham Region to learn together about what might be possible. Staff and a family connected with DAFRS, a family resource and organization, will talk about their experiences of partnering together to think about Home, Housing and Support – three essential and intertwined but separate housing issues for families. From a clear, principled foundation families have come together to learn and share their ideas and plans with each other, resulting in making workable plans and taking action. This session will include real family stories, our general approach, and a short video of our experiences with housing, home and support.

**Increasing Independence and Function in School Aged Children with Down Syndrome**

Lillie Ryan, M.Sc. O.T., is the lead Occupational Therapist at the Down Syndrome Research Foundation. Lillie received her Masters of Science in Occupational Therapy from McGill University and completed a Bachelor of Arts in Psychology at the University of British Columbia.

Hina Mahmood, M.O.T., is an Occupational Therapist at the Down Syndrome Research Foundation. Hina received her Masters in Occupational Therapy from University of British Columbia and her Bachelor of Arts in Psychology from Simon Fraser University.

Lillie and Hina will review common challenges faced by school aged children with Down syndrome in the areas of self-care, productivity and leisure. They will discuss general fine and gross motor skills, sensory strategies and environmental adaptations to increase independence and facilitate success in school aged years.
Day Two: Optimizing Physical and Mental Health

**Keynote Presentation**

Brian Chicoine M.D., is the Medical Director of the Advocate Adult Down Syndrome Center in Park Ridge, IL. He is on the faculty of Family Medicine at Advocate Lutheran General Hospital. Dr. Chicoine is co-founder of the Adult Down Syndrome Center that has served and documented the health and psychosocial needs of over 6000 adolescents and adults with Down syndrome since its inception in 1992. Dr. Chicoine graduated from Loyola University of Chicago Stritch School of Medicine and completed his Family Medicine residency at Lutheran General Hospital. He co-authored two books “Mental Wellness of Adults with Down Syndrome,” and “The Guide to Good Health for Teens and Adults with Down Syndrome” published by Woodbine House Press.

Promoting physical and mental health is an active process for people with Down syndrome just as it is for anyone. Healthy lifestyle choices, appropriate screening, and recognizing and addressing illnesses early in their course all promote health. Important considerations in health promotion for people with Down syndrome include understanding the interaction between physical and mental health; appreciating that many alterations in physical or mental health are not directly linked to having Down syndrome and often have a treatable cause; and how awareness of the common, but not universal, characteristics of people with Down syndrome can improve health promotion as well as diagnosis and treatment of illness.

**10:30 Breakout Sessions (choose one)**

**Healthy Aging and Reducing the Risk of Alzheimer's Disease**

Elizabeth Head, PhD: Dr. Elizabeth Head received a Masters in Psychology and a Ph.D. in Neuroscience from the University of Toronto, Canada. She received postdoctoral training at the University of California – Irvine. Dr. Head moved to the University of Kentucky in January of 2009 and is currently a Professor at the Sanders-Brown Center on Aging as well as the Associate Director for Education. Dr. Head has dedicated over 15 years to the study of aging and Alzheimer's disease in people with Down syndrome. In 2014, Dr. Head's team won the Mary Carter Award from the Down Syndrome of Louisville, Inc. that honors people whose contributions, actions and achievements have improved the quality of life or promoted a positive image for persons with Down syndrome. She is co-leading a longitudinal aging study in people with Down syndrome that is in its 7th year.

This presentation will focus on current research into possible interventions that will lead to healthy aging and reducing the risk for Alzheimer's disease in people with Down syndrome.

**Oral Sensorimotor Development in Down Syndrome: Impact on Speech and Feeding**

Riley Rosebush, M.Sc. RSLP completed her master's degree in Speech-Language Pathology at the University of British Columbia after studying psychology and linguistics at the University of Victoria. She has worked at DSRF since 2012 providing individual and group therapy to people of all ages. Riley loves working with clients and their families to provide individualized support for communication and feeding development. She has additional training in PROMPT Therapy, Talk Tools, myofunctional therapy, and breastfeeding support.
Sensory and motor challenges in the mouth are common in children with Down syndrome. These issues can affect how your child learns to talk and eat. This presentation will outline the profile of oral sensorimotor development typically seen in Down syndrome and what issues you might expect to see in your child’s speech and feeding. We’ll discuss some treatment approaches focusing on speech, as feeding development will be discussed further in a later presentation.

Promoting Healthy Sexuality in Adults with Down Syndrome

Nadia Mia MSW, RSW, is a social worker who has worked at Surrey Place Centre in Toronto for over 10 years. Nadia has provided individual and group counselling to adults with developmental disabilities, including Down syndrome.

This presentation will provide caregivers with information and resources to make the conversation about sexuality and healthy relationships easier. Caregivers will reflect on their own values and understand the importance of sexual health education. Sexual health education materials developed for adults with developmental disabilities will be shared.

Q&A with Dr. Brian Chicoine

Brian Chicoine M.D., is the Medical Director of the Advocate Adult Down Syndrome Center in Park Ridge, IL. He is on the faculty of Family Medicine at Advocate Lutheran General Hospital. Dr. Chicoine is co-founder of the Adult Down Syndrome Center that has served and documented the health and psychosocial needs of over 6000 adolescents and adults with Down syndrome since its inception in 1992. Dr. Chicoine graduated from Loyola University of Chicago Stritch School of Medicine and completed his Family Medicine residency at Lutheran General Hospital. He co-authored two books “Mental Wellness of Adults with Down Syndrome,” and “The Guide to Good Health for Teens and Adults with Down Syndrome” published by Woodbine House Press.

A Q&A following Dr. Chicoine’s keynote presentation on optimizing neurodevelopment for individuals with Down syndrome.

1:00 Breakout Sessions (choose one)

Sleep and Learning in Down Syndrome

Dr. Jamie Edgin is an Assistant Professor at the University of Arizona, Department of Psychology, representing the Sonoran UCEDD on the council. Dr. Edgin serves on a number of national, state and local community boards to support individuals with developmental disabilities. In the last several years she has visited parent advocacy groups across the globe, including recent talks in Kansas, Canada, and Mexico. Dr. Edgin is an associate editor of the American Journal on Intellectual and Developmental Disabilities. Dr. Edgin’s work in the early 2000s was instrumental in characterizing the specific learning/memory profiles (i.e., the individual strengths and weaknesses) of individuals with Down syndrome and autism. For these efforts, she received the 2008/2009 Charles Epstein award from the National Down Syndrome Society and the 2015 David Cox “Rising Star” Award from the LuMind Foundation. In 2014 she was awarded a Bill and Melinda Gates Foundation Grand Challenges Explorations Grant to study sleep disturbance in at-risk infants and in 2016 she received 2.9 million dollars from the National Institutes of Health to develop touch-screen based assessments of learning and memory for children with intellectual and developmental disabilities. She has lived in Arizona for 10 years and enjoys this outdoor playground with her two children.

In this workshop Dr. Jamie Edgin from the University of Arizona will provide an update on new work on the
cognitive neuroscience of sleep suggesting that sleep states are very important for the acquisition of new memories, and even language concepts. She will highlight some recent discoveries in her lab, including the relation between Obstructive Sleep Apnea (OSA) and poorer cognitive outcomes, findings that help to highlight the importance identifying and treating sleep disorders in Down syndrome across the lifespan. The workshop will provide those in attendance 1) a thorough understanding of sleep role's in healthy cognition, 2) knowledge of how sleep disorders are identified and treated, and 3) an understanding of new research directions that may advance our ability to provide the best sleep health for those with Down syndrome.

Toilet Training: Where to Begin?

Lillie Ryan, M.Sc. O.T., is the lead Occupational Therapist at the Down Syndrome Research Foundation. Lillie received her Masters of Science in Occupational Therapy from McGill University and completed a Bachelor of Arts in Psychology at the University of British Columbia.

Hina Mahmood, M.O.T., is an Occupational Therapist at the Down Syndrome Research Foundation. Hina received her Masters in Occupational Therapy from University of British Columbia and her Bachelor of Arts in Psychology from Simon Fraser University.

This presentation will be an introduction to first time toilet training for young children with Down syndrome. Lillie and Hina will cover the following topics: when to begin toilet training, toileting approaches, readiness skills and strategies for success. This presentation is geared towards families with young children who have not yet tried toilet training and are interested in basic information and steps to take prior to beginning a toileting program.

OCD and Anxiety Disorders in Individuals with Down Syndrome: Risk Factors, Interventions and Family Supports

Dr. Khush Amaria received her PhD in clinical psychology from the University of Waterloo and completed her predoctoral internship training at Toronto’s Hospital for Sick Children (Sick-Kids). Following her internship, Dr. Amaria completed a two-year specialized clinical research health psychology postdoctoral fellowship, followed by a one-year Research Associate position with SickKids’ Chronic Pain Program. As part of her interest in community outreach, Dr. Amaria is involved in supporting parents, educators and caregivers on a variety of topics related to general child and adolescent development, mental health in children and youth, social skills and risk-taking behaviours in adolescence. She has been invited to teach workshops on cognitive behavioural therapy (CBT) for children, adolescents and adults to mental health care providers across Ontario.

At CBT Associates, Dr. Amaria provides treatment for children, adolescents, and adults with anxiety disorders, depression, adjustment difficulties, parent-child relational difficulties, and other health- and coping-related problems. Dr. Amaria is a member of the College of Psychologists of Ontario, Canadian Association of Cognitive and Behavioural Therapies (CACBT-ACTCC) and the Ontario Psychological Association. She is credentialed as a CACBT-ACTCC Certified Cognitive Behavioural Therapist.

Learn why individuals with Down Syndrome are at increased risk for Obsessive-Compulsive Disorder (OCD) and other Anxiety Disorders throughout development. Understand ways in which cognitive-behavioral treatments (CBT) can be effective for individuals to use on their own and with support by family members and care providers.
Meeting the Health Needs of Adults with Down Syndrome: Lessons From Research and Clinical Practice

Robert Balogh is an Assistant Professor at the University of Ontario Institute of Technology, Faculty of Health Sciences. Dr. Balogh completed his postdoctoral Fellowship at the Centre for Addiction and Mental Health and the Institute for Clinical Evaluative Sciences. He has a Master's degree in epidemiology and is a registered physiotherapist. His research interests include health disparities, primary care and health service models among those with developmental disabilities. He is a member of the Health Care Access Research and Developmental Disabilities (HCARDD) team where he co-leads a project that investigated health and health service outcomes in persons with developmental disabilities including Down syndrome.

William F. Sullivan, CCFP (COE), FCFP, PhD is Associate Professor, Family Practice Unit, St. Michael’s Hospital, Department of Family and Community Medicine, University of Toronto and Surrey Place Centre. Dr. Sullivan has qualifications as a family physician and bioethicist. He has a certificate of added competency in care of the elderly and is a Fellow of the College of Family Physicians of Canada. He has a teaching practice at St. Michael’s Hospital and is an Associate Professor of the University of Toronto. Dr. Sullivan’s research work in medicine is primarily through his work associated with the Developmental Disabilities Primary Care Program of which he is the founding director. This Ontario initiative was established to enhance the health and wellbeing of adults with developmental disabilities. It is co-funded by Ontario’s Ministry of Health and Long-Term Care, Ministry of Community and Social Services and is a program of Surrey Place Centre.

In this two part presentation, we will first learn about new research from Ontario that is looking at the health and health service use of a cohort of over 7000 adults with Down syndrome. Information will be compared to others with intellectual disability and the general population. In the second part, we will learn about a Health Watch Table for people with Down syndrome (a checklist that highlights particular health concerns at different life stages) and get an update on the primary care guidelines designed to address the health needs of people with Down syndrome.

3:00 Breakout Sessions (choose one)

Health Promotion: Facilitating the Participation of People with Down Syndrome in Their Own Health Promotion

Brian Chicoine M.D., is the Medical Director of the Advocate Adult Down Syndrome Center in Park Ridge, IL. He is on the faculty of Family Medicine at Advocate Lutheran General Hospital. Dr. Chicoine is co-founder of the Adult Down Syndrome Center that has served and documented the health and psychosocial needs of over 6000 adolescents and adults with Down syndrome since its inception in 1992. Dr. Chicoine graduated from Loyola University of Chicago Stritch School of Medicine and completed his Family Medicine residency at Lutheran General Hospital. He co-authored two books “Mental Wellness of Adults with Down Syndrome,” and “The Guide to Good Health for Teens and Adults with Down Syndrome” published by Woodbine House Press.

Increasing the understanding and participation in one’s own health promotion improves the individual’s health. Promotion of healthy lifestyles and other beneficial choices requires providing information that is understandable and encouraging. For people with Down syndrome, the associated intellectual disability and the common learning skills provide both challenge and opportunity to develop health-promoting information that educates and motivates.
Feeding Development in Down Syndrome

Riley Rosebush, M.Sc. RSLP completed her master’s degree in Speech-Language Pathology at the University of British Columbia after studying psychology and linguistics at the University of Victoria. She has worked at DSRF since 2012 providing individual and group therapy to people of all ages. Riley loves working with clients and their families to provide individualized support for communication and feeding development. She has additional training in PROMPT Therapy, Talk Tools, myofunctional therapy, and breastfeeding support.

In this presentation we will review the issues that affect feeding and eating safely in children with Down syndrome. We’ll discuss when to seek additional support for your child’s feeding development, and where you might look for help in your community. Issues such as difficulty transitioning to new stages, restrictive eating, food refusal, mealtime problem behaviors, and sensory selectivity will be discussed.

Promoting the Mental Health of Families of Children and Adults with Down Syndrome

Dr. Yona Lunsky is a Clinician-Scientist in Adult Neurodevelopmental Services and Director of the Health Care Access Research and Developmental Disabilities (H–CARDD) Program at the Centre for Addiction and Mental Health. She is Professor and Developmental Disabilities Lead in the Department of Psychiatry at the University of Toronto and Adjunct Scientist at the Institute for Clinical Evaluative Sciences (ICES). Dr. Lunsky has focused her research on the mental health needs of individuals with intellectual and developmental disabilities, and their families. She studies psychosocial risk factors for psychiatric disorders and health service utilization patterns in this population. Dr. Lunsky is the principal investigator of several studies examining clinical and systems issues related to health services. She is also involved in a number of projects focused on improving primary and emergency health care.

Although it has been well established that the experience of raising a child with Down syndrome can be stressful for families, there has been surprisingly little emphasis on addressing the needs of the family, separate from the child. This presentation will review what is known about the family experience and offer some practical suggestions around family mental health promotion, with a focus on teaching families skills to manage their stress. Attention will be paid to the unique needs of mothers, fathers and siblings, as well as innovative approaches where families, experts in their own right, can play a major role in helping one another.

Alzheimer’s Disease: Modifying Risk Factors and Supporting Communication for Optimal Functioning

Jillian Baldwin, M.Sc. RSLP is a speech and language pathologist at the Down Syndrome Research Foundation in Burnaby, BC. She completed her Master’s degree in Speech-Language Pathology at UBC and her Bachelor of Arts degree in Psychology at the University of Saskatchewan. Before joining DSRF, she provided speech, language, and swallowing support to children in schools and adults in a rehabilitation centre.

This presentation will discuss the relationship between Down syndrome and Alzheimer’s disease and how to recognize the early signs and symptoms associated with Alzheimer’s disease. Jillian will emphasize healthy aging and protective strategies to reduce the risk of Alzheimer’s disease and treatable conditions to consider and rule out. She will also provide general strategies to support communication with older individuals with Down syndrome who develop Alzheimer’s disease.