

2021 Friends of Doernbecher Grant Recipients

Jamie B. Warren MD, MPH; Sandra Banta-Wright PhD, RN, NNP-BC; Megan Quinn PhD, RNCNIC

Project Title: Growing @ Home: Effects of an Early NICU Discharge Program on the Transition to Home and Breastmilk Feeding Success

Award: \$11,099.77

Admission to the neonatal intensive care unit (NICU) is frequently an unexpected occurrence that causes significant stress for families. One source of stress for parents is the unknown of when they will get to bring their baby home from the hospital. The most common reason that babies require continued NICU hospitalization is the inability to eat all feeds by mouth. In 2019, the Doernbecher NICU started a remote patient monitoring program called Growing @ Home (G@H), which allows babies to safely go home with their families while they learn to eat. While we have determined some of the financial impacts of this program over its first 2 years, we want to better understand the impact this program has on families, including the safe transition to home and support of successful breastmilk feeding. We will conduct semi-structured interviews with parents to elicit descriptions of their transition from the NICU to home, particularly the ways in which Growing @ Home influenced this transition. We will also email surveys to participants that will track breastmilk feeding status for these babies and determine the facilitators or challenges to continuing breastmilk feeding. We hypothesize that the Growing @ Home program will support families in a safer transition to home and more successful breastmilk feeding—truly focusing our care on the family. Through the support of a Friends of Doernbecher grant, we aim to prove that the Doernbecher NICU's Growing @ Home program should be the standard of care for NICU babies who are learning how to eat, not only in Oregon, but beyond.

Mohammad Alnoor, MD; Lars Grosse-Wortmann MD; Cristina Fuss, MD

Project Title: Infrared thermographic imaging: A point of care test to detect femoral vessel thrombosis in pediatric patients after cardiac catheterizations

Award: \$32,838

Arterial blood clots are a common complication after cardiac catheterization in young patients and can result in significant short and long term impacts.

Cardiac catheterization is an important part of treating patients with congenital heart disease. However, vascular complications at the insertion sites are common with rates reported as high as 23% in neonates. (Glatz, Catheter Cardiovasc Interv. 2013) The development of a femoral arterial blood clot can result in pain, leg length discrepancy, and even limb loss. Prompt identification of the clot and initiation of blood thinners are key to preventing these complications. Vascular ultrasound imaging is required to confirm or rule out a suspected vascular occlusion. However, due to the cost and time involved it is often implemented as a second line study and more clots may be missed than detected. (Kamyszek, Catheter Cardiovasc Interv. 2019) In order to arrive at

an accurate diagnosis more quickly, a more cost effective and reliable point of care method to detect these arterial complications is desirable.

Infrared thermography (IT) has the potential to make cardiac catheterization safer for children and infants.

IT uses the natural infrared radiation that is emitted from human skin to create an infrared color map, based on its temperature, which is directly related to blood flow. The aim of our proposed study is to evaluate the ability of IT to accurately identify femoral (leg) artery clot as compared to vascular ultrasound in children after cardiac catheterization procedures. Eligible pediatric patients undergoing catheterization procedures will be imaged using ultrasound and an infrared camera, using their contralateral leg as comparison. Patients with confirmed clot by ultrasound will be reimaged at a second time point to assess for clot worsening or improvement by serial IT. We will be including 100 patients under the age of 10 years, over a 12 months period. We are requesting funding, primarily to pay for the infrared cameras and for the clinical vascular ultrasounds that will be used as a gold standard.

Expected results, study significance and future directions

We hypothesize that there will be a significant difference in thermography profile of the lower limb that contains a blood clot, mirroring the results of vascular ultrasound. If confirmed, this study will support routine use of this technology in the post catheterization care and monitoring of patients. Future applications of IT will be other vascular territory compromises as well as assessment of tissue perfusion variations, for example as a response to drug treatments.

Jennifer Huang, MD; Alissa Lyman, PA

Project Title: Virtual Pediatric Cardiac Rehabilitation at Doernbecher

Award: \$6,900

Cardiac rehabilitation is a supervised program for people with heart failure or those who have undergone a cardiac surgery. It is designed to provide a safe, supportive and engaging environment to complete exercises that will, over time, lead to optimal heart health and quality of life. Additional benefits may also include reduced need for medication and fewer hospitalizations. For the adult population, cardiac rehabilitation has been a standard of care for patients following cardiac surgery for many years.

Until now, for pediatric patients with heart problems, the primary focus has been on survival and surgical outcomes and rehabilitation programs have not been developed to meet the needs of these children. Research has shown that children with the most severe forms of congenital heart disease have a predictable and often steep decline in their exercise capacity². This means that by the time they reach early adulthood, they may start developing heart failure symptoms. Cardiac rehabilitation programs have been shown to change this trajectory, not only in the short term during the program, but extending years beyond. The second target outcome of a cardiac rehabilitation program is the children and parent's quality of life. When a child is born with heart disease and has to undergo one or many open heart surgeries, the natural inclination among caregivers and the children themselves is to exclude themselves from heart healthy activities such as recreation sports or PE classes in school.

There is a shift beginning in pediatric cardiology and we are starting to recognize how negatively impacted our patients' quality of life is by their heart problems and additionally, how negatively their heart is impacted by inactivity. There is a great deal of adult research and emerging pediatric data to show that Cardiac Rehabilitation has a profound positive impact not only on objective measures of exercise capacity, but also on patient centered quality of life outcomes.

Cyndi N. Williams, MD, MCR; Trevor A. Hall, PsyD, ABPdN

Project Title: Sleep disturbances among critically injured children: Novel early sleep intervention to optimize recovery after traumatic brain injury

Award: \$38,846

Each year, more than 60,000 children nationally are hospitalized for traumatic brain injury (TBI), including hundreds in Doernbecher's pediatric intensive care unit. Survivors suffer a constellation of chronic physical, cognitive, emotional, and social problems. Further, there are currently no evidenced-based interventions shown to improve recovery from pediatric TBI. **Our pioneering research shows sleep problems complicate recovery in over 50% of pediatric TBI survivors, leading to worse physical, cognitive, and emotional morbidities as well as worse quality of life. This is a vital finding because sleep problems are MODIFIABLE through intervention.** Our multidisciplinary team expertly treats pediatric TBI survivors with a holistic approach as part of OHSU's award winning Pediatric Critical Care and Neurotrauma Recovery Program (PCCNRP) at Doernbecher Children's Hospital. Utilizing the well-established PCCNRP infrastructure, this proposal will test a novel early intervention, rather than waiting weeks to start therapy when sleep problems are established, and will advance translational science seeking to understand mechanisms of differential response to intervention.

We hypothesize combining a developmentally tailored cognitive behavioral therapy intervention (for children and their parent/caregiver) while still hospitalized with online supplemental resources targeting healthy sleep will significantly reduce sleep problems. **This is critical because a successful and generalizable early intervention that PREVENTS sleep problems after TBI would greatly accelerate recovery given the importance of healthy sleep to healing of the injured brain and its development during childhood.** Restoring healthy sleep will improve the trajectory of recovery from TBI across global health domains (e.g. physical and family functioning, social reintegration, emotional wellbeing, academic performance, etc.). The proposal's resulting online resources will directly benefit Doernbecher families for years to come struggling with sleep problems. In addition, biomarker data collected in this proposal will further our team's ongoing and innovative research, which seeks to improve recovery from pediatric critical illness and trauma through early, personalized interventions.

Trisha Wong, MD, MS

Project Title: Doernbecher Children's Hospital SCD Transition Pilot Program

Award: \$14,400

Sickle cell disease (SCD) is a chronic, inherited disease of red blood cells that contributes to high rates of medical complications and early mortality. Most patients living with SCD are Black or people of color. Medical care becomes particularly complex in adolescence and young adulthood as our patients age-out of their pediatric clinics and when we see usage of evidence-based interventions decrease, rates of complications and hospital admissions increase, and the effects of inequitable care become magnified. Copious evidence proves that structured transition

programs that facilitates smooth and gradual transition from pediatric-based to adult-based healthcare improves quality and quantity of life. Yet, few programs at DCH and OHSU, including OHSU's Hemoglobinopathy Program, have structured transition programs. This puts our already vulnerable patients who suffer from discrimination and chronic illness at even more risk. Other data shows that having more social and community support also improves mental and physical health. In partnership with the Division of General Pediatrics and with our regional SCD community-based organization, we propose a family-centered transition program to be built and piloted within OHSU's Hemoglobinopathy Program. As policies and procedures are created and integrated into clinical care, the model can be expanded to other programs that serve high-risk patients with chronic healthcare needs. This transition program proposal includes three main mission: a clinical mission to create family-centered transition policies and procedures, an education mission to educate providers, patients and their families, and a community mission to better partner with our patients and families to build a stronger clinical and social support during transition.