

### **Strategic Grants**

#### ***Canadian Child Health Clinician Scientist Program, Dr. Norman Rosenblum, The Hospital for Sick Children, 1.8 million over 6 years starting in 2007-08***

The Foundation is pleased to renew funding for the Canadian Child Health Clinician Scientist Program for another six years. In 2000-01, the Foundation approved a six year grant in the amount of \$1.8 million (\$300,000/year) towards the CCHCSP. The CCHCSP is a Canada-wide child and youth health research clinician-scientist development program, based in part on training models developed at SickKids. The program is founded on the principle that a transformation of child and youth health research is dependent on the participation of the breadth of disciplines involved in the care of children and youth; that career scientists with expertise in these disciplines will be well-positioned to identify critical gaps in child and youth health; that cross-talk between scientific disciplines among researchers with diverse clinical expertise is needed to advance child and youth health research; and that we must enhance the capacity for paediatric research in all geographic regions of Canada. Research training is supervised by a research mentor and advisory committee and structured to facilitate excellence in research with an interdisciplinary focus. Four types of awards are offered: Predoctoral, Postdoctoral, Career Development, and Rising Researcher Support Program Awards

### **New Investigator Awards**

All New Investigator Awards are peer reviewed by three external reviewers and two committee reviewers, and competitively rated. Below are the 15 New Investigator grants funded this past year.

#### ***Role of Osteopontin in Inflammatory Colitis, Dr. Ron Zohar, University of Toronto, \$115,796 over two years.***

Osteopontin (OPN) is a pro-inflammatory cytokine required for cell mediated immune response and wound healing. OPN is required for the mucosal protection in inflammatory bowel diseases and successful restoration of the mucosal barrier. The main objectives of this study are to determine the functional significance of OPN in inflammatory colitis using mice that does not express OPN, and to examine if purified milk OPN administered orally or injected can improve resistance to inflammatory colitis. Expected outcomes of this research are that administration of purified milk OPN should improve the immune response as well as healing.

#### ***Functional Genomic Dissection of the Initiation and Progression of Medulloblastoma, Dr. Michael Taylor, SickKids Hospital, \$130, 000 over two years.***

Brain tumours are the most common solid malignency seen in childhood, and medulloblastoma is the most common malignant paediatric brain tumour. Current treatment protocols are inadequate as five year survivals are less than 70%, and survivors are left with considerable cognitive and neurological deficits. Progress on more effective therapies is hampered by lack of knowledge about the molecular pathogenesis of the disease. The research team plans to identify a collection of genes that are important in either the prevention of differentiation, or in promoting the transformation of cerebellar EGL cells. This gene set will need to be evaluated to determine its role in human

medulloblastoma, and individual gene set members considered as possible targets for future rational therapies.

***Improvement of ICU Therapeutics during Mechanical Ventilation, Dr. George Hatzakis, Hôpital Sainte-Justine Centre de Recherche, \$120,060 over two years***

Thousands of Canadian children are mechanically ventilated every year in the Pediatric Intensive Care Unit (PICU). Pilot studies suggest that 20% of these children fail to be detached from the ventilator and have to be re-intubated, thus impacting their overall health status. The objective of this study is to identify optimal patient treatment in the PICU leading to a rationale regarding strategies on mechanical ventilation (MV). Continuous patient monitoring in the PICU generates clinical information which, if properly assessed, could identify patient progression and concomitantly indicate optimal timing and critical pathways when clinical intervention would be mostly favored. The investigator will explore the diagnostic value of vital signs to predict hard epidemiological outcomes and inflection points prompting to optimization and standardization of clinical practice.

***Early Detection of Brain Injury by Measuring Cerebral Oxygen, Dr. Keith St. Lawrence, Lawson Health Research Institute, \$126,635, over two years***

Despite improvements in intensive care practices, the incidence of brain injury amongst survivors of neonatal intensive care remains high. Fortunately the damage caused by suffocation can be reduced if treatment is applied within the first few hours of life. To predict newborns at risk of developing brain injury and to monitor treatment effectiveness will require a technology capable of measuring brain function in the neonatal intensive care unit. Light-based technologies are receiving considerable attention for this purpose. Early diagnosis will permit prompt medical intervention. This project represents the beginning stages of developing an optical method aimed at improving the early detection of brain injury in newborns. It is expected that the experience gained in this project will help spearhead the development of a similar system for use in neonatal intensive care units.

***A Cognitive Intervention for Children with Asperger's Syndrome: A Pilot RCT***

**Dr. Angela Mandich, The University of Western Ontario, \$112,493, over two years**  
Asperger's Syndrome (AS) is a developmental disorder that affects approximately 3-4% of the childhood population. A large number of children with AS are treated by occupational therapists using sensory-motor-based treatment (SMT) approaches. There is little evidence of the effectiveness of these on performance. Three single case experimental design studies indicated that CO-OP, a cognitive, performance-focused treatment approach, has the potential to improve the performance of children with AS. Children with AS, receiving CO-OP, will have significantly better functional outcomes than those receiving SMT. The objectives of this study is to determine if there is evidence for better functional outcomes from CO-OP than SMT for children with AS. It is anticipated that the pilot will support the further investigation of CO-OP for children with AS.

***Investigation of Placental Insufficiencies Caused by Caspase 8 Disruption, Dr. Andrea Jurisicova, Mount Sinai Hospital, 130, over two years***

Successful pregnancy depends upon a coordinated series of developmental events in both the embryo and the placenta. Proper establishment of the placenta during the early developmental stages allows the fetus to grow and attain its developmental potential in the third trimester, in preparation for postnatal life. A compromised intrauterine environment - resulting from either decreased maternal nutrition, reduced uteroplacental perfusion or defects in trophoblast differentiation - can have long-term consequences that extend beyond fetal life. The objective of this project is to establish the importance of cell death during placental development and to elucidate the sequence of molecular events that regulate this process. The focus of this application is to establish whether aberrant caspase-8 activity in placental tissue contributes to abnormalities in fetal growth and development.

***Mechanistic Analysis of the Oncoenic Role of EAR-2 in Leukaemia, Dr. Richard Wells, Sunnybrook and Women's College Research Institute, \$130,000 over two years***

Acute leukaemia is the most prevalent type of childhood cancer. It has recently been shown that the growth and spread of many types of cancers, including acute leukaemia, depend upon a specific type of cell known as the cancer stem cell. These cells make up only a small proportion of the cells in a tumour, the bulk of the tumour being composed of cells capable of limited or no growth. Since the cancer stem cells are the cells driving the growth and spread of cancer, successful treatment depends upon the eradication of the cancer stem cells. The Principal Investigator discovered that EAR-2 is turned down when leukaemia cells stop growing and undergo differentiation, changes that are hallmarks of loss of 'stem-ness'. The expected results is an understanding of the genes that control the growth and differentiation of the cancer stem cell will lead to the development of novel therapeutics that target specifically those cells responsible for the maintenance of the disease. This project will form the basis for exploring EAR-2 as a novel therapeutic target for the differentiation therapy of acute leukaemia.

***Examination of the Respiratory Coronaviruses Group-specific Genes, Dr. Brian Lichty, McMaster University, \$130,000 over two years***

Respiratory coronaviruses can cause serious infections in young children and neonates. These viruses are responsible for bronchiolitis, pneumonia and lower respiratory tract infections leading to hospitalization. These viruses have not been studied in great detail and each express a series of genes whose functions are currently unknown. The objective of this study is to survey these group-specific genes for functions related to the innate immune response. The hypothesis is that virtually all viruses have evolved mechanisms to impair the innate antiviral response exemplified by the interferon system. The expected outcome of this study is that these analyses should enable the identification of genes expressed by these viruses that manipulate the anti-viral response of the infected cell. The identification of these genes will allow will provide a potential therapeutic target for future interventions in coronaviral infections.

***Role of Innate Immunity and Toll-Like Receptor Signalling in Protecting Children from Severe Pneumococcal Infections, Dr. Stuary Turvey, British Columbia's Children's Hospital, \$127,000 over two years***

Infectious diseases are a major public health issue and rank among the top five causes of illness and hospitalization in children. These diseases have enormous impact on the health and well-being of children and their families, and have costs associated with physician visits, hospitalization, prescription medication, loss of productivity, and antibiotic resistance. As such, it is crucial to improve diagnosis and treatment of infectious disease in children, including those who are at very high risk for adverse health outcomes. Pneumococcus is the leading cause of invasive bacterial infections in children and one of the key targets of Canada's new national immunization strategy. It is anticipated that the results from this project will help to improve diagnosis, management and eventually treatment of this prevalent infectious disease.

***Regulation of the Germinal Centre Response by TNF Family Members, Dr. Jennifer Gommerman, University of Toronto, 130, over two years***

In children, leukemia, neuroblastoma and lymphoma are the 3 main causes of cancer mortality. The majority of human B-cell lymphomas arise during immune responses within the germinal center (GC). The objective of this project is to uncover how the molecular events that drive the GC reaction are regulated. This information will allow for the identification of potential therapeutic targets for treating childhood lymphoma. The expected results is that by dissecting the role for these molecules, they can determine if they will be effective targets for treatment of childhood lymphoma.

***Predictors for Diagnostically Accurate Ultrasound in Children with Suspected Appendicitis, Dr. Andrea Doria, The Hospital for Sick Children, \$128,783 over two years***

Appendicitis is the most common cause of abdominal surgery in children. Its diagnosis is challenging because clinical examinations and laboratory findings do not reliably exclude this disease. Ultrasound (US) constitutes the initial imaging tool for assessment of appendicitis in children. However, it can be inconclusive or inaccurate which may delay the diagnosis and result in second imaging, prolonged Emergency Department (ED) stays or lead to unnecessary surgery. The objectives of this project is to identify clinical-laboratory-operational parameters that are able to predict whether US will be inaccurate, which may help clinicians decide which children should not have US and should have other tests instead. The results of this study may help identify children that are not suited for US which may increase the accuracy of this test.

***SBDS in Granulopoiesis, Dr. Yigal Dror, The Hospital for Sick Children, \$128,960 over two years***

Shwachman-Diamond syndrome (SDS) is a genetic disease with low blood counts because of non-functional bone marrow and diarrhea caused by a non-functional pancreas. Mutations in the newly discovered gene, SBDS, are the cause of the disease. The function of the SBDS gene are unknown. As an inherited disorder with high risk of marrow failure and leukemia, SDS is very important for understanding how genetic defects cause low blood counts and cancer. During normal white blood cell development cell numbers increase. However, patient cells, which are deficient in the SBDS protein, are reduced and are characterized by increased cell death. This project will help to understand the cellular role of SBDS and how it functions. The ultimate goal of this study is the correction of the blood problems of SDS patients by providing more effective treatment with fewer side effects. It is anticipated that studying SDS will also have therapeutic potential for other inherited and acquired disease of bone marrow failure and cancer.

***Correcting Purine Nucleoside Phosphorylase (PNP) Deficiency Using Lenti-Virus Mediated Human PNP Gene Delivery Into Hematopoietic Stem Cells, Dr. Eyal Grunebaum, The Hospital for Sick Children, \$130,000 over two years***

Abnormalities in the purine nucleoside phosphorylase (PNP) gene result in a severe metabolic and immune deficiency. Currently, treatment for most patients is only supportive and they often die in the first decade of life from infections or malignancy. Introducing a normal gene into the patients' cells may correct the metabolic and immune defects, as demonstrated recently in similar diseases. Immune reconstitution will be evaluated by improvement in thymocytes numbers and function of peripheral lymphocytes. Within 4 weeks after the injection of these cells into PNP-deficient mice, it is anticipated that lymphocytes will express human PNP and that the abnormal purine metabolism will be corrected. Six- eight weeks later, immune reconstitution should be evident.

***The Critical Illness Impact Scale for Young Children, Dr. Janet Rennick, McGill University Health Centre Research Institute, \$128, 145 over two years***

Research demonstrates that children requiring paediatric intensive care unit (PICU) hospitalization may go on to develop negative psychological sequelae. Younger children, and those exposed to high numbers of invasive procedures appear to be at particular risk. Dr. Rennick and colleagues recently developed the Children's Critical Illness Impact Scale (CCIIS). While the CCIIS works well with children aged 9 to 12 years, a completely different method of post-PICU psychological distress is needed for younger children. This multi-site study will develop and test a developmentally appropriate pictorial measure of psychological distress for children aged 6 to 8 years post-PICU hospitalization. The outcome if this study will be a valid and reliable pictorial measure of post-PICU psychological distress for children aged 6 to 8 years will be developed and tested, results disseminated, and strategies identified for integration into clinical practice, and future research.

***Brain Growth and Development in the Fetus with Congenital Heart Disease, Dr. Catherine Limperopoulos, McGill University, \$129,970 over two years***

Congenital heart lesions are among the most common birth defects affecting almost one in every 100 newborns. Recent medical and surgical advances have greatly enhanced the survival of children with congenital heart defects (CHD). However, brain injury and resulting developmental disabilities in children with CHD are a serious and common problem. It remains largely unknown whether brain injury in this population is present before birth. This prospective cohort study will evaluate brain development in fetuses diagnosed with a CHD in-utero as compared to healthy fetuses of similar gestational age. This study will provide a first look into the potential causes of antenatal brain injury in fetuses with CHD. The goal is to better understand what impact CHD has on the developing fetus. The ultimate long-term objective is to develop the capacity to identify fetuses with CHD at risk for impaired brain growth to guide further innovation and development of fetal cardiac interventions.

## **Complementary and Alternative Health Care and Paediatrics**

### ***2nd Annual IN-CAM Research Symposium - CAM Research in Canada: Sharing Successes and Challenges, Dr. Heather Boon, University of Toronto, \$3,250***

Interdisciplinary Network for Complimentary and Alternative Medicine (IN-CAM) is committed to facilitating, supporting and creating high-quality, interdisciplinary, collaborative Complimentary and Alternative Medicine (CAM) research and increasing CAM research capacity, specifically in the areas of emphasis on knowledge transfer. Integral to IN-CAM's strategic plan is the hosting of an annual symposium. Annual face-to-face networking meetings are essential to present emerging ideas and research results, foster new collaborations, and strengthen existing partnerships, thus ensuring a viable research program.

### ***North American Research Conference on Complementary and Integrative Medicine, Dr. Sunita Vohra, University of Alberta, \$20,000***

This conference represents the first joint research meeting of all leading Canadian Complementary and Alternative Medicine (CAM) research networks, including Pediatric Complementary and Alternative Medicine (PedCAM), the Natural Health Products Research Society (NHPRS), and the Canadian Interdisciplinary Network for Complementary and Alternative Medicine Research (IN-CAM). The conference will showcase by way of keynote and plenary presentations, oral and poster presentations and integrative scientific sessions, original scientific CAM research in several key areas including paediatrics.

### ***Research Cross-Training Award, Dr. David Brule, HD, Riverdale Homeopathy, \$9,022 over two years***

Dr. Brule is interested in building interdisciplinary teams, and he recognizes the need for joint expertise. He received cross-training funding to study under Dr. Sunita Vohra and her colleagues at the Stollery Children's Hospital to gain a better understanding of research methodology. Dr. Brule's practice is in paediatrics and his future interest in research is determining the efficacy of homeopathy in the paediatric field.

### ***Complementary and Alternative Health Care and Paediatrics Masters Award, Mr. Jean-Jacques Dugoua, ND, University of Toronto, \$5,000 over two years***

Dr. Dugoua will attend a graduate course in Clinical Pharmacology. This current project will contribute to the scientific knowledge of natural health products (NHPs) in pregnancy and lactation. There is a well-defined knowledge gap between what is known on the safety of NHPs and what is needed to educate pregnant women and clinicians as to NHP usage during pregnancy.

### ***Complementary and Alternative Health Care and Paediatrics Masters Award, Simerpal Gill, University of Western Ontario, \$5,000 over one year***

Ms. Gill's Field of Study is in Clinical Pharmacology and Toxicology. She will study the in vitro effects of polysaccharide extracts obtained from ganoderma lucidum polysaccharides (GLPS). The goal of her study is to help elucidate the potential for GLPS as an adjunctive to paediatric oncology patients undergoing chemotherapy.

***Complementary and Alternative Health Care and Paediatrics Masters Award,  
Dr. Dugald Seely, University of Toronto, \$5,000 over two years***

Dr. Seely will be working on a pilot study to determine the potential for drug interactions between natural health products (NHPs) and chemotherapy in a paediatric oncology population. Evidence has clearly demonstrated that children with cancer are using natural health products for a variety of reasons. It is critical to learn more about the safety of these therapies. It is important to research how they may interact with conventional treatment, and also to explore their potential efficacy.

***Complementary and Alternative Health Care and Paediatrics Masters Award,  
Ms. Larissa Shamseer, University of Alberta, \$5,000 over two years***

Ms. Shamseer's project will include an evaluation of the efficacy of exogenous antioxidant vitamins in the treatment of inflammation associated with Cystic Fibrosis-related lung disease. If such treatment proves effective, antioxidant supplementation may contribute to increased quality of life, increased pulmonary function, and decreased hospitalization and antibiotic administration for the Cystic Fibrosis population.

***Transpersonal Group Work with Children, Building Self-Esteem and Transforming Self-Awareness: Investigating Spiritually-Influenced Helping, Dr. Diana Coholic, Laurentian University, \$98,709 over two years***

Although greater attention is being directed towards spiritually-influenced and holistic practice approaches in helping professions such as social work and psychology, the knowledge development in this field is emergent. In particular, little is known about the helpfulness of these approaches in psychotherapeutic work with children. The aim of this project is to assist children to develop their self-awareness, self-esteem and resilience - factors which contribute to a more healthy developmental process. It is anticipated that the research results will have influence on the development of programs and services in agencies that work with children.

***Docosahexaenoic Acid (DHA) for Very Premature Infants, Dr Sylvie Dodin, Université Laval, Saint-François d'Assise Hospital - CHUQ, \$118,622 over two years***

Very premature infants are vulnerable to deficiency of omega-3 fatty acids, particularly docosahexaenoic acid (DHA). A pilot trial will be conducted to assess the feasibility of DHA supplementation to breast-feeding mothers of very premature infants. It is expected that DHA supplementation of the mother will increase DHA in breast-milk and, compared to placebo, will better optimize DHA levels in the very premature infant. Consequently, more DHA will be available to meet the high DHA needs for the brain development. If so, a main trial will be planned to determine whether a higher DHA level of breast-fed very immature premature infants within the first weeks of life has a beneficial effect on neuro-developmental outcomes.

***Therapeutic Touch for Management of Procedural Pain in Preterm Neonates less than 28 Weeks Gestational Age, Dr. Celeste Johnston, McGill University , \$85,509 over two years***

Decreasing pain from necessary procedures in very premature babies is especially challenging because the treatments typically used for pain can be harmful to these tiny babies. Therapeutic touch is a non-invasive method used in other populations to calm and comfort. The intention of this study is to determine if Therapeutic Touch can decrease pain and recovery time from routine heel stick in very premature babies. The expected results will be that babies receiving Therapeutic Touch will have less pain response and will recover faster than those who do not. If effective, future research could include teaching parents how to do Therapeutic Touch.

***Natural Health Products Protect the Newborn from Brain Injury, Dr. Jerome Y. Yager, University of Alberta, \$130,345 over two years***

Brain injury occurring before or during delivery can result in a broad range of developmental disabilities with long term consequences for children and their families. This happens when the fetus is not getting proper nutrition from the placenta and/or there is a lack of oxygen. The use of complementary and alternative medicines (CAM) to prevent injury to the fetus and newborn offers an exciting approach to this important health issue. The investigators have already obtained preliminary results suggesting that the use of broccoli sprouts and/or vitamins and minerals may prevent this injury. The beneficial effect of folic acid supplementation to prevent spina bifida is an example of the success that CAM can have in preventing disorders that can occur during fetal life and the immediate perinatal period.

### **Children and Youth HomeCare Network:**

The Foundation invests \$400,000 a year in the Children and Youth Home Care Network (CYHN). The goal of the Network is to promote best practices through research and knowledge translation and to ensure that children and their families' needs are reflected in policies affecting home and community care. Foundation funded home care initiatives include sustaining a network of diverse stakeholders interested in home care by convening meetings, distributing a bi-monthly newsletter, and brokering new relationships; masters, doctoral and post-doctoral awards to build capacity in this area; an about-to-be-launched prize for Paediatric Home Care Innovation; and, in partnership with other organizations, advocacy for changes within provincial home care systems. A central part of this initiative is a yearly research grant competition. Two research applications, described below, were approved by the GAC. The Grants Advisory Committee subsequently approved masters award, one doctoral and one post-doctoral award

#### ***Development of a New, Functional Speech and Language Outcome Measure for Preschool Children in their Community***

**Professor Nancy Thomas-Stonell**

**Department of Rehabilitation, University of Toronto, \$130,000 over two years**

Over the past 10 years, health care paradigms in rehabilitation have shifted from a focus on impairment to a focus on activity and participation. Outcome measures need to reflect the broader community-based focus of today's health care. There are currently no measures that link speech and language treatment to the child's ability to participate in their world. The research team's objectives are to develop a new outcome measure that will quantify changes associated with speech and language treatment provided in the child's home and community; and to pilot-test and evaluate the reliability of the new measure prior to validation testing.

#### ***Careful Transitions: Developing an Integrated Service Delivery Model for Paediatric Palliative Care (Kid-HPCNet)***

**Dr. Beverly Antle**

**Department of Social Work, SickKids Hospital, \$129,900 over two years**

When a child is dying the emotional impact is profound. The vulnerability of children, the sense that children should have a long life and the desire to protect children from suffering all contribute to the emotionally-charged nature of care for children with life-threatening conditions. In spite of these strong motivators to ensure excellent care at end of life, parents and professionals continue to articulate that children who are dying get lost in the system. The primary goal of this study is to test the feasibility of an integrated and co-ordinated service delivery model in paediatric palliative care that will facilitate seamless care, 24/7, in preparation for future Canadian clinical trials.

**Ms. Tanja Anick Des Rosiers-Fuchs – Masters Award**

**Approved for funding: \$5,000 over one year**

Ms. Des Rosiers-Fuchs is currently enrolled in the Master of Science Program at The University of British Columbia's Faculty of Medicine, School of Rehabilitation Sciences. Her supervisors are Dr. Susan R. Harris and Dr. Catherine L. Backman, both of whom work in the area of

identifying and treating infant neuromotor delays. Ms. Des Rosiers-Fuchs' primary area of study will be gross motor development in infants and whether it is the same across cultures.

**Ms. Sandra Thompson – Doctoral Fellowship**

**Approved for funding: \$20,000/year over 3 years**

Ms. Thompson is currently enrolled in the doctoral program at the University of Alberta's Faculty of Rehabilitation Medicine. Her studies focus on the effectiveness of home and community-based interventions that target sensory processing issues for children with autism. Ms. Thompson aims to systematically examine how community-based interventions that involve the application of tactile input affect the ability of children with autism to maintain attention to task, decrease distractibility, and decrease self-stimulatory behaviours. Her supervisors are Dr. Joyce Magill-Evans and Dr. John Misiaszek.

**Dr. Barbara Gibson – Post-doctoral Fellowship**

**Approved for funding: \$45,000/year over 2 years**

In January 2006, Dr. Barbara Gibson will be doing her post doctoral training at Sick Kids in the Population Health Sciences Department, under the supervision of Dr. Katherine Boydell and Dr. Nancy Young. Her primary area of study will be social and ethical dimensions of childhood disability, rehabilitation, and community care. Specifically, she will continue to pursue the research on which her doctoral thesis was based, looking at the experience of teenagers and young men who have Duchenne's muscular dystrophy and require mechanical ventilation in the home.

## **Conference Grants**

### ***Youth Program at Vision Quest 2005 (conference on retinitis pigmentosa)***

#### **Ms. Sharon Colle, The Foundation Fighting Blindness, \$5,000**

The Foundation Fighting Blindness (FFB) is dedicated to fighting retinal diseases. They are the major supporter of eye research in Canada. The goal of this conference is to transfer knowledge, create awareness and support the community. This conference offers a unique opportunity to bring together families and professionals to learn about new research, and to create networking opportunities for families and young people.

### ***Canadian Family Advisory Network (CFAN) Pre-Conference Workshop (CAPHC Conference), Mr. Frank Gavin, Canadian Association of Paediatric Health Centres, \$5,000***

The goal of this pre-conference workshop for the Canadian Family Advisory Network is to continue building stronger links between family-based advisory groups and to share strategies for promoting family-centred care and family-professional partnerships within Canadian Association of Paediatric Health Centres and its member institutions across Canada. These groups are helpful and sometimes essential in raising the profile of issues related to children's health within the larger community and in advocating for resources to improve children's health.

### ***Conference 2005 - On the Move, Ms. Nita Goldband, Ontario Prader-Willi Syndrome Association, \$5,000***

The Ontario Prader-Willi Syndrome Association (OPWSA) is registered charity which serves individuals with Prader-Willi Syndrome (PWS) and their personal and professional caregivers. Their mandate is to ensure the optimum quality of life for adults and children affected by PWS. This conference will help to enhance knowledge of new scientific and medical information to attendees. It will help to provide effective management strategies in an age related and appropriate manner. There will be an opportunity for attendees to share and connect and establish informal support networks. Attendees will become more knowledgeable of Ontario Prader-Willi Syndrome Association and its services.

### ***2006 1st ARVD Patient Education Conference, Dr. Robert Hamilton, The Hospital for Sick Children, \$5,000***

The electrophysiology section within the department of cardiology deals with patients with arrhythmogenic right ventricular dysplasia / cardiomyopathy (ARVD/C). ARVD is an inheritable disorder that predisposes the patient to sudden death. Early detection of the disease is the key prevention to sudden death. Currently there is no Canadian network or conference that addresses this specific disease condition. This conference will provide an opportunity to network and gain social support as well as resources for these patients and families. It is helpful for patients to hear and see how others positively cope with the disease and make creative solutions around life style adjustments.

***Many Hands, One Dream: New Perspectives on the Health of First Nations, Inuit and Metis children and youth, Ms. Melanie Laffin, Canadian Paediatric Society, \$5,000***

The Canadian Paediatric Society (CPS), along with a group of organizations concerned with Aboriginal children and youth planned this summit. The intention is to culminate with an action plan that will be carried forward into the next steps of the project, including provisions for community involvement. This project was inspired by a challenge issued to the CPS by former Assembly of First Nations Chief Ovide Mercredi in 1999. He called on the CPS to take a leadership role in finding answers to the health problems facing Aboriginal children and youth. The overall goal of the summit is to promote a climate for lasting change and positive action among participants, so that individuals, organizations and government make the health and well-being of Aboriginal children and youth a priority.

***National Spinal Deformity Symposium, Dr. Edmond Lou, Northern Alberta Benefits Society for Scoliosis, \$3,000***

The Northern Alberta Benefits Society is a family-based organization whose members (or someone close to them) have been afflicted with scoliosis. The organization supports adolescents and their families with issues related to scoliosis, they also support research into scoliosis and raise community awareness of the disease. The goals of this conference are to identify and prioritize important research questions and to identify means of sharing resources and expertise among Canadian researchers, clinicians and families. The intention of this symposium is to share research from different locations across Canada. They also intend to work on the creation of a Canadian network for research on spinal deformities.

***Partnerships in Patient Safety: Taking Care of the Kids, Dr. Anne Matlow, University of Toronto, \$5,000***

Promoting patient safety has become a health care priority worldwide. At The Hospital For Sick Children, Patient Safety is recognized to be of utmost importance, and a culture of safety is underway. One of the recent initiatives at the Hospital has been development of the Families as Partners in Patient Safety Working group. This multidisciplinary task force includes parents and healthcare workers. During the conference the group will identify patient safety issues and potential contributing factors, develop communication strategies for increasing the awareness and for promoting the partnership between parents and staff in patient safety.

***Western Canada Neuromuscular Community Network Conference, Ms. Donna Peach, Muscle Dystrophy Canada, \$4,760***

Muscular Dystrophy Canada is committed to improving the quality of life Canadians with neuromuscular disorder and funding leading research for the discovery of therapies and cures for neuromuscular disorders. The Western Canada Neuromuscular Community network Conference provides a vehicle for clients and health professional to come together to collaborate and provide mutual support regarding issues vital to the positive development of children, youth and adults with physical disabilities. The goal of this conference is to enable clients, parents, youth and health professional to meet and share current information and practices relating to living and dealing with neuromuscular

disorders.

***Retinoblastoma 2006, Ms. Emma Plant, Canadian Retinoblastoma Society, \$5,000***

Retinoblastoma is a rare form of eye cancer that affects children primarily before the age of five. One of the primary objectives of the Society is to provide support to Canadian retinoblastoma families. They believe that an important component of educating families is bringing them together regularly to share their experiences while being provided with the most current medical information available. The goal of this conference is to help Canadian families with retinoblastoma learn more about this disease while providing mutual support; thus helping them cope with this rare cancer.

***Canadian Child Health Clinician-Scientist Program Annual Symposium -- Newfoundland, 2005, Dr. Norman Rosenblum, The Hospital for Sick Children, \$80,000***

One of the central components of this national program is its annual symposium, which brings together all of the program trainees from across the country, along with their mentors and centre leaders, to share the exciting research taking place with the program's support. Every year funded trainees give presentations on their research.

***10th International Child Neurology Congress - Family Forums, Dr. Michael Shevell, Montreal Children's Hospital, Canadian Association for Child Neurology, \$5,000***

The International Child Neurology Congress holds a meeting every four years around the world. The scientific program features more than 200 invited international paediatric neurology specialists recognized for their academic and clinical achievements as world leaders in their respective fields. The Family Forums, for this conference, will take place for the first time. These are information sessions through which local parents can be informed on current knowledge and research that may improve the condition affecting their child. The main objective is to unite parents, children and professionals to share knowledge and discuss ideas and issues.

***"Take Action" The Spina Bifida and Hydrocephalus Association of Canada National Conference., Ms. Cindy Smith, Spina Bifida and Hydrocephalus Association of Northern Alberta, \$5,000***

The goal of this conference is to provide education and a forum for exchange of ideas for parents, professionals and individuals living with Spina Bifida and Hydrocephalus (SB/H) across Canada. The conference will provide a forum for parents and professionals to exchange information and ideas in a non-clinical setting. They will have the opportunity to create an opportunity for those affected by SB/H to network and discuss common issues and provide support to each other. Participants will learn about new procedures, products and services available to those affected by SB/H.

***Family Focus 2006 - The Voyage Together  
Mr. Si Stainton, Family Focus Society, \$5,000***

The conference will enable BC families who have children with disabilities and chronic health challenges to enhance their strengths and resources through education, information and connections. There will be educational opportunities for families on a variety of

topics of relevance. Family Focus believes that empowered families strengthen the communities in which they live.

***Movin' On! Managing Life Sized Obstacles*, Ms. Colleen Talbot, Spina Bifida and Hydrocephalus Association of British Columbia, \$5,000**

Spina Bifida and Hydrocephalus Association of British Columbia (SBHABC) is a support group for parents with children born with Spina Bifida and Hydrocephalus and also for adults with this birth defect. This conference offers an opportunity for the exchange of ideas between parents and professionals and gives parents across Canada the opportunity to communicate. It will also provide a forum for professionals and parents to exchange ideas in a non-clinical setting

***2006 Symposium on Children and HIV/AIDS*, Ms. Karen Vance-Wallace, The Teresa Group, Child and Family Aid, \$5000**

The XV International AIDS Conference will be held in Toronto this year. Conference delegates will have the opportunity to hear some of the world's leading scientists, physicians, health care workers and community leaders share current knowledge about various aspects of the AIDS epidemic. The Hospital for Sick Children and The Teresa Group are coordinating a two-day pre conference symposium on the issues specific to children affected by HIV/AIDS. In particular, the focus of the symposium will be on the psychosocial dimensions of the disease.

