

The National Grants Program at SickKids Foundation

*"It would be of benefit to children to establish a Foundation directed specifically towards exerting a leadership role in child health, particularly on a provincial and national basis".
(SickKids Foundation Annual Report 1973-74)*

As a national charity, SickKids Foundation not only invests in the important work taking place at SickKids hospital and Research Institute, we also invest in some targeted strategic initiatives which are national in scope, to benefit child and youth health in Canada and complement the work done at SickKids. This commitment to child and youth health in Canada is true to the spirit of the Foundation's founders, who articulated a vision for the Foundation that went well beyond the hospital walls over 33 years ago.

In 2004-05, the Foundation invested over \$3.5 million into various grants initiatives across the country. The Foundation is very careful in selecting national priorities for investment. We have two areas of strategic focus: building capacity for paediatric health research, and investing underdeveloped areas of child and youth health and health care. We also make a number of strategic grants to projects which fit within our larger priority of benefiting child health in Canada by playing a catalytic role through our national granting.

Building on our strengths -- Strategic Grants

The community engaged in paediatric health care and research in Canada is a relatively small one, with 16 major paediatric centres across Canada. This community tends to be collaborative in nature, knowing that success depends on engaging in joint research projects, sharing results, and ensuring that promising students get training at diverse centres. The Canadian paediatric research landscape provides numerous opportunities for child health researchers and clinicians. To help them take advantage of these, the Foundation has made several strategic grants this past year.

The Foundation is proud to support the newly developed *National Child and Youth Health Coalition* with a three-year grant to cover start up operating costs. The *Coalition* represents a collaboration between four national organizations which together will advance the cause of child and youth health in Canada: the Canadian Association of Paediatric Health Centres; the Canadian Child Health Clinician Scientist Program; the Council of Canadian Child Health Research; and Paediatric Chairs of Canada. The *Coalition* will strengthen the ties between paediatric health care and research organizations, and ensure that they are working together to achieve common goals. The Foundation also supported a national workshop to establish Canadian paediatric health care indicators - against which we can measure our progress for select areas - organized by the Canadian Association of Paediatric Health Centres. This is an important national initiative.

This past year the Foundation also supported some important family initiated projects, including the Canadian Family Advisory Network's meeting in October 2004 (and again in October 2005), as well as an innovative project titled *Working Together for Change*. This latter project, to which the Foundation has made a three-year grant, is a partnership between on the one hand, children, youth and young adults with disabilities and their families, and on the other researchers and educators and students in post secondary educational settings. This partnership will increase the latter's understanding of issues of importance to the former and develop collaborative research projects.

Building capacity for paediatric health research

It is important to ensure that, coast to coast, the environment for child health research is as healthy as it can be. Beyond supporting initiatives such as the *National Child and Youth Health*

Coalition, this means supporting trainees and young researchers to develop their talent and get the training and support they need. This investment in research capacity will ultimately benefit children, youth and families by improving the health care they receive, leading to new cures and treatments, more effective systems, and a better understanding of what supports the health of the child as a whole.

More than half of the Foundation's national granting budget this past year was invested in capacity development in child health research. The Foundation's role in the sector is complementary to the activities of the larger funding bodies such as the Canadian Institute of Health Research and Health Canada. We welcome the opportunity to partner with organizations on projects and programs. In particular, the Foundation has an ongoing partnership with the Canadian Institutes of Health Research's Institute of Human Development, Child and Youth Health (IHDCYH) on our New Investigator Awards Program, to which IHDCYH contributed \$900,000 this past year. The purpose of this program is to develop Canada's capacity in child and youth health research by funding investigators who are within the first six years of their research careers. The Foundation invested \$1.5 million in the New Investigators Award program in 2004-05, not including the funds from IHDCYH.

In addition to the New Investigator Awards program, the Foundation is also a lead national partner in the Canadian Child Health Clinician Scientist Program, an innovative transdisciplinary national training program which provides support for highly qualified child health clinicians to develop their requisite knowledge and skills for a career as an independent scientist in child health research (www.cchcsp.ca). The Foundation's commitment to this program, together with a multi-year commitment to the Pediatric Scientist Development Program which supports Canadian physicians who need to do their research training in the United States, totals \$400,000 per year.

Investing in underdeveloped areas of child and youth health and health care

The Foundation also plays a convening and organizing role in several areas in which we invest -- particularly in the areas of Complementary and Alternative Medicine and in Home and Community Care for children, youth, and families.

This past year was a busy and exciting one for the National Grants Program in both these areas. The Foundation continues to play a catalytic role in the area of home and community care. Five years ago we created the Children and Youth Home Care Network, which undertakes a range of activities from funding research studies, and supporting students working in this area, to convening a network of researchers, policy makers, practitioners and parents by maintaining a website, sending out a regular newsletter -- which was revamped this year -- and organizing national forums. In February 2005, the Network hosted its third national priority setting forum in Banff, with 75 experts from across the country attending. Outcomes of that meeting range from the organization of a group to develop a national advocacy plan in this area, to better links to policy makers, and greater involvement by parents in the Network. Please visit the Network's website at www.cyhn.ca.

The Foundation also organized the first Canadian forum bringing together paediatric researchers and people interested in Complementary and Alternative Medicine in December 2004. This one-day forum showcased the 17 research projects the Foundation has funded to date since launching this grants program. This forum was also the first meeting of the Pediatric Complementary and Alternative Medicine (PedCAM) Network (www.pedcam.ca), an initiative funded through SickKids Foundation. In 2004-05 we also approved funding for five new research projects and two new master's student awards.

Looking forward:

SickKids Foundation's National Grants Program is currently engaged in a new strategic plan, which will result in several new strategic initiatives to benefit child and youth health in Canada. We will continue to engage with experts across the country to ensure that our next dollar goes to where we can most make a difference for children, youth and their families.

Below is a list of the new grants and awards we made in each of our grants programs.

Strategic Grants

National Workshop to Establish Canadian Paediatric Healthcare Indicators May 27 & 28, 2004, Ms. Elaine Orrbine, Canadian Association of Paediatric Health Centres, \$5,000

National indicators and standards in Canada specific to the paediatric population do not exist. The establishment of paediatric healthcare indicators and standards would assist policy and decision-makers with paediatric resource planning and allocation, providing a tool to help achieve an optimal level of health service delivery for Canadian children and youth. This workshop was the first step in establishing goals and a framework for this national initiative.

National Child and Youth Health Coalition, Ms. Elaine Orrbine, Canadian Association of Paediatric Health Centres (CAPHC) and Paediatric Chairs of Canada, \$243,000 over three years

Four national organizations have joined together to create a coalition to advance the cause of child and youth health in Canada: Canadian Association of Paediatric Health Centres; Canadian Child Health Clinician Scientist Program; Council of Canadian Child Health Research and; Paediatric Chairs of Canada. The National Child and Youth Health Coalition will provide a powerful framework to stimulate new knowledge development, promote the application of this knowledge to practice, training and education, and strengthen national advocacy to improve the health and health care of children and youth. (www.caphc.org/partnerships_indicators.html)

Working Together for Change, Ms. Barbara Ostroff, CanChild Centre for Childhood Disability Research, \$130,500 over three years

Children, youth and young adults with disabilities and their families currently play a crucial role in changing the attitudes and expectations of their neighbours, those in the helping professions and public policy makers. The purpose of this project is to influence the thinking and behaviour of researchers, educators and students in post secondary educational settings in ways that will increase their understanding of issues of importance to children, youth and young adults with disabilities and their families. As well, this project aims to increase collaborative partnerships between families and researchers regarding research directions and process, and teaching about disability issues. (www.communityfaculty.ca)

New Investigator Awards

All New Investigator Awards are peer reviewed by three external reviewers and two committee reviewers, and competitively rated. Below are the 16 New Investigator grants funded this past year, of which four are focussed on asthma. Allergic diseases, including asthma, have been on the rise for the last 20 years in the Western world. Asthma is most common in childhood, is a leading cause of hospitalization in children aged 1-9 and accounts for approximately 1/4 of school absenteeism. Asthma occurs in approximately 10% of the paediatric population and can evolve into a long-term chronic health problems. Its total annual economic burden exceeds \$750 million.

A Novel Noninvasive Marker of Asthma Airway Inflammation: Urine NMR, Dr. Darryl J. Adamko, University of Alberta, \$130,000 over two years

Asthma causes airways to become inflamed and narrowed. Treatment often requires anti-inflammatory drugs using inhaled and/or oral corticosteroids, which can have unwanted side-effects. Adjusting the dose of corticosteroids is more difficult in children because they can't perform some of the adult asthma tests (e.g. lung function tests). A better test to measure airway inflammation to guide therapy in children is urgently needed. This study will test a novel method to measure airway inflammation in children's urine samples using Nuclear Magnetic Resonance (NMR).

Role of Caveolae and Caveolins in the Integration of Signals that Mediate Airway Smooth Muscle Cell Proliferation in Asthma, Dr. Andrew J. Halayko, University of Manitoba, \$130,000 over two years

Understanding of asthma's disease process will provide clues for designing drugs to inhibit and reverse the disease. Smooth muscle encircles the airways of the lung and contraction of the muscle decreases airway diameter. An increase in the amount of airway smooth muscle is a primary feature of asthma and leads to excessive contraction that can completely close the airways, as occurs in sometimes-fatal asthma attacks. A large number of bio-molecules accumulate in the lungs of asthmatics due to inflammation caused by inhaled allergens and toxins. Many of these molecules induce growth of airway smooth muscle. Our studies investigate how the signals from different receptors for these molecules are controlled by distinct membrane microstructures called caveolae.

Phosphatidylinositol 3-kinase Sub-pathways in Allergic Sensitization and Asthma, Dr. Aaron J. Marshall, University of Manitoba, \$130,000 over two years

About 75% percent of asthmatic children are sensitized to specific allergens that can cause acute exacerbations of the disease. The objective of this research project is to bridge a scientific gap by bringing together leading-edge issues and technology in cell signaling with in-depth modeling of asthma pathogenesis, in order to break down and define the role of a critical signaling pathway. Increasing our understanding of the underlying signaling processes involved in allergic sensitization will provide a scientific basis for primary prevention strategies. Definition of the signaling networks involved in airway inflammation will identify appropriate targets for development of more refined and effective treatments in the future.

Early Life Stress and Asthma, Dr. Harissios Vliagoftis, University of Alberta, \$130,000 over two years

Genetic susceptibility plays an important role in asthma, as do environmental factors. Psychological stress, whether early or late in life, may also be a factor contributing to the increasing prevalence of allergic diseases. The objectives of this project are to define the role of early life stress on the development of allergic airway inflammation and on the response of allergic inflammation to stressful psychological events later in life. Identifying the exact role of stress, especially early in a child's life, on asthma development and on the severity of the disease and the mechanisms leading to these effects will help us develop strategies to decrease disease burden in children and subsequently in the adult population.

Cell Death Signaling Pathways Controlled by ATRX, Dr. Nathalie Bérubé, University of Western Ontario, \$130,000 over two years

Mental retardation (MR) affects 2-3% of all children. Mutations that alter the normal function of proteins such as ATRX are a common cause of syndromal X-linked mental retardation, yet their role in brain development is largely unknown. Children born with ATRX mutations present with significant global developmental delays and some affected boys never walk or develop speech. Profound mental retardation is often accompanied by seizures, self-biting and hitting, craniofacial anomalies, mild anemia, and genital abnormalities. This study will examine the role of the

ATRX mental retardation gene in brain development. The knowledge acquired in this study will be used to develop strategies to counteract the debilitating outcome of cell loss in the nervous system of children affected with mental retardation.

Role of Fanconi Anemia Proteins in Development, Dr. Madeleine Carreau, CHUQ-Hôpital St-François d'Assise, \$128,918 over two years

Fanconi anemia (FA) is an orphan genetic disease affecting children at an early age. Children affected by this disease have congenital abnormalities, bone marrow failure and a predisposition to cancer such as leukemia. Eight of the eleven possible FA genes involved in the pathophysiology of the disease have been cloned; thus, FA provides a useful model to study the genes involved in stem cell maintenance and development and in molecular processes leading to leukemia. This project proposes to study the role of FA genes in molecular signaling events involved in development. Results derived from this project will lead to the development of new therapeutic approaches aimed at increasing hematopoietic stem cells numbers in children affected by Fanconi anemia or other diseases associated with developmental defects.

Exposure to Hyperhomocysteinemia During Development and Epigenetic Regulation of Vascular Gene Expression, Dr. Angela M. Devlin, British Columbia Research Institute for Children's and Women's Health, \$106,000 over two years

In Canada, one third of all deaths are due to cardiovascular disease (CVD) and stroke and 80% of adults have at least one risk factor for CVD and stroke. The economic burden - approximately \$18.5B annually - is staggering. Recent reports suggest that prenatal and early postnatal nutrition plays a significant role in the development of risk for CVD, suggesting that early detection and intervention may contribute to mitigating its impact. The fetal environment may be a potent predictor of risk for disease, via a 'programming' of the individual's responsiveness to environmental stimuli and susceptibility to adult-onset chronic diseases like CVD. This research project will test hypotheses related to potential effects of prenatal exposure to elevated maternal blood levels of homocysteine, a CVD risk factor, on the epigenetic regulation of vascular gene expression in young adult mice. The research results have the potential to increase our understanding of the impact of nutrition on health status during fetal development and early childhood.

PSA-NCAM in Enteric Nervous System, Dr. Christophe Faure, Sainte-Justine Hospital, \$130,000 over two years

The gastrointestinal tract is under the influence of nerves situated in the wall of the esophagus, stomach, small intestine and colon. Although significant advances in the development of the enteric nervous system have emanated from extensive research in the past 15 years, the mechanisms involved in the adaptation of the immature enteric nervous system after birth need to be elucidated. In this research project the role of the adhesion molecules, found at the surface of the neurons, in the development of the enteric nervous system will be investigated. By examining the expression and the regulation of adhesions molecules in the intestine of rats, new therapeutic insights for infants and children with congenital or acquired anomalies of the enteric nervous system will be discovered.

Regulation of Muscle Progenitor Cells in Response to Muscle Damage, Dr. Thomas J. Hawke, York University, \$130,000 over two years

Duchenne Muscular Dystrophy (DMD) affects approximately 1 in 3,500 live male births per year and is the most common and most devastating of the muscular dystrophies. This genetic disorder involves the mutation of a structural gene within the muscle. The absence of this structural protein renders the muscle extremely fragile and in response to repeated muscle contractions, there is widespread muscle damage. Between the ages of 7 and 12, children with DMD lose the

ability to walk and in the late teens failure of the heart and respiratory muscles leads to death. There is currently no cure for DMD and limited success has been achieved using conventional therapies. This research program will address issues relating to the regulation of the muscle progenitor cells in response to muscle damage and will enhance the use of this unique cell population in cell transplant therapies for Duchenne Muscular Dystrophy.

Evaluating Children's Roles in the Governance of a Paediatric Hospital: The Perceived Impact of a Children's Council, Dr. Donna Koller, SickKids Hospital, \$97,145 over two years

Youth participation is on the rise with young people involved in various aspects of community life. However, there is a need to address the efficacy of such interventions, particularly in the area of health care. Currently, there are no systematic reviews or evaluations of children's councils in paediatric settings. A range of perspectives solicited from various participants will generate an in-depth understanding of the impact and role of the children's council. Findings may also illuminate other issues related to children's roles in the governance of a paediatric hospital. Recommendations for enhancing the efficacy of children's involvement will assist other institutions in their endeavors to increase youth participation in their settings.

The Determinants of Health in Children with Hydrocephalus, Dr. Abhaya V. Kulkarni, SickKids Hospital, \$94,536 over two years

Hydrocephalus (the excess accumulation of fluid in the brain) is one of the most common of the serious brain conditions affecting children. Hydrocephalus impacts substantially on all aspects of a growing child's life, but the predictors of health outcome in this population are not known. This project will identify the determinants of the long-term health outcome of children with hydrocephalus and provide the most detailed data available about the kinds of health issues that are most affected in children with hydrocephalus. By identifying the determinants of their health, the results of this project will be used to target specific therapeutic interventions for specific patient subgroups in order to improve their overall outcome and to help guide further research endeavours to the most needed areas.

Novel Signaling Pathways in Neutrophil Degranulation, Dr. Paige Lacy, University of Alberta, \$130,000 over two years

Neutrophils are the most common white blood cell type observed in injury and bacterial infection. During bacterial infections, neutrophils are essential for the eradication of microbes. They do this by engulfing and killing invasive microorganisms. Without neutrophils, we would die within days of rampant, unchecked growth of opportunistic fungal and bacterial infections. However, neutrophils can release toxic mediators, and they are capable of inducing tissue injury if excessively activated. Acute respiratory distress syndrome (ARDS), the most common cause of severe respiratory distress in the newborn, is accompanied by high rates of morbidity and mortality, and has not improved in the past 20 years in spite of efforts to improve therapies and supportive care. The manifestation of ARDS correlates with increased neutrophil infiltration in the lungs, as well as increased products of neutrophil activation, which actively damage lung tissues. The study aims to reveal novel intracellular targets for therapeutic intervention and reduce the incidence of ARDS in newborn babies.

GSK3 β Signalling in Coxsackievirus-Induced Myocardial Injury, Dr. Honglin Luo, University of British Columbia, \$130,000 over two years

Coxsackieviruses are the leading causative agent of myocarditis, or heart muscle inflammation. Infection on newborns and children is often fatal, accounting for ~75% of sudden death in newborns and ~20% in children and adolescents. Even in non lethal infections in the young, long term heart failure is a common sequela. Recently, the importance of heart injury induced by both

virus and the associated inflammation in viral myocarditis has been established. This proposal will study the signalling mechanisms by which coxsackievirus damages the heart during infection. The study will provide valuable insights into the mechanisms of coxsackieviral pathogenesis. Novel therapeutic strategies may emerge against viral myocarditis, hugely impacting on child health care in Canada.

Dissection of the Developing Program of the Hypothalamus, Dr. Jacques Michaud, Hôpital Sainte-Justine Centre de Recherche, \$129,298 over two years

The hypothalamus is a region of the brain that is important for the control of several physiological processes, including the regulation of food intake. The *Sim1* gene is critical for the development of the hypothalamus. A decrease of this gene causes a severe increase of food intake resulting in early-onset obesity in mice as well as in humans. Several observations suggest that *Sim1* controls food intake by disrupting the development of the hypothalamus. It may be that other genes important for the development of the hypothalamus are also involved in the regulation of food intake and cause obesity. The study proposes to identify these genes in mice in order to shed some light on common forms of obesity controlled by the hypothalamus.

Are Executive Dysfunctions in Autism Reflected in Altered Coordination Dynamics of Brain Activity? Dr. Jose Luis Perez Velazquez, SickKids Hospital, \$129,290 over two years

The particular behavioural characteristics of children with autism suggest that their brains may process information differently from that of non-autistic persons. One model predicts that coordinated activity between brain cells in small, local brain areas is enhanced, while global (widespread) brain activation is decreased in the brains of people with autism, relative to controls. The proposed study will reveal differences in the collective coordination dynamics of cortical networks in autistic brains. In addition to contributing to a basic understanding of autism, these studies may provide insight into possible interventions or educational supports that will enhance processing abilities in individuals with autism, or even contribute to the diagnosis of autism early in development.

Complementary and Alternative Health Care and Paediatrics

Complementary and Alternative Health Care & Paediatrics Masters Scholarship, Ms. Denise Lauren (Durda) Adams, University of Alberta, \$10,000 over two years

Ms. Adams' project will focus on the potential efficacy of Traditional Chinese Medicine (TCM) as compared to standard therapy, for mononucleosis. Mononucleosis is a relatively common illness, affecting both children and adults, for which biomedicine does not offer an effective treatment. Preliminary investigation indicates that this illness may be responsive to TCM.

CAHC & Paediatrics Masters Scholarship, Ms. Brenda Leung, University of Calgary, \$5,000

Ms. Leung's masters degree will incorporate research as a means to broaden her clinical work as a naturopath by learning about research methods, statistical methods, proposal writing, budget development and preparing grant applications. These skills are needed to conduct research that will be beneficial in building an evidence base for naturopathic medicine and the proper use of nutraceuticals in clinical practice.

Complementary and Alternative Health Care (CAHC) in Children with Arthritis and Physical Disabilities, Dr. Debbie Feldman & Dr. Maria Victoria Zunzunegui, Université de Montréal, \$60,650 over two years

Although a number of studies have described use of Complementary and Alternative Health Care (CAHC) in children, few have described use among children with disabling paediatric conditions such as cerebral palsy and juvenile idiopathic arthritis (JIA). This research will study patterns of CAHC use over 12 to 24 months in two groups that are reportedly high users of CAHC and will

explore factors associated with use of CAHC in these two cohorts. In addition to data on CAHC utilization, this research will document whether parents found CAHC to be beneficial for their children, which types of CAHC were thought to be beneficial, and for which types of conditions. The relationship between adherence to conventional treatment and CAHC use in children with JIA will also be explored.

Feasibility and Impact of Qigong as Compared to Aerobic Exercise in the Treatment of Childhood Chronic Musculoskeletal Pain: A Pilot Randomized Controlled Trial, Dr. Shirley M. L. Tse and Dr. Brian M. Feldman, SickKids Hospital, \$128,223 over two years

Childhood fibromyalgia (FM) is a common and sometimes devastating paediatric disorder resulting in widespread pain, fatigue, tenderness and significant disability. The prevalence of FM is steadily increasing, leading to an increase burden of illness on the patient, family and health care system. Medical therapy has not been successful in curing or controlling FM. Exercises like Qigong have shown to be safe and effective in the treatment of adult FM. No data is available for treatments like Qigong in children. This research will study the feasibility of enrolling, randomizing and studying participants with FM into a trial and then it will acquire pilot data to compare two forms of exercise - standard aerobic fitness exercise, and a specially designed Qigong program. Physical exercise training represents a potentially feasible, safe and effective alternative therapy and may therefore emerge as a pivotal mode of therapy to all children with FM.

Maternal Acupuncture and Neonatal Abstinence Syndrome, Dr. Patricia Janssen, University of British Columbia, \$91,228 over two years

Approximately 6-10% of babies in Canada are exposed to illicit drugs in utero. As a consequence, these newborns experience painful withdrawal from narcotics or cocaine after birth. The purpose of this study is to determine if daily acupuncture treatments given to pregnant women can reduce the severity of neonatal abstinence syndrome (withdrawal) among their infants. These will be compared with the infants of women who have received standard care (methadone maintenance) without acupuncture treatments. It is expected that babies born to mothers receiving acupuncture will have fewer and less severe symptoms of withdrawal because the acupuncture will alleviate mothers' cravings for street drugs and/or methadone.

Orthomolecular Therapy for Childhood Asthma, Dr. Badri Rickhi and Ms. Sabine Moritz, Canadian Institute of Natural and Integrative Medicine, \$114,250 over two years

Many children with asthma take vitamins and minerals for their illness but it has not been tested whether these treatments are beneficial. This research will test the feasibility of a larger investigation into the value of orthomolecular therapy (vitamins and minerals) in the treatment of asthma. The research will test whether the suggested methodology is feasible, whether the orthomolecular treatment produces any side effects, and whether there is some indication that the use of vitamins and mineral supplements allows asthmatic children to reduce their medication (inhaled corticosteroids).

The Effect of Belladonna and Pulsatilla in Reversing the Morphological Changes and Hearing Loss Seen in Otitis Media, Dr. Algernon C. Karim, University of Manitoba, \$78,400 over two years

Middle ear infection (otitis media) is a common childhood disease that has experienced a steady rise over the last 10 years. The widespread use of antibiotics in the treatment of this disease has caused several strains of bacteria to become resistant to the medication. The focus of the present study is to investigate in an animal model the effect of homeopathic remedies on middle ear infection, looking at the changes that will occur in the hard and soft tissues within the ear, and

correlate these with hearing loss. Once this is established, the effectiveness of homeopathic remedies in reversing the hearing loss will be studied.

Children and Youth Home and Community Care Network

Home-based Occupational Therapy for Preterm Infants, Dr. Denise Reid & Ms. Teresa Chiu, University of Toronto, \$130,000 over two years

This study will be conducted to describe the changes in premature infants who are less than 12 months old who receive in-home occupational therapy intervention for six months. The research will help describe the changes in developmental outcome and the parent-child interaction of infants who receive occupational therapy intervention. In-home intervention, if determined to cause changes, will provide options for service delivery. It is anticipated that parents will benefit from the consultative approach of the in-home model and learn how to handle and interact better with their infant. The direct treatment approach that is delivered in hospitals fails to incorporate a teaching component to the delivery of service.

From Promise to Practice: An Analysis of Case Management for Children Receiving Home Care in Ontario, Ms. Karen Parent, Queen's University, \$125,736 over two years

Case Managers perform a variety of tasks and activities that contribute to the management and coordination of services for children and their families needing home care in Ontario. Working with their community partners (therapy, nursing, personal support etc.) in the community, Case Managers help families navigate the system to provide information, referral and service to meet the child's often complex needs. This study has been designed to study case managers' clients and families. Results will be used to improve care processes and refine the case management role with the aim of achieving optimal client and family outcomes and determining a set of preliminary indicators for ongoing measurement and evaluation of case management in Ontario.

Paediatric Home Care Outcomes, Dr. Lynne Ray, University of Alberta, \$134,326 over two years

This project has as its goal the creation of an evaluation research template which can be used by paediatric home care programs across Canada, with the long-range aim of encouraging and supporting researchers and program evaluators to use valid and clinically useful measures consistently across studies and, where possible, over time. This will make evaluation of programs easier for those who are not experienced researchers, as well as facilitating comparison of various home care programs and combining study outcomes. Such an approach will also enable this group and others to acquire a sense of the relative utility and limitations of the best current instruments. It will be possible to identify gaps in the availability of measures, potentially leading to the development of new measures as well as instruments with improved measurement properties.

Ontario Rehabilitation Research Network (ORRN) Knowledge Translation Initiative, Dr. Beverly Antle, SickKids Hospital, \$2,000 over two years

This grant provides seed money to the Ontario Rehabilitation Research Network Knowledge Translation working group to develop a template for plain language reports on research and other tools. These tools will be publicly available on the ORRN website and linked to CYHN's website.

Duncan L. Gordon Fellowships 2005

Dr. Bradley Johnston

Dr. Johnston has received a three-year post-doctoral fellowship to study clinical epidemiology at the University of Alberta and to undertake research on the use of probiotics for the prevention of paediatric antibiotic associated diarrhea. Dr. Johnston's future plans are to be a practicing

naturopath at Stollery Children's Hospital, to teach complementary and alternative medicine (CAM) providers evidence-based medicine skills, and to continue research in paediatric CAM.

Dr. Dimitri J. Stavropoulos

Dr. Stavropoulos was awarded a three-year fellowship to develop his clinical, research and teaching skills in medical genetics at SickKids. Once his fellowship is completed, Dr. Stavropoulos would like to do research in a genetic diagnostics laboratory and work with physicians to implement diagnostic assays for the management of childhood illness.

Conference Grants

22q11 Deletion Syndrome Community Education Day, Ms. Andrea Shugar, SickKids Hospital, \$10,000 for two separate education days

The 22q11-deletion syndrome is a complex and under-recognized condition and yet it is the second most common chromosome abnormality, after Down syndrome. The syndrome is characterized by: physical birth defects, immunodeficiency, respiratory disease, feeding problems and renal anomalies, developmental delays, learning disabilities, and an increased lifetime risk for psychiatric illness. Community education days give parents a comprehensive overview of the 22q11 Deletion Syndrome, as well as strategies to help children and young adults with the syndrome.

"For the Kids" - Developing Readiness for the Future of Children's Mental Health, Dr. Melanie Barwick, The Hospital for Sick Children, \$1,500

This workshop focussed on generating dialogue and a sense of excitement for the future of children's mental health and an appreciation for the capacities required to implement change. Service providers, policy analysts, decision-makers, and advocates from the children's service sector met for a day to reflect on what is required to develop readiness for advances and innovations in the sector. Several recent events have created an opportune time to identify strategies to move forward to implement and integrate the most effective mental health services in Ontario.

Annual Conference of the Ontario Association for Families of Children with Communication Disorders, Ms. Alison Morse, Ontario Association for Families of Children with Communication Disorders, \$5,000

Approximately 6-10% of children will have a communication disorder, making it one of the most common disabilities affecting children. Speech or language disorders may occur alone, but many children with other disabilities are also likely to have a communication disorder. This conference brought together families and professionals to share information and strengthen partnerships.

10th Annual International Paediatric Nursing Research Symposium, Dr. Janet Rennick, MUHC Montreal Children's Hospital, \$3,000

The 10th annual International Paediatric Nursing Research Symposium provided opportunities for involvement of parents, community groups, clinicians, educators, and researchers in dissemination activities for paediatric nursing research as well as fostering knowledge translation at both the institutional and the community level. The symposium focussed on the results of recent research on neonatal and paediatric pain; self-management education concepts in children with chronic conditions; interventions to enhance coping in mothers of critically ill and low birth weight children.

CHARGE SYNDROME: Parents as Partners, Ms. Ann Gloyn, Canadian Deafblind and Rubella Association, \$5,000

CHARGE Syndrome can now be considered one of the leading causes of deafblindness for infants and children. It is known that through early therapeutic intervention and the use of assistive devices, these children are able to grow and develop. However, there are many adolescent issues emerging, including pubertal delays, growth delay, scoliosis, migraines/seizures, retinal detachment, sleep apnea, behavioural and psychological phenotypes. This conference aimed to increase awareness of CHARGE syndrome in Canada and provide opportunities to discuss the most recent research on the syndrome.

Care for the Caregiver: Creating a supportive social environment for parents of children with special needs living in Sudbury & District, Ms. Eve Kremyr, Jubilee Heritage Family Resources, \$5,000

The goal of this conference is to promote improved understanding of the complex issues that parents face when raising a child with special needs. Every aspect of the parent's life is impacted - career, daily experiences, relationships, worldview, future plans, and self-fulfillment. Professionals who assess, diagnose, provide case management and services are often not fully cognizant of the immense pressures of parenting a child with special needs. Learning about and acknowledging these pressures can move parents and their professional providers towards positive action and power on behalf of their special children.

Canadian Family Advisory Network (CFAN) Pre-Conference Workshop (CAPHC Conference), Mr. Frank Gavin, Canadian Association of Paediatric Health Centres, \$2,000

This meeting of the Canadian Family Advisory Network built stronger links between family-based advisory groups. Participants shared strategies for promoting family-centred care within CAPHC and its member institutions and across Canada. Topics discussed included: the relation between family-centred services and family/patient satisfaction and mental health; information about organizing family-advisory bodies; developing effective partnerships with institutions; establishing stronger links between CFAN members.

Beginning with Patience and Understanding...An Attention Deficit Hyperactivity Disorder Workshop for Parents & Professionals, Dr. Alan Bowd, Lakehead University, Thunder Bay, \$4,500

This workshop for caregivers and professionals focussed on supporting youth with attention and behavioural difficulties living in northern and rural Canada. The workshop provided access to new strategies for effective and culturally appropriate service delivery; increased networks of rural, remote and northern resources; and provided information about interventions that can be immediately implemented.

2005 4th Annual Pacing Buddies Gathering, Ms. Christine Chiu, Department of Cardiology, SickKids Hospital, \$5,000

Special issues related to children with pacemakers include life long dependence on the device, repeated surgeries to replace the system, and patients fears of sudden death or shocks from the device. Often times, these children have to give up on their favorite sports activities, take daily medications or make other changes to their lifestyle. Parents may also exhibit psychological anxiety, thus increasing the child's stress. This yearly conference is aimed at helping these children and their parents adjust.

16th Annual Reach for the Rainbow Conference, Mr. David Neal, Reach for the Rainbow, \$5,000

Reach for the Rainbow is an organization determined to bolster integration awareness and to promote and expand integrated programs in the province of Ontario. It has worked to support and modify the framework of established summer camps to provide integrated opportunities for

children with disabilities. These partnerships and programs create a need for well trained and informed front line camp counselors and other service providers – which is the purpose of the annual Reach for the Rainbow conference. The conference is open anyone interested in learning about children with disabilities.

Families First...Building A Strong Foundation, Ms. Jane Falconer, Huron County Child Abuse Prevention Committee, \$4,960

Huron County Child Abuse Prevention Committee is a community driven and community funded agency that attempts to prevent child abuse through education and community awareness. The goal of this conference was to provide educational information, as well as practical strategies for professionals, organizations and families to eliminate child abuse, violence and bullying. The conference also aimed to strengthened and sustained collaboration between parents, children and professionals.

Vancouver Family Support/Information Conference and Ottawa Family Support/Information Conference, Ms. Pam Husband, The Canadian SADS Foundation, \$5,000

These conferences provided an opportunity for individuals living with cardiac arrhythmias and families who have experienced a sudden unexplained death of a young person, to hear leading edge diagnosis and treatment options and to network with each other. Participants were given a clearer understanding of options for therapy; more appreciation for the necessity for genotyping both for diagnosis purposes and for treatment options; and were given the opportunity to join a network of parents who provide emotional support/sense of community/reduction of sense of isolation.

Growing Up With Heart Disease Conference 2005: Celebrating the Young at Heart, Ms. Laurie Cender, Pacific Children's Heart Network, \$5,000

The goal of this conference was to provide education about issues related to congenital heart disease (CHD) and foster effective relationships between children, youth, families and health care providers. At the conference, information on new innovations and research related to CHD were presented and a forum for dialogue between children, youth, families, health care providers and related professionals on issues related to living with CHD was provided.

RTS Perinatal Bereavement Support Training, Ms. Jan Pearce, Perinatal Bereavement Services Ontario, \$5,000

Perinatal Bereavement Services Ontario provides, at no charge, bereavement support services to families who have experienced miscarriage, medical termination, ectopic pregnancy, stillbirth or neonatal death. This bereavement support training conference trained participants to understand perinatal grief and its normalcy as a response to the death of a baby. Participants were given tools and information to assist parents, siblings and extended family in their grief journey and learnt the impact of caregiver's actions on the grief experience of the family.

The Grants Process

The Grants Advisory Committee, a standing committee of the Board of Directors of the Foundation, establishes the policies of the National Grants Program. All of our research grants and training awards are subject to external peer review by at least three reviewers. These peer reviews insure a level of excellence in our grant making. The applications are then assessed by the Grants Review Committee, the Duncan L. Gordon Fellowship Selection Committee, the Complementary and Alternative Health Care Review Committee or the Children and Youth Home Care Network Steering Committee. The members of these committees include scientists and clinicians from SickKids

Hospital, as well as representatives from the broader child health community. Informed by the peer reviews and by their own expertise, committee members rate the applications on both scientific merit and the proposed study's overall impact on child health. The Foundation's Board, or in the case of Children and Youth Home Care Grants and of Complementary and Alternative Health Care Grants, the Grants Advisory Committee, makes final funding decisions based on these committees' recommendations. Through this careful three-stage process, which draws on the expertise of many people in paediatric health science across Canada and beyond, we are confident that we fund only the very best and most promising research and trainees.

We would like to thank the following individuals who have kindly volunteered their time and expertise on these committees over the past year.

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