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Mind the Gap: Therapeutic Products for the Child

Health Canada (HC) has promoted a step towards safer medicines for children and youth. MICYRN was represented as an invited guest at a workshop organized by the Health Products and Food Branch (HPFB) of Health Canada (November 23-24th, 2010/Ottawa) with Health Canada's Pediatric Expert Advisory Committee (PEAC). The goal was to develop a Letter of Intent in response to the Council of Canadian Academies and the Government of Canada's 9th joint call for assessment topics. The proposed study is entitled, "*Mind the Gap: Therapeutic Products for the Child.*" In keeping with the required format, an overarching question and 4 sub-questions were proposed, as follows:

What does Canada need to do to enhance science and innovation that enables safe and effective use of therapeutic products for the child?

1. **Better Science:** What are the gaps in the body of knowledge for the use of therapeutic products to treat the child?
2. **Improved Processes:** How can Canada organize itself to prioritize, conduct and evaluate studies to address these gaps?
3. **Facilitate Communication and Build Awareness:** How can Canada communicate information about these gaps, and the knowledge obtained through existing and future studies, to the intended audiences?
4. **Action:** How can Canadian governments, and others, act on the information and knowledge obtained, and contribute to the global efforts to protect, promote, and maintain child health?

For this application, the term "child" refers to conception through the young adulthood. HPFB is moving on to the next steps of drafting a full submission which is due Jan 14th, 2011. The submission of this proposal was supported by the Assistant Deputy Minister Meena Ballantyne. Co-sponsorship with the Public Health Agency of Canada and the Canadian Institutes of Health Research is being discussed.

The meeting was chaired by Monica Haas (Pediatric Initiatives, HC). PEAC members include Chair, Robin Walker (IWK, Halifax), Vice-Chair, Noni MacDonald (IWK, Halifax), Stephanie Atkinson (McMaster, Hamilton), Max Coppes (Children's National Medical Center, Washington, DC), Lee Dupuis (Sick Kids, Toronto), Lorella Garofalo (Pfizer-Canada), Gideon Koren (Sick Kids, Toronto), Mary Lye (Childhood Cancer Foundation), Stuart MacLeod (CFRI, Vancouver), Patricia Malloy (Sick Kids, Toronto), Gary Pekeles (Montreal Children's), Laurie Proulx (Canadian Arthritis Patient Alliance), Patricia Rennie (Drugless Therapy-Naturopathy, Toronto), and Ellen Tsai (Queen's, Kingston). Invited guests included Paul Gully (HC), Margaret Moore (HC), Robert Peterson (Drug Safety Evaluation Network, CIHR), John Adams (Canadian PKU), Luis Barretto (Sanofi Pasteur), Marie Adele Davis (Canadian Pediatric Society), Elisabeth Fowler (CIHR), Shinya Ito (Sick Kids, Toronto), Judith Hall (CFRI, Vancouver), Michel Rieder (U Western Ontario), Doug Maynard (CAPHC), Régis Vaillancourt (CHEO, Ottawa), and Anne Junker (MICYRN).

Funding Opportunities

The Canadian Paediatric Society is calling for nominations for a **Young Investigator Award: Accomplishments in Child and Youth Health**. Do you have a colleague whose accomplishments in basic or clinical research in child and youth health should be recognized? Nominate her or him before the deadline of January 17th, 2011 @ <http://www.cps.ca/>

Grand Challenges Canada has posted requests for proposals for their Canadian Rising Stars in Global Health which is a unique call to action for young Canadian scientists to make their contribution to global health. Up to \$20 million Canadian is available for this program. Grand Challenges will accept full proposals for the first competition until March 2011. Please submit queries to info@grandchallenges.ca.

Challenges in the Conduct of Pediatric Clinical Trials

The Summary Report on CHALLENGES in THE CONDUCT OF PEDIATRIC CLINICAL TRIALS IN LOW AND MIDDLE INCOME COUNTRIES has been posted to the websites of MICYRN (Reports) and Star Child Health (www.starchildhealth.org). This meeting was held September 12th, 2010 as a satellite meeting of the Vancouver Star Child Health Summit. This meeting was the third in a series, held for the purpose of discussing the use of standards in pediatric clinical trials in developing countries. Presenters spoke to development of consensus guidelines on critical ethical issues in child health research: Dr. Robert Nelson (Office of Pediatric Therapeutics, US FDA); Dr. Denise Avard, Centre of Genomics & Policy, McGill University); Dr. Gitanjali Batmanabane (WHO, SEARO, New Delhi, India). Four speakers presented case studies relating to their experience with clinical trials in developing country settings (Drs. Goldsmith, Simon Fraser University, Vancouver; Collet, CFRI, Vancouver; Ansermino, CFRI, Vancouver; and Wiens, School of Population and Public Health, Vancouver). Dr. Terry Klassen (Manitoba Institute of Child Health, Winnipeg) spoke to the importance of a carefully planned knowledge translation strategy in seeing that the promising results from clinical research are implemented in the form of practice change that will improve health outcomes.

USA Pediatric Clinical Research Networks: Optimizing Effectiveness

MICYRN was represented at a second annual USA American Academy of Pediatrics sponsored workshop (November 9-10th, 2010/Washington, DC) led by R. "Mort" Wasserman, director of Pediatric Research in Office Settings (PROS). The objectives of the conference series, extending over a three-year period, are to bring network leaders together to identify shared interests and barriers to inter-institutional collaborations; exchange strategies and share best practices to promote network research; explore opportunities for cross-network collaboration; and to link networks to entities within the AAP and partnering organizations. It was no surprise that there are many similar issues north and south of the 49th parallel. See the article: *Pediatric Clinical Research Network: Current Status, Common Challenges, and Potential Solutions* — Pediatrics 126:741-745, 2010.

Mindful of the M in MICYRN

A presentation about MICYRN was made to the Board of Directors of the Association of Professionals of Obstetrics and Gynecology (APOG) (December 2nd, 2010/Toronto), inviting comment to put meaning into the M of MICYRN. "Maternal" with "Infant Child & Youth" acknowledges the influence of events from preconception through pregnancy, on the origins of child (and adult) disease. But motherhood is about more than outcomes of pregnancy. Family planning and pregnancy call into question lifestyle choices and can influence "Makeover" decisions about diet, exercise, smoking, alcohol and addictions. Pregnancy also un-"Masks" susceptibility to disorders including diabetes, and mental health, connective tissue or cardiac disease, which have an impact on individual and family well-being. There was a very favourable discussion about the relationship between APOG and MICYRN, promoted by Drs. Alan Bocking (Chair, APOG; Mt Sinai, Toronto) and Bill Fraser (Ste.Justine, Montreal).

Upcoming Events

ALLERGEN'S sixth annual research conference "Innovation from Cell to Society" will be held at the Westin Bayshore in Vancouver, BC February 6-8, 2011 <http://www.allergen-nce.ca/>

The 2011 Cochrane Canada 9th Annual Symposium - Early Exposure to Cochrane: Accessible, Credible, Practical will be held at the Fairmont Pacific Rim in Vancouver, BC February 16-17, 2011 with the pre-symposium program on February 14-15. <http://ccc-symposium.org/>

Canadian Obesity Network—2nd Annual Symposium— will be held April 28th–May 1, 2011 at the Sheraton Centre in Montreal. www.con-obesitysummit.ca/

Canadian Society of Pharmacology & Therapeutics meeting will be held at the Hilton Hotel in Montreal May 25-27, 2011. <http://www.pharmacologycanada.org/>

Canadian Paediatric Society—88th Annual Conference will be held at the Hilton Hotel in Quebec City June 15-18, 2011. <http://www.cps.ca/>

NeuroDevNet Second Annual Brain Development Conference will be held in Vancouver, BC. June 19-21, 2011 <http://www.neurodevnet.ca>

Network & Consortium Updates



NeuroDevNet awarded \$900,000 over two years for research on child brain disorders in Canada this fall. Researchers from this Network of Centres of Excellence will explore how new medical, genetics, informatics, and video game technologies can help diagnose and treat children with brain disorders, including autism spectrum disorder, cerebral palsy, and fetal alcohol spectrum disorder (FASD). The funds are available through NeuroDevNet's Opportunities Initiative program, which supports research that will improve how researchers and clinicians understand, diagnose, and treat brain development and disease. Nine new research projects will receive up to \$75,000 a year to improve diagnostics and therapeutics for children with autism spectrum disorder, cerebral palsy, and FASD. Researchers will apply cellular and molecular technologies to model brain development of children with cerebral palsy, and will study how autism-related genes function in brain cells. To locate the cause of stroke in newborns, researchers will use new medical technologies. To organize complex genetic data, researchers will conduct informatics analysis. Researchers will also monitor how exercise video games increase fitness and social interaction for teens with cerebral palsy, and measure how computer exercise games and computerized training materials will improve learning, memory, and attention for children with autism spectrum disorder and FASD. In other projects, researchers will characterize genes and models to further understand brain development.

In a very exciting and novel initiative, NeuroDevNet joined forces with GRAND another Networks of Centers of Excellence, (Scientific Director, Kellogg Booth) whose goal is to address complex issues in digital media and transform multidisciplinary research into user-centered solutions applied in a variety of settings including entertainment, healthcare, education, environmental sustainability and public policy. NeuroDevNet researchers awarded under the Opportunities Initiative program include Drs. Alan Peterson (McGill University); Ann-Marie Craig (University of British Columbia); Chris Bertram (University of the Fraser Valley); Brian Christie (University of Victoria); Darcy Fehlings (Holland Bloorview Kids Rehabilitation Hospital); Kimberly Kerns (University of Victoria); Adam Kirton (University of Calgary); Paul Pavlidis (University of British Columbia); Daryl Wilson (Queen's University); and Elizabeth Kelley (Queen's University). GRAND researchers are Drs. Bruce Gooch (University of Victoria); Regan Mandryk (University of Saskatchewan); and T.C. Nicholas Graham (Queen's University). www.neurodevnet.ca

CANADIAN PEDIATRIC GENETIC DISORDERS SEQUENCING CONSORTIUM CONSORTIUM CANADIEN DE SÉQUENÇAGE DES MALADIES GÉNÉTIQUES PÉDIATRIQUES

Genetic disorders of children are individually rare but collectively frequent,

affecting the lives of approximately 500,000 children in Canada. These disorders cause a variety of medical problems including birth defects, intellectual disability, difficulty with growth and organ failure. Most genes that cause these conditions have not yet been found, mainly because gene-discovery studies are difficult to perform when DNA from only a small number of affected children is available. Recently a new technology (called Next Generation Sequencing) has been developed which allows a person's entire genetic code (about 22,000 genes) to be analyzed within a few days at reasonable cost. This new type of DNA sequencing has revolutionized the study of rare genetic diseases because it is now possible to find disease-causing genes using a relatively small number of patients. The Consortium has created a large network of Canadian doctors and scientists who will now have access to this powerful technology for their patients. Through this national collaboration they will be able to rapidly identify many genes responsible for genetic disorders that affect children in this country and throughout the world. The Canadian Pediatric Genetic Disorders Sequencing (CPGDS) Consortium has 150 members and will ensure that Canada becomes a world leader in this exciting field. The Consortium brings together doctors from all genetics centres across Canada, internationally-recognized Canadian scientists with expertise in finding genes, and teams from the three Genome Canada Science and Technology (GC S&T) Innovation Centres (Montreal, Toronto, Vancouver), which have already set up the new sequencing technology. The CPGDS Consortium will:

- 1) Assist doctors to identify patients with rare childhood diseases. Because the Consortium has members from all the medical genetic clinics in our country, for any given disorder they will be able to enroll children and families from across Canada. Therefore, even for very rare conditions, they will be able to find disease-causing genes. So far, over 100 genetic disorders that affect Canadian children have been submitted for study partly through the help in communication provided by MICYRN.
- 2) Sequence the genomes of patients to identify disease-causing genetic changes.
- 3) Set up a national data coordination centre to streamline and improve existing large-scale sequence analysis tools. This will improve the ability to distinguish genetic changes that cause disease from ones that are normal variants contributing to human diversity.
- 4) Create national ethical guidelines for analyzing sequence data from entire genomes and for sharing results with families.

www.cpgdsconsortium.com



**INSTITUTE
OF FAMILIES**
for Child and Youth Mental Health

There has been no formal mechanism to engage families of children and youth with mental health issues to contribute to policies, research, programs and practices related to child and youth mental health in Canada. The Institute of Families (IF) for Child and Youth Mental Health was formed in Vancouver BC in February 2009 in response to this need. The co-founders, Dr. Jana Davidson and Keli Anderson, are modeling the relationship between families and professionals. A first action of the IF took place in May of 2010 when researchers, youth and parents/caregivers were brought together for the day to talk about outcomes that matter to youth and families and to set some research priorities that are important to them. A Research Report from this day will be available in January 2011. The Institute of Families is currently undergoing strategic planning with the goal to be recognized as **the** national organization dedicated to linking families and systems to improve child and youth mental health in Canada. instituteoffamilies@gmail.com.



**Children's Cancer
& Blood Disorders**

The C¹⁷ Council is a non-profit organization composed of the institutionally appointed heads of the 16 pediatric hematology, oncology, and stem cell transplantation programs in 17 institutions across Canada. C¹⁷ acts as a voice representing the interests of Canadian children and adolescents with cancer and serious blood disorders. Our goal is to improve health outcomes and quality of life for children and adolescents with cancer and blood disorders. The past year has seen the organization getting results from the ongoing work of the committees, and to start to grow into several new areas.

The C¹⁷ **Standard & Guidelines Committee**, with guidance and training from CPAC, released its first evidence-based clinical guideline. The C¹⁷ Guideline for **Platelet Transfusion Thresholds for Pediatric Hematology/ Oncology Patients** was adopted and disseminated. It is available on the C¹⁷ website www.c17.ca. The APHON Guideline for **Prevention of Infection in Asplenic Patients** is under consideration for endorsement. Three other guidelines are currently under review for 2010-11. The research network grant competition has now funded 19 research projects across Canada and committed \$2.2 million dollars since 2005. For the period of 2009 – 2011, the total funding into research projects will be \$1.6 million.

Under the leadership of Co-chairs Sylvain Baruchel and Sandra Dunn, the **C17 Developmental Therapeutics (DVL) Committee** was created last year to provide greater access across Canada to Phase I trials; allowing children and their families to stay closer to home. There are eight C17 centres participating, providing access across Canada for 80% of the children eligible for these studies. The sites are: BC Children's (Vancouver), AB Children's (Calgary), Stollery Hospital (Edmonton), CancerCare (Winnipeg), Hospital for Sick Children (Toronto), Children's Hospital of Eastern Ontario (Ottawa), Ste. Justine (Montreal) and IWK (Halifax). The C17 DVL Committee has a partnership with NCIC CTG, and the first study opened in September 2010, and has enrolled 4 patients. Two additional studies with pharmaceutical companies are in development. The C17 DVL Committee is also in the process of bridging the gap from bench to bedside with the development of a preclinical program, linking researchers across the country to work together to bring evidence from the lab into clinical studies.

The **"Workshop on Adolescents and Young Adults with Cancer, Towards Better Outcomes in Canada"** was held March 11-13, 2010 in Toronto, Ontario. Sponsored by Canadian Partnership Against Cancer and C17 it brought together 100 Canadian and international stakeholders to discuss critical issues relating to the development of a national AYA plan; 25% of attendees were survivors or family of survivors. The Task Force's goal is to improve outcomes and health-related quality of life for AYA with cancer and AYA survivors of cancer in childhood by developing a list of recommendations for their care and strategies for implementation and identifying research priorities for these groups. Conference proceedings will be published in the journal *Cancer* in 2011.

Cancer in Young People in Canada (CYP-C) - Cancer Chez Les Jeunes aux Canada (CCJC) was originally the Canadian Childhood Cancer Surveillance and Control Program (CCSCP). The program objectives of the CCSCP, launched in 1992, were to fill gaps in knowledge from cancer registries and clinical trials and to evaluate cancer control across its entire continuum. CYP-C continues work on a national, population based, cancer surveillance system for children and youth, by establishing a database that can be used by researchers to examine patterns of incidence, health care utilization, treatment and outcomes. Data collection forms are developed and translated into an electronic system, constructed by Dapasoft, Inc. Each pediatric oncology centre collects their own data, and transfers anonymized information to the national database administered by the Public Health Agency of Canada. The electronic system has been installed at five out of 11 centres, and data is being collected on paper forms at the others. The first phase of the project, retrospective data collection for children under the age of 15, who were diagnosed between 2001 and 2008, is well underway.

BIOBANKING

The Research Centre for Women's and Infants' Health (RCWIH) at Mount Sinai Hospital in Toronto, has established a biorepository and has made available their Standard Operating Procedures (SOP). The SOP can be accessed by going to the Specimen Archive page of the BioBank's website (<http://biobank.lunenfeld.ca/?page=Specimen%20Archive>) and selecting one of two links – either the last item under the Content list on the left side of the screen, or the link within the section titled 'Overview of collection services'. The SOPs and a link to the biobank have been posted on the MICYRN website at Resources/ Biobanking.



Research Centre for Women's and Infants' Health (RCWIH) BioBank
<http://biobank.lunenfeld.ca>

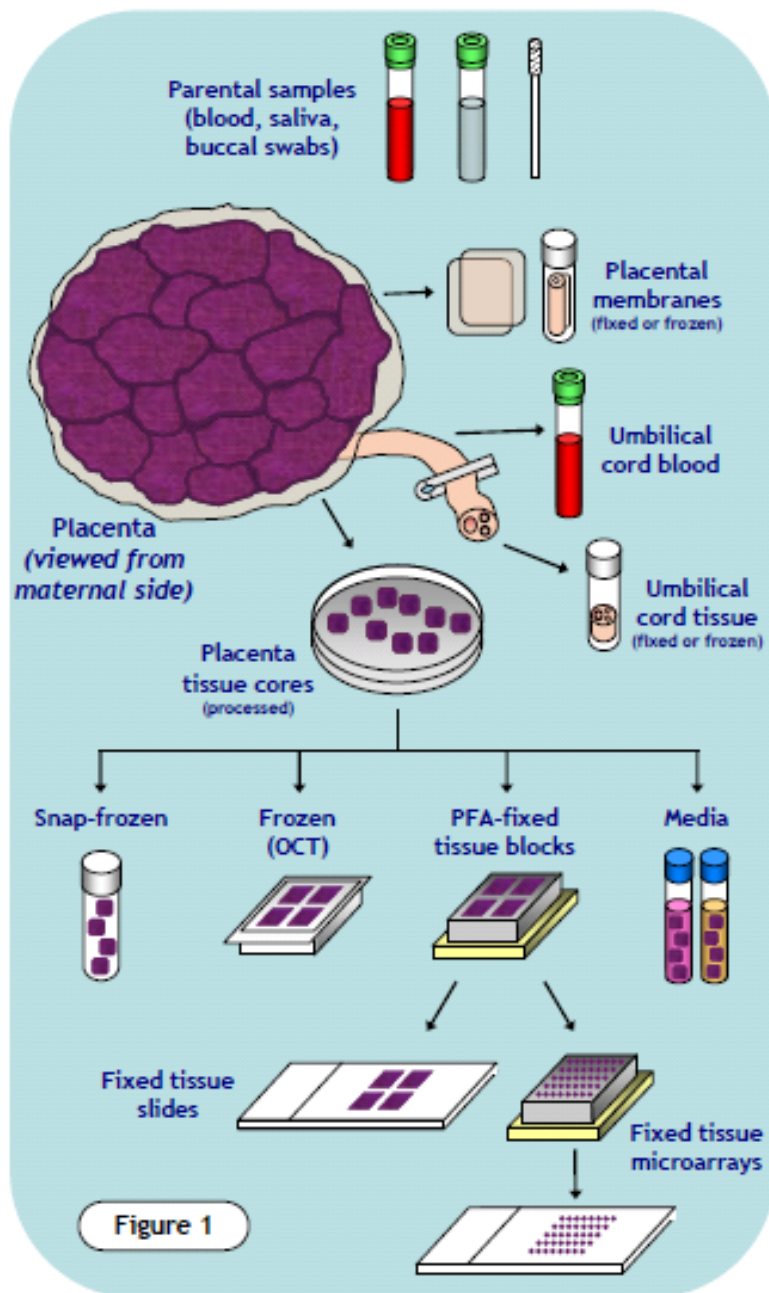


Figure 1

Who we are

The RCWIH BioBank of Mount Sinai Hospital* is a biorepository established to support perinatal research programs and provide access to normal and pathological tissue specimens and associated clinical data.

The RCWIH BioBank program operates on a fee-for-service (cost recovery) basis, with full ethics approval from the Mount Sinai Hospital Research Ethics Board, and all program activities are overseen by the RCWIH BioBank Governance Committee.

Specimens available

RCWIH BioBank staff are dedicated to the procurement, processing and archival of specimens for a wide range of applications in perinatal research (Figure 1). Samples are available in a variety of formats including:

- Fresh
- Frozen: snap-frozen, or embedded in Optimal Cutting Temperature medium (for cryosections)
- Fixed: paraformaldehyde (standard), or formalin (upon request)

For more information please contact:

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* A program of the Samuel Lunenfeld Research Institute and the Mount Sinai Hospital/University Health Network Department of Obstetrics & Gynaecology

Announcements

Child Health Co-ordinator, Terry Klassen, named to USA Institute of Medicine

The founding director of MICYRN, Dr Klassen, along with 64 others, was elected into the Institute of Medicine (IOM) on 11 October 2010 for his demonstrated outstanding professional achievement and commitment to service. Election into the IOM is considered one of the highest honours in the field of health and medicine. Dr Klassen, along with being Coordinator of the Cochrane Child Health Field, is director of the Manitoba Institute of Child Health and professor in the Department of Pediatrics at the University of Manitoba and the Winnipeg Children's Hospital. Visit the IOM website for the election announcement @ <http://www.iom.edu/Global/News%20Announcements/2010-New-Members.aspx>

News about MICYRN Partners

The Canadian Child & Youth Health Coalition

(CCYHC) welcomed Dr. Sarah Jones (Head of Pediatrics at Queens University) as the new co-chair. MICYRN shares membership in the CCYHC with 10 other national organizations. Dr. Anne Junker (Director, MICYRN) sits on the CCYHC executive. <http://www.ccyhc.org/>

CAPHC Archives—Annual Conference

Presentations are now on the CAPHC Annual Conference website at www.conference.caphc.org. Specifically, there is an 'Archive' section where all resources for previous conferences are posted.

CAPHC Knowledge Exchange Network—This is a wiki style knowledge exchange website for professionals, parents, and families looking to find and offer information about healthcare and health services for children and youth. Webinars, powerpoint presentations and other references are posted in subject categories. This is a growing resource @ <http://www.ken.caphc.org>

The Sandbox Project was launched December 2nd, 2010 as a new organization founded by Dr. Kellie Leitch (Pediatric Orthopedic Surgery, Toronto Sick Kids) to respond to findings from her report "Reaching for the Top" which was conducted on behalf of the Government of Canada in 2007/2008. The report can be found at <http://www.hc-sc.gc.ca>. The Sandbox Project aims to foster collaboration among leading Canadian experts, translating knowledge through the development of interactive tools, social media and best practices by building partnerships between parents, academic leaders, industry, and governments to make Canada the healthiest place on earth for children and youth to grow up. The goal is to make measurable progress against international health indicators within the next five years, with a specific focus on improving health outcomes with respect to children's mental health, healthy weights, injury prevention, and the environment. <http://sandboxproject.ca>

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*Building capacity for high quality clinical
research in Canada and beyond*

The Maternal Infant Child Youth Research Network (MICYRN) was formed in 2006 to build capacity for high quality clinical research in Canada and beyond. MICYRN links 17 participating academic health centers, and hundreds of investigation teams across the country.

MICYRN is committed to enhancing the productivity of the Canadian child-maternal research community, through sustaining and augmenting existing activities, and reducing impediments to multicentre research activity.

maternal infant
child & youth
research network



réseau de recherche
en santé des
enfants et des mères