

## **2009 Telethon Competition Projects Awarded**

**Ten projects were awarded funding from the 2009 Telethon Competition amounting to \$240,909 from the BC Children's Hospital Foundation. These projects were selected from 36 initial applicants who submitted letters of intent in back in January. The Telethon Review Committee, under the chairmanship of Dr. Stuart Turvey, worked very hard to select projects that were innovative, well designed and led to outcomes that would lead to improved practice or further research.**

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**1. Amed, Shazhan                      Patient and family satisfaction of care and health related quality of life in children and youth with diabetes living in British Columbia-A pilot study**

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The health care system is changing and it is a priority, both nationally and provincially, to improve the way health services are delivered to people with lifelong diseases. Researchers at BC Children's Hospital are working to improve the quality of diabetes care for children by developing new ways of delivering health services. It is critical to evaluate how these changes in the health system improve the quality of care both from the perspective of the health system and the patient. At present, health administrative databases can be used to describe how children with diabetes use the health care system to better understand the quality of the care they receive. However, these databases do not contain information on patient perspectives. Questionnaires have been developed that measure patient satisfaction and quality of life in children with diabetes. But, these tools have not been used to measure the effectiveness of health system change from the patient/family perspective in children with diabetes. In this study, we explore different methods of administering questionnaires that collect patient perspectives and reasons why patients complete or do not complete questionnaires. This study will involve children with diabetes seen at the diabetes clinic at BC Children's Hospital. The results of this preliminary study will be used to inform the design of a larger study that will collect patient perspectives from children with diabetes and their families across BC. This information will be critical in evaluating the ongoing efforts to improve the quality of health services for children with diabetes in BC.

**Co-Applicants: Jean-Paul Collet, Laura Stewart, Jenny Scott  
Amount Awarded: \$27,000**

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**2. Black, Alec                              Midfoot break: A clinical description and a new perspective**

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Cerebral Palsy (CP) refers to a group of conditions caused by brain damage at birth or during infancy, resulting in poor muscle coordination. The muscles in a child with CP are often very tight, which can lead to bone and joint deformities. Midfoot break (MFB) is a deformity that occurs in many children with CP (see Fig. 1 below). This problem occurs because the muscles that cross the ankle joint are constantly active (spastic), resulting in a breakdown of foot joints between the heel and the toes. In turn, this creates excessive motion at the middle of the foot. The foot is then unable to push off the ground effectively, resulting in an inefficient and painful walking pattern. There needs to be a standard quantitative method for detecting MFB in the early stages, so it can be treated before further breakdown occurs. Currently, this does not exist. The proposed study will measure the movement at the "midfoot joint" and will give us a better understanding of when and how to treat children with tight and spastic muscles that cross their ankle joints. In order to get an accurate measurement of the foot during walking, we will use specialized motion capture cameras and pressure measurement devices to understand the interaction of the foot with the floor and how the foot moves through space. This will be an important step to improve the management of children with spastic muscles and midfoot breaks.

**Co-Applicants: Richard Beauchamp, Christine Alvarez, Jessica Maurer, Tanja Mayson, Valerie Ward  
Amount Awarded: \$24,566**

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**3. Chilvers, Mark****Evaluation of ciliary beat frequency and beat pattern in children with chronic nasal and respiratory symptoms: A new non-invasive method to improve diagnosis**

Cilia are small hair like structures found throughout the body. In the respiratory tract, the role of cilia is to clear mucus. Primary ciliary dyskinesia (PCD) is a genetic condition causing abnormal ciliary movement. This causes continuous nasal and respiratory symptoms. If untreated, it will result in progressive lung damage and destruction. The survival of patients is significantly reduced and they may die in mid-adulthood<sup>1-4</sup>. Our experience to date suggests that PCD is significantly under-diagnosed in BC. Diagnosis relies only on assessment of ciliary structure by transmission electron microscopy (TEM) which is expensive, technically difficult, time consuming and not readily available. Consequently, the diagnosis of PCD is often markedly delayed with children suffering significant ill health and inappropriate investigation/treatment<sup>1,3-6</sup>. If early diagnosis is made, decline in lung function can largely be prevented by appropriate care<sup>3</sup>. Due to TEM issues, standards of care for diagnosing patients with PCD<sup>5,7</sup> now require full assessment of ciliary movement. Currently, in Canada no pediatric or adult centre is able to do this. Digital high speed video-microscopy (DHSV) is a simple, accurate, less labour intensive tool which allows ciliary movement to be seen. In the proposed study, we will use DHSV to view ciliary movement in patients with clinical features of PCD. The primary aim is to develop a non-traumatic method for detecting abnormal ciliary motion in children with PCD that is efficient, accurate and cost effective. This will result in a reliable and early diagnosis and allow treatment to start before significant lung damage occurs.

**Co-Applicants:****Amount Awarded: \$12,630**

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**4. Dionne, Janis****Vitamin D insufficiency and deficiency in pediatric renal transplant**

Vitamin D is essential for growth and bone development. Recent research has also shown that Vitamin D affects many parts of the body, and lack of this vitamin may increase the risk of health problems such as diabetes and high blood pressure. It is found in food and produced by skin after sunlight exposure. However, many children do not get enough Vitamin D in their diet and there is inadequate sunlight exposure during Canadian winters to make enough Vitamin D. Children with kidney transplants also cannot make as much of the active form of Vitamin D as is needed. It is especially important in children with kidney transplants; they have other risks for poor growth, bone disease and diabetes. We do not know how many children with kidney transplants have low Vitamin D levels, and whether this is different from healthy children.

In this study, we will compare Vitamin D levels between a healthy group of children, and a group of children with kidney transplants. This will give us an estimate of the percent with low levels in each group. Vitamin D levels in the blood will be measured when generally healthy children need blood tests or minor surgery and with regular blood tests for children with kidney transplants. We will measure levels over the course of one year to compare summer and winter levels. The results of this study will help us to decide which children need to be monitored and targeted for Vitamin D therapy.

**Co-Applicants: Mina Matsuda, Kirsten Ebbert, Jennifer Krempien****Amount Awarded: \$25,000**

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**5. Guzman, Jaime****Measuring what counts: Documenting the impact of arthritis on children's daily community activities**

Children with Juvenile Idiopathic Arthritis (JIA) are less active and less involved in community activities than their healthy peers. Children and families who attend the arthritis clinic say what "counts" for them is

how much JIA interferes with the child's ability to participate in family and peer/community activities. Currently, this is assessed by informal conversations or standard questionnaires; but these tools reflect poorly changes induced by disease or treatment. **Our goal is to develop a better method to measure how JIA treatments impact the child's Physical Activity (PA) and Community Participation (CP).** In studies in adults we have developed Participation and Activity Records (PAR-24h), a method that combines information from accelerometers, GPS tracking and short phone questions to reflect changes in PA and CP. We aim to show that PAR-24h can capture these changes in children who received a steroid injection in a lower limb joint to reduce pain and swelling. This standard treatment has rapid, predictable benefit. Twenty children with JIA aged 8-16 will wear an accelerometer and GPS-equipped cellular phone for one week before and one week after a joint injection. We will use text messaging and will directly observe the activities of some children to gather additional information about the child's activities. If this method works for children with JIA, it will allow us to evaluate the effect of treatments in larger studies, and in children with other chronic diseases, positioning our team and BCCH/CFRI as leaders in this field.

**Co-Applicants: Kristin Houghton, Lori Tucker**  
**Amount Awarded: \$29,350**

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## **6. Malherbe, Stephan      Evaluation of the intubating laryngeal airway in children**

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When a patient receives a general anesthetic, either an endotracheal tube (ET tube) or a laryngeal mask airway (LMA) is inserted to provide oxygenation and ventilation to the patient during surgery. The majority of airways are easy to manage, implying that oxygenation and ventilation is easily controlled by the anesthesiologist. Under certain circumstances and for a variety of reasons, airway management may become difficult. Difficult airway management is one of the most challenging aspects of providing perioperative care in neonates, infants and small children. The LMA is usually considered the first line "rescue tool" and is well established in managing difficult airways in adults; however the existing variations of the LMA function less optimally in children. The current versions of the pediatric LMA are simply miniature versions of the adult LMA and do not consider the unique anatomical differences between airways of adults and children. Consequently, current LMAs restrict the options available for difficult airway management and, at worst, even increase the risk of lack of oxygen to the child.

The ideal pediatric LMA would provide an excellent seal at low inflation pressures, facilitate easy endotracheal intubation, and be available in a variety of sizes. Such a device would be invaluable to difficult pediatric airway management, as it would increase the likelihood of effectively securing the difficult airway, and decrease the risk of life threatening hypoxemia, thereby increasing perioperative safety for children.

Until now, there has not been a LMA available for use in children that can intrinsically maintain the airway, facilitate ventilation and also act as an easy conduit for fiberoptic intubation. The newly developed Air-Q<sup>®</sup> intubating laryngeal (Air-Q<sup>®</sup> ILA) device has features that encompass the characteristics of the ideal LMA. However, this device has not been rigorously evaluated. It is vital that such a device be tested prior to its widespread usage, both in and outside the operating room. The goal of this study is to determine if the novel pediatric Air-Q<sup>®</sup> ILA addresses the limitations of existing LMAs, thereby improving patient safety.

**Co-Applicants: Simon Whyte, Andrew Morrison**  
**Amount Awarded: \$29,500**

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## **7. Mayson, Tanja      The determinants of crouch gait in children with cerebral palsy**

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Cerebral palsy (CP) is a lifelong disability that results from damage to the parts of the brain that control movement. CP has no cure and affects more than 2 out of every 1000 children born in British Columbia. Among the many challenges that result from CP are difficulties with walking, which can get worse with age. A key sign of deteriorating mobility is when a child starts to walk with bent knees, known as "crouch walking". As children get older, the amount of knee bending increases until they can no longer hold

themselves upright and stop walking independently. Crouch walking may also cause significant knee pain and can lead to degeneration of joints, further affecting independent walking.

Current practice is aimed at trying to maintain or improve a child's ability to walk. In certain children with CP, surgery may offer short-term positive outcomes although this can later lead to crouch walking. Information regarding which children with CP are at higher risk for the development of crouch walking is currently lacking.

Our project will be the first *to determine which factors are related to the development of crouch walking in children with CP*. By providing clinicians and families with this important information, we will be assisting them to make treatment decisions that may lead to better long term outcomes for children with CP, including the ability to continue walking and to participate in life activities.

**Co-Applicants: Christine Alvarez, Richard Beauchamp, Alec Black, Jessica Maurer, Valerie Ward**  
**Amount Awarded: \$13,874**

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**8. Miyanji, Firoz                      Use of 2-octylcyanoacrylate (Dermabond) versus standard staple for wound closure in children with neuromuscular scoliosis undergoing spinal deformity correction surgery-A phase II study**

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Each year over 150 to 200 children undergo major spinal surgery for scoliosis at British Columbia's Children's Hospital (BCCH). One of the most dreaded complications in these cases is post-operative wound infection. This is especially true for children with neuromuscular scoliosis in whom the infection rate ranges from 8 to 13%. In most cases, faecal contamination of the surgical wound is suspected to be the leading cause for infection. Dermabond is a tissue adhesive that has been well-documented in the literature as a safe and effective alternative to sutures for wound closure. It has no toxic effects and is approved by both the FDA<sup>[1]</sup> and Health Canada<sup>[5]</sup>. It also has specific properties that may reduce the incidence of wound infection. However there are no studies to date that have looked at using Dermabond for closure of very large surgical incisions. We propose to conduct a randomized controlled trial to determine if there is a difference in the incidence of wound complications, time taken for wound closure, wound cosmetic score and caregiver satisfaction when using Dermabond versus staples for wound closure in children undergoing spinal surgery for neuromuscular scoliosis. The results of this pilot study will allow researchers to determine if Dermabond is an effective and more advantageous option for wound closure of large surgical incisions. It will provide evidence for revision of current wound closure techniques for large surgical incisions for children undergoing spinal surgery. This will support BC Children's Hospital mandate of delivering expert specialized care to children.

**Co-Applicants: Chris Reilly**  
**Amount Awarded: \$22,624**

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**9. Montgomery, C.                      Emergence delirium in children: Total intravenous anesthesia with propofol-remifentanil versus inhalational sevoflurane anesthesia**

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Recovery from anesthesia in children typically follows one of two courses. Ideally the child is pain free, relaxed and interacts with caregivers, all of which facilitates high quality postoperative care. However, after some anesthetic agents, approximately one-half of children develop agitation, incoherence, and are uncooperative; they may thrash, cry or moan, and are typically inconsolable. This abnormal state, which is not due to postoperative pain, is referred to as emergence delirium (ED). These episodes are harmful as they may result in physical and psychological injury to the child and distress to parents. They impact resource utilization by prolonging Post-anesthesia Care Unit (PACU) stay and increasing nursing interventions. Current preventive therapy is of low efficacy and often leads to the inappropriate use of sedation.

Local experience suggests total intravenous anesthesia (TIVA) has a reduced incidence of ED compared to inhaled sevoflurane (SEVO) anesthesia. Both methods of anesthesia are safe and effective to perform operations in children and are routinely used at BCCH. This study will be the first to compare the recovery profiles of these two methods of administering anesthesia. The aims of this study are to minimize the

incidence of ED, and improve anesthetic recovery in children, thereby increasing patient safety and reducing the distress experienced by parents. The results of this trial will have the potential to change practice in this institute, across Canada and in the developed world. This study conforms to the BCCCH core value of providing the best possible quality patient care and research; enabling local and widespread knowledge translation and clinical practice adoption.

**Co-Applicants: John Chandler, Elizabeth Lamb, Michelle Misse**

**Amount Awarded: \$27,000**

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**10. Verchere, Cynthia “Why is my child falling down?” Does a brachial plexus injury at birth lead to a long-term coordination and balance problems?**

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The brachial plexus is a group of nerves that originate in the spinal cord and branch out towards the hands of each arm. Injury to these nerves during birth may result in an arm that is paralyzed temporarily or permanently. This is called a brachial plexus birth palsy and can range from mild to severe. Children with more severe brachial plexus birth palsies can have serious long-term side effects such as weakness and sensory loss from injury to the nerve supply. We have observed that children with brachial plexus birth palsies may also be generally clumsier and have difficulty with balance and coordination. Our team is providing expert care in the acute management of this injury but we are unsure about the long-term effects of this injury on balance and coordination. This pilot study will evaluate the extent of the balance and coordination problems in these children using two special physiotherapy assessment tools. In addition to the tests of balance and coordination, we will also conduct a complete functional physical examination and will assess how well these children are managing basic daily tasks. This project is unique because it is the first long-term follow-up study focusing on balance and coordination in children with this injury. After identifying and quantifying the extent of the problem, we hope to be able to take steps to prevent this problem from occurring in the future.

**Co-Applicants: Doria Bellows**

**Amount Awarded: \$29,365**