



CAROLINA FOR THE KIDS

2022 Carolina For The Kids Foundation Grants

UNC Children's Bereavement Events

Project Director: Mary-Claire Derrickson and Meg Kihlstrom

Project Abstract: In April 2017, we provided the first "Seasons to Remember" event for families of children who had passed away in the Pediatric Intensive Care Unit at UNC Children's Hospital. Since that time, the involvement has increased as the support extended to all families experiencing a death at UNC Children's Hospital in the PICU, Hematology/Oncology, 5CH, 6CH, 7CH and Emergency Department. UNC continues to see an increase of the number of pediatric deaths. As a result, the number of families needing bereavement support continues to increase. In addition to Seasons to Remember, UNC Child Life staff created a sibling bereavement support program called SibsCARE with the generous financial assistance from CFTK. Through the works of the interdisciplinary staff members used to conduct such events, the SibsCARE and STR teams will be combining efforts to provide consistent bereavement care and events for UNC Children's Hospital. Grant funding will support these efforts by allowing two family-centered events as well as two sibling-specific events to take place each year. With feedback from the families who have participated in such events, there is benefit to both a therapeutic and memorial event as well as social meet-ups to allow families to connect, share stories and find support from one another through similar experiences.

Pediatric Diabetes On the Go Bags

Project Director: Katherine L. Cooper

Project Abstract: A new diagnosis of Type 1 Diabetes can be overwhelming for both the child and the family. UNC's Pediatric Diabetes Program aims to educate our patients and their families at the time of diagnosis. Equally important is empowering them to undertake the management of what will be a serious, chronic, lifelong medical condition. Patients/families must: understand what diabetes is; learn how to monitor food and drink intake and physical activity; and be able to identify other factors that can affect blood glucose levels in order to accurately and safely administer insulin multiple times daily. UNC's program is the only one in the state of NC to offer patients a comprehensive outpatient diabetes education curriculum from the time of their diagnosis. This rapidly expanding program, started in 2016, now enrolls, on average, 120 new patients per year from all across the state, for a total census of 800 patients. Offered at both UNC Hospital in Chapel Hill and UNC Children's Specialty Services at Raleigh, the program consists of four to six appointments. During these visits, our staff present the patient and family with support, as well as a large amount of information and educational materials, so they can quickly master such skills as counting carbohydrates and calculating/injecting insulin doses. We recognize that our families incur significant expenses to cover the medications/supplies needed for the daily care of their children. We are seeking funding for "On the Go Bags." Each bag would contain items specific to each patient's educational needs and supplies to support individualized treatment plans. It would also contain enough non-prescription supplies to cover two weeks of care so that our patients have the necessary supplies at home and at school to maintain safety. The bags will hold such items as diabetes literature, Buzzy pain relief aids, a reusable carrying bag, an insulated bag for

supplies and insulin pens, 1Plate nutrition handouts, adhesive patches for glucose monitoring systems, adhesive remover wipes for glucose monitoring systems, and diabetes alert medical bracelets. These bags will provide families with resources they can use immediately as they learn to adjust to life with diabetes.

A Spacer For Spacers

Project Director: Barbara Gwinn, RN, AE-C

Project Abstract: Patients who suffer from asthma must use a spacer with a metered dose inhaler (MDI) to ensure the medication is effective. Gamble, et al. (2020) states using a spacer allows for the most effective way for a patient to receive inhaled medication for asthma. The spacer allows for optimal delivery of medication into the lungs. Thus decreasing asthma exacerbations. Furthermore, Root, et al. (2019) adds a significant issue is the management and control of asthma is incorrect use of spacers and asthma medications. According to the Global Initiative for Asthma (GINA) estimates that up to 80% of individuals with asthma and 67% of health care providers cannot demonstrate correct inhaler technique (GINA, 2016, 2019).

Developmental Feeding Tools for Feeding Team Patients & Their Caregivers

Project Director: Anne Adams

Project Abstract: Pediatric Feeding Disorders (PFD) affect all members of a family and cause additional stress when caregivers are unable to access and acquire developmental feeding tools. Many caregivers in our clinic are unable to purchase feeding tools for their children due to financial difficulties, store scarcity or lack of local resources. We would like to provide our patients and their caregivers with the support needed to improve the home feeding setting and quality of the child-caregiver feeding relationship.

Embrace2 Seizure Detection Device

Project Director: Alyssa Draffin

Project Abstract: As of 2020, nearly 500,000 children in the United States are living with active symptomatic epilepsy and it is the fourth most common neurological condition worldwide. New cases of epilepsy are most common in children, particularly from birth to age 1. For many people, the disease can be controlled with effective seizure-management practices, such as avoiding seizure triggers and including the support of an epilepsy specialist. For children with the most severe types of difficult to control epilepsy, there are steps families can take to lower one's risk, including epilepsy surgery, neurostimulation devices, dietary therapies, and seizure detection devices. The Embrace2 seizure detection device is the only FDA-cleared wrist-worn wearable in epilepsy. It detects possible convulsive seizures and instantly alerts caregivers, whether they're sleeping next door or across town. Any child with tonic/clonic seizures could benefit from this device, however, the cost of \$250.00 is prohibitive for low-income families, which are the majority of our population. This device not only tracks seizures, but exponentially increases quality of life of both children and parents. One Embrace 2 parent of a pediatric patient said "the Embrace Watch for me means I can fall asleep knowing I am a little safer against SUDEP. It means lower rates of depression for myself. It means more freedom for me during the day." Two years ago, we were awarded a grant to receive 6 devices for our families and all of them were ordered in less than a month span. Last year, we were awarded enough for 8 devices, and they were all ordered within less than 2 months. This demonstrates the true need for funding to provide additional devices to our families to reach low income, uninsured or Medicaid recipients to help address these health disparities and provide low-income families with the same access as their higher income counterparts.

Supporting Drug Exposed Infants in the NCCC

Project Director: Lauren Quinn

Project Abstract: Each year, the UNC Newborn Critical Care Center (NCCC) treats over 900 newborns from more than 50 counties in North Carolina. UNC's NCCC is focused on developmentally supportive care for a variety of preterm and critically ill infants to include those exposed to drugs and toxic substances while in utero.

Intrauterine Drug Exposure (IUDE) is a condition for which a fetus is exposed to a noxious and/or toxic substance (examples include amphetamines, barbiturates, cocaine, marijuana, opioids and alcohol) taken by the mother while pregnant. In the last 15 years, there has been a fivefold increase in NAS, which is associated with the rise of opioid use during pregnancy (Brandt and Finnegan, 2017). This puts a heavy burden on health resources since these newborns require prolonged medical treatment and longer hospital admissions (Ornoy, 2013). Maternal use of toxic substances can cause an infant to become dependent upon the drug which results in congenital syndromes and/or withdrawal behaviors upon delivery.

Within the NCCC, it is our role to care for each infant to the best of our ability, yet most drug exposed infants require more time, attention and forms of stimulation that a single caregiver can provide. Our Carolina for the Kids grant request is for items to better support intrauterine drug exposed infants while they are admitted to the NCCC through use of non-pharmalogical interventions. The items below (to include Tranquilo Mats, Lullavibes, DandleWraps, DandlePALs and MamaRoo Swings) will address the severe agitation frequently experienced by these infants, offering them comfort, improved sleep and healing.

Our Neonatal Critical Care Center thanks you for your consideration in assisting us in providing developmentally appropriate medical care for the infants of North Carolina.

Transplant & Dialysis Pediatric Patient Assistance

Project Director: Kimberly A. Lemasters, MPA

Project Abstract: UNC Center for Transplant Care provides lifesaving transplants (heart, lung, liver, kidney, and pancreas) to the pediatric patient population that often can require multiple transplants over time. Additionally, kidney transplant patients often require dialysis prior to transplant. Pediatric patients and their families face the same financial challenges as adults dealing with a chronic medical illness, and also experience pediatric specific complications. Through this grant, we hope to increase our support of pediatric transplant and dialysis patients and their families in need.

Adaptive Stroller Project

Project Director: Alyssa Draffin

Project Abstract: People with developmental disabilities often benefit from the use of assistive devices and adaptive equipment for daily living. This equipment is needed to keep them safe at home, at school and in the community and helps foster a sense of independence. Adaptive equipment specifically, adaptive strollers with head supports are crucial for children to live as normally as possible. Unfortunately, the funding for these items is limited. Insurance coverage, even for pieces of equipment that can be justified as medically necessary, is often limited or denied. Sometimes there are pieces of equipment that will significantly improve quality of life, but insurance companies will identify these as "items of convenience". To add to the barriers family's face, there are the often long wait times families must endure as insurance companies deliberate through denials and appeals for coverage. This project will allow direct access to a light weight adaptive stroller with heads supports, to keep the child mobile and safe.

UNC Rex - Smileyscope Initiative

Project Director: Marshall Alexander Ahearn

Project Abstract: In early 2020, UNC Children's extended their care to children in Wake County through the establishment of an inpatient pediatric service at UNC Rex Hospital. Since that time, UNC Health has continued to grow our services in the region with the expansion of UNC Children's Specialty Clinics and UNC Children's Urgent Care in Raleigh.

Services for children admitted to UNC Rex Hospital have also continued to expand, but there remain significant opportunities for improvement. Children admitted to UNC Rex receive high-quality medical care, but they don't have access to a Child Life Specialist to help them through the more challenging aspects of their experience. Smileyscope is an award-winning tool that uses virtual reality to help children through common medical procedures, such as blood draws, IV placement, and prolonged imaging studies. Peer-reviewed data suggests the use of Smileyscope during procedures can decrease a child's reported pain, caregivers' anxiety, and reduce the use of medications and restraints when performing needed medical evaluations. The opening of the pediatric service at UNC Rex allows hospitalized children to be cared for closer to home. Smileyscope is an opportunity to ensure their hospital experiences are as positive as possible, reducing children's emotional distress and helping them cope with and recover from illness.

Children and their families have borne tremendous stressors since the onset of the COVID pandemic. By attending to their emotional well-being, we can help them navigate illness with resilience and minimize the burden of each hospitalization.

Helmets for the Kids – Providing Children and Adolescents with Helmets to Prevent Serious Traumatic Brain Injuries

Project Director: Elizabeth O'Neil

Project Abstract: Unintentional injuries are the leading cause of morbidity and mortality among children in the United States. In particular, bicycle use leads to the highest number of sport and recreation-related emergency department visits for traumatic brain injuries in the United States³. Helmet use in children and adolescents is one of the most effective measures to prevent serious injury during a bicycle-related crash². There is good evidence to support that in bicycle crashes, correct helmet use reduces serious head injuries by 60%². Helmet use can be as low as 20% in children, and is even lower amongst children who are black or insured by Medicaid¹.

As a pediatric resident at UNC, I have cared for several patients in the pediatric ICU who have suffered from traumatic brain injuries. While most of these patients did not sustain their injuries from bicycle-related crashes, seeing the challenges these children and their families face when recovering from a traumatic brain injury has motivated me to try and implement measures to prevent the injuries from occurring in the first place.

Part of our job as pediatricians at a child's annual visit is to focus on a child's overall wellness. In addition to working to identify potential medical problems, it is also important to identify ways to prevent future health problems to keep a child healthy throughout their growth and development. Many children do not wear a helmet simply because they do not own one. Given how important helmet use is to prevent potential traumatic brain injuries, my goal is to provide a child with a helmet in our clinic as well as to provide parents with the information to ensure their child's helmet fits appropriately to help keep them safe and prevent future injuries.

Cuffs & Scales for Kids

Project Director: Rebecca Wellborn, RN, MSN

Project Abstract: The children of North Carolina who live with chronic kidney disease receive outstanding care at UNC Children's Hospital, and we are constantly searching for ways to make that care even better. One way to

improve care is to provide these children and their families with the equipment they need at home to monitor blood pressures and weights on a daily basis.

While many families have the financial means to purchase blood pressure cuffs and home scales, there are families who do not have the financial means to make this purchase. These are the very families who we find to be most medically vulnerable. Any assistance we are able to provide has the potential to offset a lack of resources in other areas of need, such as medications. It is an unrealistic expectation and a burden on these families to have blood pressure and weight monitored every day at the pediatrician's office, or some other location, outside of the home. Further, evidence has shown that monitoring blood pressure and weight at home with the same equipment and operator provides more accurate data, therefore providing a more accurate picture of disease management. It is our hope that by joining with Carolina for the Kids to provide home blood pressure cuffs and scales, there will be a decrease in hospitalizations, a decrease in the length of stay for necessary hospitalizations, and there will be an overall increase in the quality of life for both the child and the family.

Diabetes Camp Scholarships

Project Director: Katherine L. Cooper

Project Abstract: One in 400-600 children, in the United States, has insulin dependent diabetes mellitus (IDDM). A unique aspect of being a child with diabetes is learning to successfully become an independent adolescent and young adult with IDDM. A significant number of children with diabetes will show decreased compliance and worsened metabolic control during adolescence as parents attempt to transition diabetes care responsibilities to the child. Studies have shown, however, that children who participate in a specialized camp for children with IDDM achieve a higher level of self-care activity and, in turn, maintain better metabolic control. North Carolina offers several overnight camps in that provide children and adolescents with diabetes a specialized camping experience over a 6-day period. Campers are given the unique opportunity to interact with age matched peers who also have diabetes. Campers participate in activities such as hiking, swimming, canoeing, and arts and crafts while learning about leadership, teamwork, and community. This grant would allow the Pediatric Endocrinology Department at UNC the opportunity to award 3 scholarships to patients at UNC Healthcare who could otherwise not afford this incredible opportunity.

It's in the Bag: Homecare Products for enhanced Compliance and Safety in Pediatric Bone Marrow Transplant Recipients

Project Director: Karen Lynn

Project Abstract: Pediatric stem cell transplant patients require intensive monitoring even after discharge as their risk for infection and other complications is high. A majority of UNC pediatric SCT patients have limited financial resources making the purchase of essential home care items a challenge. For example, hand sanitizer and disinfecting wipes are crucial to keeping the environment free of germs, while thermometers are critical to the early detection of infection. Most SCT recipients go home with a central line and also require daily showers or baths. A waterproof central line covering is essential. Children often also go home with IV fluids. Play and movement are essential to healing. A fannypack provides children freedom to do both by holding supplies and infusion equipment. IV fluid use also leads to bed wetting which in turn interrupts sleep and can lead to skin breakdown. Washable bed pads can be changed quickly with minimum sleep disruption. Many of our patients go home on complex medication regimens. A compartmentalized pill box enhances medication compliance. Skin sensitivity is a frequent byproduct of SCT. Use of effective, general soap, lotion, and daily sunscreen is essential to skin health. Finally, many of our patients get chemotherapy that requires bathing every six hours to prevent chemotherapy burns. The use of a small swimming pool during bath time makes the bathing experience less traumatic. This grant affords pediatric SCT recipients optimal home care and we believe, better health outcomes.

Death and Dying Support and Legacy Memory Making

Project Director: Sarah Frantz

Project Abstract: Child life provides positive coping environments for families experiencing traumatic, life altering, and end of life situations at UNC Children's Hospital including children of adult patients throughout the medical center.

Child life meets with family members while visiting the hospital to assess a child's cognitive understanding of death and how to further this education with developmentally appropriate language. Tools utilized while providing this support in the hospital include workbooks and books. These tools are provided to both younger family members and caregivers to help guide conversations in the home setting as well.

Child Life also encourages bonding between families and patients with the creation of memory making keepsakes while in the hospital. These items include ink prints, plaster molds of hands and feet, pendant charms, wooden heart ornaments, in addition to mailing costs to send these keepsakes to families' homes.

Child Life continuously receives feedback on how meaningful and appreciated emotional support and memory making is for families during these times:

"Like any parent, I treasured the time I had caring for my infant daughter: holding her, feeding her, bathing her, dressing her. When she became critically ill ...the only thing I could safely do was hold her hands and stroke her feet... After her death, I was presented with beautiful, perfect molds of her hands and feet by the child life team. The grief of losing a child is overwhelming and enduring, but when I hold them, I feel for a moment like she is back with me."

"We have had the ability to provide our families with beautiful memory charms to continue honoring (patient), but my husband and I appreciate the molds and beads more than anything...with every single detail down to the creases in his hand and imperfections in his tiny cuticles. We have tangible items that we can continue to cherish and appreciate them so much more following his passing."

With the support of CTFK grant assistance, Child Life would have the ability to continue and expand support for families experiencing traumatic and life changing experiences at UNC Children's.

UNC Turner Syndrome Clinic Educational Materials

Project Director: Jennifer Law, MD, MSCR

Project Abstract: Turner syndrome (TS) is a chromosomal abnormality affecting about 1 in 2,000 females. TS occurs when one of the X chromosomes is completely or partially missing and can cause a variety of medical and developmental problems including short stature, premature ovarian failure, heart defects, hearing loss, learning disabilities, and social adjustment problems. When patients and their families first hear of the diagnosis of TS, they are often overwhelmed by its complexity and potential gravity and seek information about the condition. While some families and patients learn about TS solely from discussions with their medical providers, hard copies of educational materials are invaluable for families to reference. Therefore, trusted guides should be made available to families for their reference.

One such guide is the "Turner Syndrome: A Guide for Families," by M. Davenport and P. Rieser, former members of UNC Pediatric Endocrinology. Dr. Davenport founded the UNC Turner Syndrome (TS) Clinic, and Ms. Rieser was a family nurse practitioner with UNC Pediatric Endocrinology. This booklet was written to address the main questions and concerns raised by families and patients facing a new diagnosis of TS. "The Clinical Practice Guidelines for the Care of Girls and Women with Turner Syndrome: Brief Synopsis for Turner Syndrome Girls and

Women and for Their Parents/Caregivers/Families” is a booklet which summarizes the 2017 “Clinical Practice Guidelines for the Care of Girls and Women with Turner Syndrome,” by C. Gravholt, et al. This booklet is a practical guide for families to understand the most recently published guidelines. It has empowered many families and patients to advocate for proper medical care. These booklets are now published in English and Spanish through the Turner Syndrome Society of the United States and are available for purchase.

The UNC TS Clinic is one of the largest TS clinics in the United States, providing multidisciplinary care to approximately 110 established individuals, and approximately 40 new patients per year. I am seeking \$1,200 to purchase these booklets for patients who have never received these resources, recently referred patients, and newly diagnosed patients with TS.

Nutrition kit for infant with cystic fibrosis

Project Director: Kelly Baumberger

Project Abstract: Cystic Fibrosis (CF) is a progressive, genetic disease with impacts to the respiratory system and digestive tract. A build-up of mucus in the pancreas prevents the body from properly digesting and absorbing nutrients, which results in malnutrition and poor growth. Medical Nutrition Therapy is an integral part of CF care. Parents of infants are taught to administer pancreatic replacement enzymes and sodium and to monitor the weight of their child at home. Specific supplies are needed to complete these tasks and they are key to an infant with CF growing and thriving early in life. This early good growth is, in turn, associated with better outcomes later in life such as lung function and survival.

Empowering Families Through Developmental Play in the Neonatal Critical Care Center

Project Director: Sara Hammond

Project Abstract: Each year, the UNC Newborn Critical Care Center (NCCC) treats over 900 newborns from more than 50 counties in North Carolina. The NCCC aims to empower families to learn skills within the NCCC that can be transferred home. By promoting families’ self-efficacy to care for their infants, we are positively impacting infants’ neurodevelopmental outcomes, infant weight gain, and parental mental health (Carter, Willis, Knackstedt 2020 and Kim and Kim, 2022).

At UNC, Neonatal Occupational and Physical Therapists work diligently to spend time with each infant’s parents, educating on how to support their infant’s development through play, positioning and stimulation. A large part of this education includes modeling the home environment and providing hands on practice to empower parents to take an active role in supporting their infant’s neurodevelopment in the hospital and at home.

Currently during therapy sessions, neonatal therapists utilize floor mats and developmental items to educate parents on how to appropriately handle and stimulate their baby. Our neonatal therapists bring these items to the bedside for hands on use during a session and remove them in order to utilize these items with other infants and families on the unit. The goal of this project is to move toward a model where these resources (floor mat, developmental items) remain in the each NCCC pod, thus allowing parents to engage their infant in age-appropriate play whenever they wish. The NCCC is divided into 7 large rooms or pods, each with 6 to 10 beds. We are requesting funding to supply each pod (7 in total) with a floor mat and developmental items in order to provide families with access to the items needed to follow through with education provided for the developmental growth of their infant. In doing so, we hope to promote families’ confidence to directly impact their infants’ neurodevelopmental outcomes and more appropriately support families as they prepare for discharge home.

We greatly thank you for your consideration in funding a project to support our NCCC infants and their families.

CAS Activity Kits

Project Director: Alex Keown

Project Abstract: The number of adolescent and youth reporting or being evaluated for mental health crises is increasing. Promoting and teaching the importance of coping skills are crucial for the development of children and adolescents. The CAS Activity Kits is created for adolescent/youth to promote appropriate emotion regulation, coping skills, social skills, and leisure interest. The kits consist of various activity resources and tools for independent use. Some resources include journals, reading books, musical items, arts & crafts and sensory items. Additionally, the kits will include age-appropriate educational handouts for coping skills and leisure interests. Addressing healthy alternatives to emotional dysregulations during childhood and adolescence is important for development and mental health.