



# Child Health BC

A network of health authorities and healthcare providers dedicated to excellence in the care of infants, children, and youth in British Columbia

## INTERPROFESSIONAL WORKSHOP



Better health. Best in health care.



Promoting wellness. Ensuring care.



VANCOUVER ISLAND health authority

IMPLEMENTING BEST PRACTICES IN

# DOWN SYNDROME

MAY 26 & 27, 2006



Interior Health



northern health



PROVINCIAL Health Services AUTHORITY

Presented in Partnership With the:

**DOWN SYNDROME RESEARCH FOUNDATION**

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**DOWN SYNDROME  
RESEARCH FOUNDATION**

# Child Health BC

IMPLEMENTING BEST PRACTICES

## INTRODUCTION

This is the first in a series of interprofessional workshops on the implementation of best practices for infants, children and youth in British Columbia. Presented in partnership with the Down Syndrome Research Foundation, it looks at children with complex health needs and focuses on Down syndrome.

### **Down Syndrome Research Foundation**

The workshop will take place at the Down Syndrome Research Foundation building located in Burnaby, British Columbia. Josephine Mills, Executive Director of the Down Syndrome Research Foundation will provide a tour of the Research Foundation facility and will give an introduction to the resources available.



*The Down Syndrome Research Foundation Building*

This unique Centre for community-based research, educational programs and clinical support services for children and adults with Down syndrome is the first of its kind in Canada.

### **The Down Syndrome Research Foundation**

The Down Syndrome Research Foundation was formed in 1995 in response to the need, expressed by parents and professions, for detailed and research-based information for themselves and for the community at large. Although based in British Columbia, the DSRF, by using technology to reach out to the Community, has found an audience across Canada and around the world.

#### **MANDATE:**

Our mandate is to empower people with Down syndrome to achieve their potential, lead independent and fulfilled lives, and participate fully in the communities in which they live. We do this through developing education and training programs, disseminating information and research results, providing clinical support services, collaborating with other resource centers and community service providers, and raising funds to support a broad spectrum of research projects.

#### **LOCATION:**

1409 Sperling Avenue  
Burnaby, BC V5B 4J8

Tel: (604) 444-3773

Toll Free in Canada: 1-888-464-DSRF

Fax: (604) 431-9248

E-mail: [info@dsrf.org](mailto:info@dsrf.org)

Website: [www.dsrf.org](http://www.dsrf.org)

## WORKSHOP AGENDA

### Workshop Hosts

The workshop will be Co-hosted by Dr. Robert Peterson, Director of Child Health BC, Clinical Professor of Pediatrics at the University of British Columbia; and by Dr. Mary Connolly, Director of the Epilepsy Surgery Program at BC Children's Hospital, and the Head of Pediatric Neurology in the Department of Pediatrics at the University of British Columbia.

### Introduction to Clinical Practice Guidelines (Down Syndrome Health Care Guidelines):

Dr. Robert Haslam and Dr. Jill Houbé will provide an introduction to the Down Syndrome Clinical Practice Guidelines. Dr. Naznin Virji-Babul will discuss the results of a Parent Survey.

### Case Discussions:

<b>Cardiology:</b>	Dr. Walter Duncan
<b>Respirology:</b>	Dr. David Wensley
<b>Endocrinology:</b>	Dr. Dan Metzger
<b>Neurology/ Psychiatry:</b>	Drs. Mary Connolly and Robin Friedlander
<b>Rehabilitation Therapy:</b>	Ms. Pauline Bingham and Ms. Sue Fawcett
<b>Behavioural Issues:</b>	Dr. Peter Johnson

### Panel Moderator:

Dr. Daniel Weeks will act as a panel moderator.

## FRIDAY May 26th

8:00 am—5:30 pm

8:00 am—9:00 am

### **Coffee & Continental Breakfast**

Tour, and Introduction to Resources by Josephine Mills, Executive Director of the Down Syndrome Research Foundation (DSRF), and Sheryl Dickson the Director of Programs and Services (DSRF)

9:00 am—9:15 am

Opening Remarks by Dr. Peterson

9:15 am— 10:15 am

*Introduction to Guidelines: Down Syndrome Health Care Guidelines* by Dr Bob Haslam and Dr. Jill Houbé. *How Well Are the Health Care Guidelines on Down Syndrome Being Followed By Family Physicians Across Canada? A Parent Survey* will be presented by Dr. Naznin Virji-Babul.

10:15 am—10:30 am **Health Break**

10:30am—11:00 am

*Cardiology Cases in Down Syndrome* by Dr. Walter Duncan

11:00am—11:30 am

*Respirology* by Dr. David Wensley

11:30 am—12:00 am

*The Spectrum of Endocrine Problems in Kids with Down Syndrome* by Dr. Dan Metzger

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IMPLEMENTING BEST PRACTICES

## 12:00 pm—1:30 pm Lunch

Working lunch tables for discussion of what is necessary to provide for children with Down syndrome during the transitional stages.

## 1:30 pm—2:00 pm

*The Approach to Neurological Regression in Teenagers With Down Syndrome* by Drs. Mary Connolly and Robin Friedlander

## 2:00 pm—2:30 pm

*Rehabilitation Therapy* by Pauline Bingham and Sue Fawcett

## 2:30 pm—3:00 pm

*Teenage Libido in the Context of Cognitive Development and Down Syndrome* by Dr. Peter Johnson

## 3:00 pm—3:15 pm Health Break

## 3:15 pm—4:15 pm

Panel—Moderated by Dr. Daniel Weeks

## 4:15 pm—4:30 am

Closing Remarks

## 4:30 pm —5:30 pm Reception

## 5:30 pm — Dinner

Dinner will be hosted at the Down Syndrome Research Foundation and will provide an opportunity for informal discussion, feedback, and networking.

## SATURDAY May 27th

### 8:00 am—4:30 pm

## 8:00 am—8:45 am Coffee & Continental Breakfast

## 8:45 am—9:00 am Introduction

## 9:00 am—10:00 am

*Complex Developmental and Behavioural Conditions* by Dr. Chris Loock.

## 10:00am—10:45 am

Gap Analysis: Where are the gaps in your region in implementing the guidelines?

## 10:45am—11:00 am Health Break

## 11:00am—11:45 am

Solution and Strategy Identification to Address Gaps (Group Discussions); and Advice to Child Health BC

## 11:45 am—12:00 pm

Wrap Up and Closing Remarks For Next Steps

### INTERPROFESSIONAL:

**Occasions when two or more professions learn with, from, and about each other to improve collaboration and the quality of care.**

*(Centre for the Advancement of Interprofessional Education, 1997)*

## WORKSHOP PRESENTERS

### **Ms. Pauline Bingham**

Pauline is a pediatric physiotherapist working at BC Children's Hospital. She trained in London, England and did two-year pediatric training at Queen Mary's. She then worked as a supervising therapist in a preschool community programme before immigrating to Canada in 1976. Since then she has worked in acute pediatrics at B.C. Children's Hospital and for a time, as a consultant physiotherapist for the Vancouver Infant Development Programme. For the last 12 years she has been conducting a longitudinal study of motor development in Down Syndrome; study population of one (her son Andrew). Pauline sits on the Board of the Down Syndrome Research Foundation and is on its Program and Services Committee.



### **Dr. Mary Connolly**

Mary Connolly, M.B., B.Ch., FRCP(I), FRCP(Ed), FRCP is a Clinical Associate Professor and the Head of the Division of Neurology in the Department of Pediatrics at the University of British Columbia, and the Director of the Epilepsy Surgery Program at BC's Children's Hospital. She graduated in medicine from Trinity College Dublin and trained in internal medicine and pediatrics in Ireland. She trained in pediatric neurology at the University of British Columbia and completed fellowship training in epilepsy and clinical neurophysiology at BC Children's Hospital and Children's Hospital, Boston. Since 1995 she has been Director of the Epilepsy Surgery Program at BC Children's Hospital and since January 2004, is head of the Division of Pediatric Neurology in the Department of Pediatrics at UBC.



Her clinical and academic interest are in the area of video-EEG monitoring, epilepsy surgery in children and the long-term outcome following epilepsy surgery in childhood especially the impact on seizure control, cognitive function and attention. She is interested in the comorbidity of neuropsychiatric illness in children with epilepsy and the area of non-epileptic seizures. She has a particular interest in clinical aspects of frontal lobe epilepsy in children and the associated cognitive, attention and behavioural symptoms and epileptic encephalopathy and the effects of interictal epileptiform activity on cognitive function.

Her current research studies involve comorbidity of psychiatric disorders in children with temporal lobe epilepsy, a prospective study of the influence of anti-epileptic drugs on attention and working memory, and a long term outcome study following epilepsy surgery in children, specifically frontal lobe epilepsy and hemispheric surgery.

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I M P L E M E N T I N G B E S T P R A C T I C E S

## Dr. Walter Duncan

Walter Duncan, M.D., FRCPC graduated from Medicine in Saskatchewan, trained in pediatrics and pediatric cardiology at The Hospital for Sick Children, Toronto, and later practiced in Toronto. He then returned to Saskatchewan for seven years before assuming a division head role in Ottawa for another seven years. He moved to Vancouver in 1998, has been at BC Children's for 8 years and is not moving again! A Clinical Professor in the Department of Pediatrics, his primary interests are in medical education and clinical pediatric cardiology. He is the program director for pediatric cardiology and is involved in undergraduate tutorials annually. His primary clinical interest is in echocardiography. He has published two books, several chapters and over 50 peer reviewed articles.



## Ms. Sue Fawcett

Susan Fawcett, M.Sc. acquired her degree in Speech-Language Pathology from UBC in 2003. She was given research scholarships relating to her thesis on language assessment in young children with autism. After ten years of working with people with developmental disabilities in varying capacities, Susan started at DSRF in July 2003. She is involved in the following programs: individual assessment and therapy sessions, group literacy programs, Summer Chatter Camp and Language Express, consultative services (e.g. through clinic), and involvement with post-secondary program students. She also enjoys accepting speaking engagements to parents and professions. Susan's research interest is on the efficacy of speech-language treatment specific to people with Down syndrome.



## Dr. Robin Friedlander

Robin Friedlander, M.D., FRCPC is a psychiatrist at BC Children's Hospital, Clinical Associate Professor at the University of British Columbia, and the Clinical Director of the West Coast & Fraser Valley Mental Health Support Teams, which provide specialized community based mental health treatment for adolescents and adults with Developmental Disabilities (DD) in the lower mainland of BC. He is also a Board Member of NADD (an association for people with developmental disabilities and mental health needs).

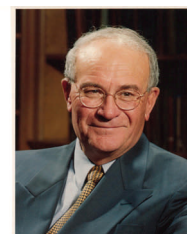


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I M P L E M E N T I N G B E S T P R A C T I C E S

## **Dr. Robert Haslam**

Dr. Haslam is a child neurologist with a special interest in the developmental disabilities. He has held a number of academic appointments including: the Director of the John F. Kennedy Institute and Associate Professor of Pediatrics and Neurology at the Johns Hopkins Hospital School of Medicine (1970-1975); Professor and Chairman of Pediatrics, University of Calgary and Chief of Staff-Medical, Alberta Children's Hospital (1975-1986); and Professor and Chairman, Department of Pediatrics and Professor of Medicine (Neurology), University of Toronto and Pediatrician-in-Chief, Hospital for Sick Children, Toronto (1986-1996). He has had a long standing interest in the medical and social issues relating to Down syndrome.



## **Dr. Jill Houbé**

Jill Houbé, B.A., M.D., M.Phil, PhD(cand), FAAP, FRCP(C) is an Assistant Professor in UBC's Department of Pediatrics, in the Division of Developmental Pediatrics at BC Children's Hospital. Her research is focused on families with infants and children at risk for abnormal growth and development because of circumstances such as preterm birth, birth defects or childhood disease and illness. Her research looks at health care services delivered to high-risk infants and children and their families.



## Dr. Peter Johnson

Peter Johnson, PhD, is a clinical psychologist and a graduate from the University of Calgary. He continues to lecture at the university and his interest and expertise is in children with developmental delay. He provides services out of the Rainbow Clinic, a cooperatively operated private psychology clinic in Surrey, for people who have experienced trauma in accidents, assaults, torture and natural disasters. He also works with teens and adults who have disabling conditions and/or sexual problems. He is the author of resources on sex education that available through the Down Syndrome Research Foundation (*Who Can I Touch, 2000* and *Good Touching and Bad Touching, 1998*).

## Dr. Christine Loock

Chris Loock, MD, FRCP(C), DAAP, is an Associate Professor in the Division of Developmental Pediatrics. Her teaching focus has been on curriculum development and student-centered learning. She received her MD from Harvard and did her pediatrics training at the University of Washington and at UBC. She was Chief Resident here and subsequently did a fellowship in medical genetics and birth defects research. She is a Developmental Pediatrician working at both Sunny Hill Health Centre and Children's & Women's Health Centre of BC. Her research and clinical work has focused on the effects of prenatal alcohol and other drugs. She is a Board member of the Canadian Centre on Substance Abuse and also a member of Health Canada's National Advisory Committee on FAS.



## Dr. Daniel Metzger

Dan Metzger, MD, FAAP, FRCPC, is a Clinical Associate Professor of Pediatrics at the University of British Columbia and a Pediatric Endocrinologist in the Endocrinology & Diabetes Unit at BC Children's Hospital. He serves as the Medical Director of the Canadian Diabetes Association's camp for children with diabetes in BC. His research primarily involves the development, prevention and treatment of Type 1 (insulin-dependent or juvenile-onset) diabetes. He is an investigator in several multicenter clinical trials involving preventing Type 1 diabetes. In addition, he collaborates with basic-science researchers from the BC Research Institute for Children's and Women's Health.



### **Mrs. Josephine Mills**

Josephine Mills, Executive Director of the Down Syndrome Research Foundation, has a background as a health professional and administrator. Over the last twenty years, Jo has played a leading role assisting families to start local and national parent groups. As a concerned professional, she helped start the Canadian Down Syndrome Society, and Down Syndrome International—both of which she was the founding chair. In 1995 Jo founded the Down Syndrome Research Foundation & Resource Centre with the help of concerned parents and business professionals in BC.

Jo has been honoured with a 2001 Chancellor’s Distinguished Service Award from Simon Fraser University, and in April 2006 Canada’s Governor General Right Honorable Michelle Jean presented her with Canada’s Meritorious Service Award in April 2006. The Governor General presents Meritorious Service Awards on behalf of all Canadians to recognize those who have demonstrated “excellence, courage or exceptional dedication to service in ways that bring special credit to the country”.



### **Dr. Robert Peterson**

Robert Peterson, MD PhD, MPH received a M.D. degree and a Ph.D in Pharmacology from Yale University in 1974, having completed the National Institutes of Public Health sponsored Medical Scientist Training Program at that university. He was a resident in pediatrics at the Yale-New Haven Hospital until 1976 at which time he became a postdoctoral fellow in Clinical Pharmacology and Neonatology at the University of Colorado.

Dr. Peterson subsequently joined the Department of Pediatrics at the University of Colorado as Assistant Professor, where he was Director of the Section of Pediatric Clinical Pharmacology. In 1983, he joined the Departments of Pediatrics and Pharmacology at the University of Ottawa, Faculty of Medicine as Associate Professor and Medical Director of the Ontario Provincial Poison Information Centre at the Children’s Hospital of Eastern Ontario. In 1987 he became Director of the Children’s Hospital Research Institute. He became Professor of Pediatrics and Pharmacology in 1989, and in 1990, Chairman of the Department of Pediatrics and Pediatrician-in-chief. He has authored numerous papers/chapters in pediatric clinical pharmacology/toxicology.

Dr. Peterson completed a Master’s of Public Health in the Department of Health Policy and Health Care Management at Harvard University School of Public Health in 1996. He joined the Therapeutic Products Program, Health Canada as Associate Director General in January 1999 and in July 2000, became the Director General of the Therapeutic Products Directorate. He left this post in March, 2005 to become Clinical Professor of Pediatrics at the University of British Columbia and Director of Child Health BC.



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I M P L E M E N T I N G B E S T P R A C T I C E S

## Dr. David Wensley

David Wensley, MBBS, FRCP, has spent time working in the West Indies while studying as a Medical Student in London, England. He trained in Paediatrics in Vancouver, and Critical Care and Respiratory Medicine in the UK and Australia and has worked in China, South Africa, the Middle East and Uganda in various capacities. While in South Africa he facilitated the design and acquisition of the information technology required for delivery of a distance education course for Maternal and Child Health to rural Health Workers. He is currently a Clinical Professor of Paediatrics and staff physician in Critical Care and Respiratory Medicine at BC's Children's Hospital.



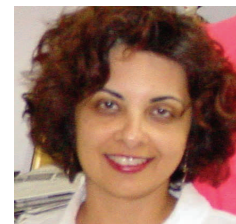
## Dr. Daniel Weeks

Daniel Weeks, PhD is Associate Professor and Chair of the Department of Psychology at Simon Fraser University. His teaching interests include motor control and learning, engineering psychology, attention and performance, history of psychology. His research interests are in visual attention, perceptual-motor behaviour, stimulus-response translation, cerebral specialization in Down syndrome.



## Dr. Naznin Virji-Babul

Naznin Virji-Babul, P.T., PhD is the Director of Applied and Clinical Research at the Down Syndrome Research Foundation. Her research interests are in perceptual-motor development, postural control and early intervention in Down syndrome. Her current research studies involve a MEG study on the perception of motion in individuals with DS and the development of a dynamic facial expression database to study the perception of emotion in children with and without DS.



## RESOURCE LIST

### MEDICAL AND CLINICAL WEBSITES

Prenatal Testing DS Growth Charts & Head Circumference Charts: [www.growthcharts.com](http://www.growthcharts.com)

Down Syndrome Health Issues: [www.ds-health.com](http://www.ds-health.com)

### NATIONAL ORGANISATIONS:

Canadian Down Syndrome Society: (403) 270-8500 or (800) 883-5608: [www.cdss.ca](http://www.cdss.ca)

Down Syndrome Research Foundation: (604) 444-3773 or (888) 464-3773: [www.dsrf.org](http://www.dsrf.org)

NDSS (US): (212) 460-9330, (800) 221-4602: [www.ndss.org](http://www.ndss.org)

Down Syndrome Association (UK): [www.dsa-uk.com](http://www.dsa-uk.com)

### Child Health BC

*Building Capacity  
For Infant, Child and Youth  
Health Services*

Child Health BC is a network of the province's five geographic health authorities, the Provincial Health Services Authority, Ministry of Health, MCFD, health professionals and care facilities dedicated to excellence in the care of infants, children and youth in British Columbia. A collaborative approach to child health ensures a quality of care beyond what any one agency can provide alone.

Child Health BC believes children should receive the right service at the right time, in the right place, by the right provider.

Through cooperative partnerships; regional subspecialty programs; education and dissemination; research; monitoring quality and performance; and developing standards, protocols and guidelines, Child Health BC is creating an integrated, standardized and accessible system of care available to all children in British Columbia.

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**Special Thanks**

- To all the presenters and participants
- To all those who have contributed their time and effort to this workshop

## **Child Health BC**

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in the care of infants, children, and youth in British Columbia

Room 2H2—4480 Oak Street      Phone: 604.875-2345 ex. 5305  
Vancouver, BC, V6H 3V4      Fax: 604.875-2074

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[www.dsrf.org](http://www.dsrf.org)