



CAROLINA
FOR THE KIDS

2020 Carolina For The Kids Grants

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, but 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.

Children's Specialty Clinic Child's Play Project

Project Director: Jennifer Ragan

Project Abstract: In 2016-2017, we received our first grant from Carolina for Kids to support the start of the Children's Specialty Clinic Child's Play Project. We were fortunate to receive another in 2017-2018, 2018-2019 and 2019-2020. With these funds, we provide artistic and interactive educational opportunities for the patients and their families to enjoy. Since beginning this project in 2016, we have been able to expand the activities. The NC Zoo continues to come and set up a table in the lobby for 4-hours with educational and hands-on learning opportunities twice a month (\$300/visit). This exhibit allows children to ask questions about animals and the habitats in which they live. They are also encouraged to respect the environment around us to help protect the animals. Children also have the opportunity once a month to listen to stories read by a local storyteller (\$150/visit). She dresses up in various kid-friendly costumes and roams the lobby going to each patient individually to interactively read. We are looking to continue these activities that our patients have enjoyed. We also hope to expand on the activities to expose local artists/musicians

and/or educational exhibits to expand the minds of our children and provide a fun, educational experience while patients and their families are waiting to see their provider.

Distraction for Pediatric kids (Use of IPADS)

Project Director: Gloria Nonnemaker

Project Abstract: This is the UNC ASC Surgical Services applying for this grant for our pediatric surgical patients. The children go through a tremendous stress pre and post surgery, and thus need a lot of distraction to calm them. We as nurses and providers have been using our phone devices to help calm the children. We are hoping to use this grant to purchase IPADS to have games or kids shows to help the children cope better before and after surgeries. It will mean a lot to parents, guardians and also staff. Thank you for giving us such an opportunity to apply for this grant.

Improving Family Experiences of Care for Seriously Ill and Dying Children

Project Director: Mariah Kaitlyn Boudreaux

Project Abstract: The Children's Supportive Care Team, a pediatric palliative care consult service, was established at the UNC Children's Hospital in 2012 to better address the needs of seriously ill children and their families. Our initial funding was courtesy of the UNC Dance Marathon, now Carolina FTK! Our team includes physicians, nurse practitioners, a child psychologist, and a social worker. We see children with serious illnesses who are at risk for uncontrolled symptoms, challenges to normal growth and development, and sometimes shortened life expectancy because of their condition. Their families face complex medical decisions and some families unfortunately also face the death of a child from a serious illness. Each year, we participate in the care of approximately 250 seriously ill children, including 30-40 who unfortunately do not survive. Losing a child is arguably the most difficult and traumatic experience for a parent, and impacts the entire family as well as the community around the child. We propose funding for supplies to support the practical needs of children and families during difficult hospitalizations and around the end of life. The items we hope to provide to them are intended to ease suffering, reduce complicated grief, and promote healing for the entire family.

Model MRI

Project Director: Kelly Clark

Project Abstract: When children need an MRI, there are many factors that can make this experience overwhelming from the equipment in the room to the sounds of the machine. They are also required to lay down motionless for about 30-60 minutes. For any child, being still for that long is not an easy task and, in the instance where a child cannot be still, they will have to go through sedation under general anesthesia. The child life specialist provides preparation for the sights, sequences, and sensations of the machine and can help a child plan strategies to remain still. Research has shown that preparation with a child life specialist reduces the need for sedation for an MRI. A model scanner allows the child life specialist to provide hands-on preparation prior to the actual MRI.

Seasons to Remember

Project Director: Meg Kihlstrom

Project Abstract: Since 2017, we have offered a "Seasons to Remember" event for families of children who received care at UNC Children's Hospital that have passed away. Initially starting with only patients in the Pediatric Intensive Care Unit, the event has now grown to include the entire Children's Hospital. The event, which is held in Chapel Hill, allows families to remember their children, connect and empathize with other families, and reconnect with hospital staff that cared for and loved their children. Grief counseling, coping activities, and resources are provided for families as well. We hope this event continues to grow and evolve to support the families of UNC Children's hospital.

Burn Prevention/Awareness

Project Director: Kelly Clark

Project Abstract: As a member of the burn team, I see pediatric patients and families who have experienced the trauma of an often preventable burn injury. In the absence of formal prevention education from the burn center, I have felt a responsibility for offering this education to current and future patients and families (meaning guests of the hospital). Each year, Fire Prevention Week is recognized in October and Burn Awareness Week in February. I organized a group this year to host an education fair and had great success with offering fire safety devices, prevention information, and other incentives for attending. The group would like to expand this with official funding so that we can have a bigger draw including children and their family members.

Community Reentry Preparation

Project Director: Kelly Clark

Project Abstract: At times, pediatric patients have experienced an injury or illness that results in a significant change in physical appearance and/or functioning and leads to anxiety about returning to day-to-day life back home. One way to prepare for this is to take patients to hospital venues to practice "facing the public" and ordering food. With many diagnoses, there is a secondary benefit as diet plays such a crucial role in healing. Appetites wane and patients are at times not hungry or interested in the food an hour or more after they've ordered, so there is instant gratification and opportunities for choice in the moment when we can go to food venues. A community reentry program can help patients increase their caloric intake, while also addressing concerns about how to respond to people who stare or ask questions. Funds would be used to provide these reentry "outings" based on individual need and anticipated length of stay.

Getting Keto Started Kits

Project Director: Carolina Sodano

Project Abstract: "Since 2007, UNC Pediatric Neurology has used ketogenic diet therapies as an evidence-based treatment option for drug-resistant epilepsy. These therapies are medically-supervised diets that are very high in fat (more than 90% of total calories), and very low in carbohydrates, mimicking the effects of fasting. This results in the production of ketones as fats are broken down for energy. We utilize a variety of ketogenic diet therapies—the Classic Ketogenic Diet, the Modified Atkins Diet, and the Low Glycemic Index Diet—to better suit the needs of our patients and their caregivers. The program is supported by pediatric neurologists, nurse practitioners, a

clinical dietitian, a clinical social worker, and pharmacists. It has grown by 32% during the last year and we expect it to continue growing over the next several years.

Following a ketogenic diet requires significant commitment from patients and caregivers, who must learn how to calculate recipes, prepare keto-friendly foods, and adhere strictly to the diet plan. Since mealtime plays an important role in socialization and development, starting the diet can be very stressful to caregivers as they adjust to feeding their children differently. For many of the families followed by our department, this stress is compounded by financial hardships associated with initiation of the diet (ex: purchasing of specialized equipment such as gram scales). Financial hardship can jeopardize a family's commitment and compliance to the diet.

We propose easing the burden for families starting a ketogenic diet by offering a Getting Keto Started Kit. The Carolina for the Kids grant received in 2019 was used for building starter kits, which were extremely well received by families. Patients initiating the diet are often admitted to ensure a safe metabolic transition into ketosis. During this time, the clinical dietitian spends an average of 14 hours with caregivers for teaching (paramount to success and patient safety) and preparing foods/formulas at bedside. We encourage the families to use the equipment provided with the Getting Keto Started Kit in the hospital setting, allowing them to become familiar with the tools required and increasing the likelihood of long-term compliance with dietary therapy."

Kids Can Cope

Project Director: Jordan Hulliger

Project Abstract: Kids Can Cope is a project to teach coping skills to children with acute or chronic medical issues in the Children's Specialty Clinic. Story books pertaining to different facets of children's coping will be chosen monthly and will be accompanied by a craft that complements the story while reinforcing the coping skill covered in the book. Children's Specialty Clinic volunteers will be utilized to assist children and families with the crafts. Additionally, a resource board will be posted in the clinic to provide caregivers with more in depth information on how to utilize the coping skills with their children.

Newborn Critical Care Center Graduate Reunion

Project Director: Karen Hogan

Project Abstract: The Newborn Critical Care Center at N.C. Children's Hospital celebrates the successes of their patients and families every two years with a themed graduate reunion. Previous graduates and their families (who have been in the NCCC from 2 weeks to over a year) look forward to reuniting with the NCCC staff and providers who cared for them during their time in the Newborn Critical Care Center. The staff and providers enjoy celebrating the health and success of the babies they have cared for. In addition for the staff and families to mingle there are a range of exciting activities and entertainment. The event's success is shared through local news and social media outlets, The reunion benefits graduate families by allowing them to connect or reconnect, which can lead to a much needed social support network for these families.

Old School or New School: Teaching Teens Life Skills is Cool

Project Director: Lauren Jones, MS, OTR/L

Project Abstract: Many adolescents who experience depression, anxiety, and other mental health conditions have low self-esteem, difficulty with self-regulation, sensory differences, and cognitive impairments. These issues make it difficult to complete everyday tasks like caring for themselves, paying attention in school, communicating effectively, and forming healthy relationships. Additionally, many youths report experiencing stigmatization and social isolation as a result of their symptoms. By learning how to use vintage and modern technologies like machine sewing and 3D printing, patients in the adolescent psychiatry unit can improve self-esteem, social participation, independent living skills, and overall well being so that they can live more meaningful lives as students, friends, family members, and community members.

Sensory Based Intervention Items for the Child Psychiatry Unit

Project Director: Angela Scott MS, OTR/L

Project Abstract: We would like to provide sensory modalities to the children in the UNC Child Psychiatry Unit. These sensory tools will be used to reduce symptoms of mental health conditions and improve children's participation in their daily activities. Additionally, patients will be able to take these items home upon discharge so they will have increased opportunities to utilize learned therapeutic strategies outside of the hospital. Through the help of a Carolina for the Kids Grant, we would be able to impact 50 patients by providing them with at least one of these sensory modalities.

Sibling Bereavement Support

Project Director: Mary-Claire Derrickson

Project Abstract: The UNC Child Life department will organize seasonal bereavement support days for siblings beginning in the fall of 2020 for families who have experienced the death of a child in the past three years at UNC Children's Hospital. This will be the first event conducted within UNC Children's to solely focus on bereaved siblings. The hope is to reach the greater UNC Children's hospital with reaching patients from a variety of units or populations including PICU, 5CH, 6CH, 7CH and Hematology/Oncology. The hope is to include representatives from pastoral care, child life, psychology, and supportive care teams. Lunch and light refreshments will be provided for the day, as many families may travel for several hours to attend. As this event is specific to that of siblings, the therapeutic activities will be developmentally appropriate related to coping with and processing death. Topics to be addressed may include legacy building and memory sharing, grief management and coping strategies. Additionally, caregiver respite time will be provided for grief sharing and coping support.

Embrace2 Access Program

Project Director: Alyssa Draffin

Project Abstract: "UNC child neurology patients with Epilepsy experience heightened seizure activity, with some experiencing up to 10 seizures per day. With seizure activity comes increased psychosocial stress on the family, with both limiting daily activities for children and care providers, excessive worry and anxiety and an interruption in "normal" daily life and financial burden. The Embrace2 Seizure detection device is an FDA-cleared watch that uses advanced machine learning to detect generalized tonic-clonic seizures, and immediately notifies caregivers. It also provides rest

and physical activity analysis to better understand the child's lifestyle and ways to improve seizure activity. The problem with the Embrace2 watch is that only higher income patients have access to its services, as it costs \$250.00 up front and then an additional \$10 per month for the monitoring service. Additionally, the Embrace2 watch is not covered by any insurance companies, including Medicaid. Our goal is to be able to attain 6 Embrace2 watches through the FTK's grant to increase access for lower income families to address this health disparity. We would like lower income/Medicaid recipients to be able to decrease psychosocial stress by allowing them the same services as higher earning families. This would allow members of the child's support system to leave the pt with other caregivers or be able to extend their rescue distance at home. This would make an incredible impact on Child Neurology patients in the UNC Specialty Clinic."

Complex Care Appointment Adherence Program (CCAP)

Project Director: Amy Stewart

Project Abstract: Children with medical complexity (CMC) and their families experience a high burden of adverse social determinants of health (aSDH) that negatively affect child health and family wellbeing. In part, this may be because CMC rely on wide networks of community services, agencies, and financial support to access needed services. In the UNC Children's Diagnostic Clinic and Complex Care Program, we have prioritized addressing aSDH as a core component of the service we provide, and have developed and implemented a systematic screening process for aSDH among our enrolled families. In screening just under half our enrolled families, 27/46 (59%) have reported at least one aSDH, with over half of those reporting financial hardship with basic necessities such as obtaining food and getting their child to medical appointments. We believe these important problems contribute to family stress and lead to missed appointments, which adversely affect families and the health care system. As such, we will provide direct assistance through food and parking vouchers to eligible families in our clinical programs who report transportation barriers to receiving care for their child at UNC. This project will serve children and families cared for longitudinally in either our Complex Care Program or in the Child Diagnostic Clinic. We expect the level of need to be high. Among 134 patients eligible for the Complex Care Program, 95 (71%) have primary Medicaid insurance. The rate of hospitalization is high, with 79 hospitalized at least once in the past 12 months. The total number of hospital stays at UNC for those 79 patients was 180, an average of 2.3 hospitalizations per patient per year. Among all 134 patients, there were an astounding 2,192 outpatient visits with physicians or nurse practitioners at UNC in the past year, an average of 16.4 outpatient visits per patient per year. For our clinical programs and for UNC Hospitals, we believe the costs of providing assistance will be far outweighed by the benefits to patients and families and, perhaps, by a reduction in the number of appointments missed for preventable reasons.

Developmental Approach to SIDS Prevention Initiative in Carolina Infants

Project Director: Anna Lyaifer, PhD, RN, CCRN, CLNC

Project Abstract: "Newborn Critical Care Center (NCCC) nurses at UNC Medical Center strive to ensure a holistic developmental approach to SIDS prevention initiative and promote awareness about baby sleep safety among all segments of the North Carolina population. We would like to continue the use of Halo SleepSack wearable blankets and swaddles in the care of the NCCC infants because they prevent SIDS, remind all caregivers to put babies to sleep on their backs, reduce the risk of overheating, and promote healthy hip development. Halo SleepSack wearable blankets and

swaddles are # 1 choice of hospitals and parents to provide a safe and comfortable sleep environment for their babies. We need to carry on the use of the "Sleep Baby, Safe and Snug," board books from Charlie's Kids Foundation, in English and Spanish versions. "Sleep Baby, Safe and Snug," board books provide the safe sleep message in the context of a beautifully written and illustrated children's story. The board book is an effective education tool due to the simpler language, appealing illustrations, emotional connection, and repeated exposures via shared reading. Because books are often a part of the traditional bedtime routine, this board book provides safe sleep instructions and reminders right before the child is placed in their sleeping environment. We will use this book to raise awareness and support of SIDS by educating families, providing resources for new parents, and promoting dialogue about SIDS and safe sleep practices. The NCCC shares the goal of Charlie's Kids Foundation and the American Academy of Pediatrics (AAP), to become passionately focused on strengthening the outreach for SIDS education and safe sleep education. We would like to start using NeoTech utility device holders, "NeoHug," as well as NeoPockets personal incubator organizer. The cute and versatile NeoHug was designed to hold a pacifier, a suction tip, a roll of tape, and more. The long, bendable arms stretch out in all directions to hold a variety of items. Best of all, it features a large suction cup which means NO TAPE! The NeoHug sticks to most smooth surfaces and can be easily removed without leaving any residue behind. Perfect for NCCC incubators. NeoPockets are a new innovation for organization in the NCCC. Pockets allow for organization and display of pertinent patient information, storage for thermometer, and display of family photos to enhance patient/family comfort. NeoTech utility device holders and NeoPockets personal incubator organizers can help the NCCC neonatal nurse to keep the environment, surrounding the critically ill and premature Carolina infants, clean and safe, which is crucial in the safe sleep and SIDS prevention initiative in the fragile infants. Through the use of the Halo Sleep Sack programs, "In Hospital" and "Take Home", the Charlie's Kids board books, NeoHugs and NeoPockets, the NCCC nurses are following the gold standard of SIDS prevention and safe sleep initiatives from the National Cribs for Kids foundation, helping every baby sleep safer. With the implementation of these programs we can decrease the rate of SIDS by providing a holistic developmental approach to SIDS prevention initiative and promoting a safer sleep environment for North Carolina infants."

Special Needs Car Seats

Project Director: Tonya Stafford, RN

Project Abstract: "NC Children's Hospital wants to ensure all children requiring special needs car seats are transported safely home. UNC offers a special needs car seat loaner program that is conducted by five certified Child Passenger Safety (CPS) Technicians. The manufacture of the original seat (Hippo) is no longer being produced and our last 5 Hippo seats are expiring in the next 18 months. This seat expires 6 years after the documented manufacture date. I am requesting to replace our expiring seats with a new version of the Wallenberg expected to come into production by the end of 2020. This new Wallenberg II will be lighter with a base that is easier to adjust (2 bolts vs 6). This new seat will provide a forward facing and rear facing option for the child in a spica cast, abductor pillow and Halo. In addition we are requesting the Wallaroo seat which provides a forward facing option for these children.

The car seat program serves children who have had hip surgery, a femur fracture, or some type of trauma who are unable to fit in their normal car seat due to the cast or device. The special needs seat accommodates the positioning of the legs that are spread wide in the cast or positioned higher on the waist to prevent bending of the hips. Our goal is to provide up-to-date seats along with a variety of options for the family to best accommodate their child's specific need. We are requesting

funds to purchase additional seats that will keep this loaner program functional and ensuring UNC Children's Hospital provides safe transport for all pediatric patients."

Transgender/Gender Nonconforming Patient and Family Resource Library

Project Director: Katherine L. Cooper

Project Description: "Children and adolescents who identify as transgender and gender non-conforming, and their families, often feel alone, misunderstood, and overwhelmed. Our job as their care team at UNC's Pediatric and Gender Wellness Clinic (PAC-G) is to provide them with all of the education, resources, and support to help them build their internal and external resources, and to feel knowledgeable and empowered on their respective journeys. Funding for this project would allow the Department of Pediatric Endocrinology to continue to serve our ever-growing clinic population (now at 130 patients), by building upon our very successful portable library that is offered to families during their clinic visits. This library consists of age-appropriate books including: early childhood inclusive books about the gender spectrum, books about living as a gender non-conforming youth, books from others who identify as gender non-conforming, books for families of these youth (including parents and siblings), books from a supportive faith-based perspective, political activism books, and personal memoirs. Books are given to families or loaned out as part of the clinic's collection of resources.

The clinic would like to further expand our therapeutic resources by providing relevant technology apps that could be accessed through existing clinic iPads, such as Headspace, Mindshift, etc. while patients are waiting to see providers or as part of a behavioral intervention. This library, as it exists now from prior CFTK funding, has been an immensely popular and tangible measure of support to our patients and their families, and we are encouraged to expand upon what we have built. In 2019, a poster about the library was accepted and presented at the US Professional Association for Transgender Health (USPATH) in Washington, DC to highlight this innovative project and was met with a great response. On a clinic level, we have received unanimous positive feedback from our patients and families to consist of quotes such as: "This is so exciting!" and "Books are great!". The wide-reaching support has fueled our desire to continue meeting this need and to enhance the care we provide; not only to patients, but to the entire family system and community."

Turner Syndrome Support Conference

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. The varying presentation along with the rarity of the condition can make it difficult to identify peers and develop adequate support networks.

The University of North Carolina Turner Syndrome (UNC TS) Clinic is one of the largest TS clinics in the United States, providing multidisciplinary care to approximately 125 individuals. It is recognized by the Turner Syndrome Global Alliance as a Level 4 Regional Resource Center (TS clinic providing the highest level of care). UNC TS Clinic has partnered with Turner Syndrome of the Carolinas to provide peer support and advocacy for UNC patients with TS. Turner Syndrome of the Carolinas is

an independent, nonprofit organization which provides social support to individuals and families in the TS community, promotes awareness of TS, and supports research efforts. The unique relationship between UNC TS Clinic and Turner Syndrome of the Carolinas has allowed for opportunities to improve the care for girls and women with TS.

The UNC TS Clinic will join forces with the Turner Syndrome of the Carolinas to host a regional conference for families touched by TS. The conference objectives include:

- Educate families of girls and women with TS about how TS can impact one's life.
- Provide much needed social support to girls and women with TS.
- Empower families of girls and women with TS to advocate for their health, education, and social needs.

Biofeedback Devices for Adolescents and Children in Inpatient Psychiatry

Project Director: Kinsey Silvers

Project Abstract: Our goal to provide emotional self-regulation resources to patients in child and adolescent psychiatry. We would like to have emotional regulation devices for each patient on the Child and Adolescent psychiatric units. We would also like to provide emotional self-regulation devices to patients leaving to hospital who would benefit from continued practice post discharge.