

Project HUG Impact Report 2016



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Dear Friends,

On behalf of NYU Langone Medical Center and the pediatrics teams at Tisch Hospital and Rusk Rehabilitation, I want to express my sincere appreciation to Project HUG for your generosity in supporting our programs for so many years.

As the only comprehensive pediatric rehabilitation program in New York City that provides both acute inpatient and ambulatory services, we are committed to providing the best rehabilitation care to children with disabilities. Support from friends like Project HUG is critical to helping us fulfill this important mission.

Project HUG members are passionate about giving back, whether it be through a special holiday visit to our children or through their tireless work in organizing the annual Help Us Give (HUG) gala. Every year, Project HUG awards grants to help fund various pediatric rehabilitation programs at Tisch Hospital and Rusk Rehabilitation and 2016 was no different.

I am proud to share with you this report detailing the impact your funding had on our pediatric patients over the past year. From music and creative arts therapies to recreation and healthy living to rehabilitation programs that utilize cutting edge technology, the generosity of Project HUG's members have enabled us to build innovative programs that have transformed the lives of children and their families.

It is impossible to enumerate all of the ways that that Project HUG has helped our pediatric patients and their families over the years. I hope that you enjoy reading about all of what your generosity has made possible.

Sincerely,



Steven R. Flanagan, MD

The Howard A. Rusk Professor of Rehabilitation Medicine
Chair, Department of Rehabilitation Medicine
Medical Director, Rusk Rehabilitation



Evening and Weekend Therapeutic Recreation and Creative Arts Programming at Rusk Rehabilitation: **\$105,000**

Project HUG's generosity has enabled us to expand the music therapy program that was initiated with last year's gift by hiring a music therapist, as well as add evening and weekend programming. This year, Project HUG's grant of \$90,000 was used to retain the music therapist, and \$15,000 of the music therapy grant helped support our programming.

The program provides individual and group music psychotherapy services to the inpatient Rusk Rehabilitation pediatric unit. Music therapy is incorporated into patient's physical therapy, occupational therapy, and speech language pathology sessions, and utilized to support patients' goals and hospitalization process. Music therapy has been utilized for procedural support, relaxation and guided imagery, coping interventions, and pain management. Techniques include song writing, music improvisation, therapeutic instrument playing, music education, and music production.

Thanks to Project HUG's funding, our program was able to do the following this year:

- **Perform at Radio City Music Hall for The Garden of Dreams Talent Show.**
A group of 10–12 kids learned to play "We Are The World" on the hand chimes, piano, and percussion instruments. Our patients were given the opportunity to perform this song on stage at Radio City Music Hall at the Garden of Dreams Talent Show.



• **Juilliard School of Music Performances for Sunday Programming**

• **Introduce adaptive music technology to the unit.**

The music glove is an adaptive interactive music instrument that improves hand and finger movements and fine motor skills. It's been utilized with kids who've experienced strokes, traumatic brain injuries or other neurologic dysfunctions to improve hand functions and motivate!

• **Introduce Licensed Neurologic Music Therapy to the unit.**

Neurologic Music Therapy (NMT) is the use therapeutic application of music to cognitive, sensory and motor dysfunctions. NMT treatment is based on stimulating music perception and production parts in the brain, and helps patients with basic behavior functions. Specialized NMT interventions are now being utilized during a patient's physical therapy, occupational therapy and speech therapy sessions to enhance their care and support their medical goals

• **Ukulele Kid's Club Collaboration**

Eight of our kids have received free ukuleles and ukulele lessons during their time at Rusk Pediatrics thanks to the donation of 18 ukuleles. The children are able to learn ukulele free of charge and take these ukuleles home after discharge.

Music Therapy Patient Stories

Zach, age 14

Zach was a percussionist who came to Rusk frustrated with his admission. We used the electronic drum kit to release frustrations, write songs, and perform a concert for his peers and family on the unit. Zach was nominated as "Artist of the Month" by ArtWorks for his musical talents and use of music during his admission. Zach also performed the drum kit at Radio City Music Hall at the Garden of Dreams Talent Show.

Nicholas, age 12

Nicholas was admitted for stroke resulting in impaired finger dexterity, walking ability and arm movements. He was a tuba player and key member of his school band, hoping to one day study music in college. Due to his surgery, doctors advised him against playing his tuba which greatly worried him. As an alternative, music therapy helped him learn the piano during his admission to help strengthen finger dexterity and keep his connection with music strong. Nicholas received piano learning techniques throughout his admission, which he really enjoyed. Nicholas' became great at playing the piano, and later performed a piano piece on stage at Radio City Music Hall at the Garden of Dreams Talent Show.





Jack age, 11

Jack was admitted to Rusk for a traumatic brain injury following a serious ski accident. The accident left him in a coma and rehabilitating at NYU HJD for four months. Music therapy was used through his entire admission. In our first session he was non-verbal and in a wheelchair. The music therapist placed a piano in front of him and he started to play the melody of "Somewhere over the Rainbow", a song he was learning prior to his accident. It was a beautiful moment for his family.

Jack re-learned to walk, talk, sing, dance, and breathe again with the help of music therapy. He took piano lessons to strengthen finger movements, and during his "standing exercises" (pictured below) to reduce focus of his pain

during standing. Singing was used to help strengthen his breath and voice and rhythm and music helped strengthen his walking ability during physical therapy. Music cognitive games were used to help strengthen his attention span, which had been affected by his injury. On Mother's Day his family visited and, together with the therapist, discussed Jack's accident and how it affected him and his family.

The therapist worked with Jack and Jack's father to create a song about Jack's accident and his goals throughout his hospitalization process. They performed the song for the hospital staff. He's since been discharged and is doing great! Jack's inspiring story was covered by the New York Post and CBS Local.

Child Life/Creative Arts in the Pediatric ICU: \$15,000

Project HUG funding in part supports a child life specialist and programming in the PICU (Pediatric Intensive Care Unit).

In the PICU setting, patients are typically not able to actively participate in the group services and programs offered in the playroom. Programs are offered at the bedside to engage both the child and, often, the parent or caregiver. One mother in particular had a child in the PICU who was sedated and on a machine to help her breathe. This mom was often at her child's bedside with very little to occupy her time while being present to support her child. After having the chance to meet with her and assess what might be helpful, she was provided with a kit of beads and beading supplies. The staff had the opportunity to make Shrinky-Dink footprints with mom and child as well. She spent most of each day stringing these tiny beads and placing a footprint on each piece so that her friends and family could wear these beautiful creations in support of her and her child. This helped to strengthen her spirit and cope with some of the many ups and downs of having a child in an PICU. Legacy making projects such as this can help a family to create memories in the hospital setting and preserve them in a powerful manner through photos, hand/finger/footprints, jewelry, scrapbooking, etc. These art activities can be used across a wide age span, engaging the youngest of children to teens, their siblings, parents, family and friends.

Child life specialists provide a host of services in the PICU setting. Medical teaching and procedural support to assist a young patient with understanding and coping with their

hospital experience is an important component of the program. This can include helping a sibling to learn about why their brother or sister is in the hospital and preparing them for making a bedside visit to their sibling in the PICU. In addition, our child life team provides ample opportunities for therapeutic play to normalize the experience as well as help a child to gain mastery, all important interventions which are regularly provided by our child life and creative arts team in the PICU.



Creative Art Therapies: \$30,000

Year after year, we rely on the generous support of Project HUG to help fund art education and art activity programming at both Tisch Hospital and Rusk Pediatrics. This therapy is critical in helping to ease the anxiety and fear that children and their families may experience.

Tisch Hospital Pediatrics Program Update (\$15,000)

Air dry clay and associated tools and materials have been purchased for use with an innovative program in collaboration with the New York University Art Therapy and Studio Art Programs. The intention of this group is to provide hands-on work with children to promote opportunities for sensory stimulation, fine motor control, and self-expression. This group is offered weekly in the playroom and is one of the most popular amongst children and their family members.

Another favorite is a weekend beading bonanza activity. We were able to purchase child appropriate beads and strings in various

shapes, sizes and textures. From foam beads for young children to glass beads for the older teens, this program has become a favorite. Kids proudly create and then wear, display, gift and share their beautiful and original creations.

In 2016 we were thrilled to hold "The Art of Expression: Patient Perspectives," a Therapeutic Recreation, Child Life and Creative Arts Therapies Department art exhibit in the NYULMC art gallery. This exhibit showcased artwork created by pediatric and adult patients. Each piece depicted many ways our patients communicate through creating art, including



feelings of pride, joy, fear, sadness, excitement, achievement, comfort, support and more. Through this opportunity for a normalizing, creative expression activity, patients could share what words perhaps could not as easily communicate and visitors appreciated the creativity and expressiveness on display.

Holiday Celebrations are a huge hit on the inpatient units. Providing familiar experiences at major holidays such as Christmas, Hanukkah, Easter, and the annual "Christmas in July" celebrations can help create a wonderful opportunity for normalizing the hospital experience for kids and their families. During these holiday celebrations, children and Project

HUG volunteers are active in the playroom, engaged in arts activities, and enjoying the goodies they had just received from Santa and Mrs. Claus, the Spring Bunny and friends. This also creates an opportunity for children to spend time together creating crafts and even sharing treasured family holiday stories with one another. Often times, the arts activities carry on over the entire week and include creating crafts to be placed on the unit Christmas tree or decorating a patient's hospital room. Once discharged, the child's craft also serves as a transition item to bring home as a reminder of some of the positive experiences that can occur in a hospital stay.



Mandalas

Your mandala can be seen as a symbol or reflection of who you are at the time it is created. Ideally, the process of creating the mandala results in some form of self-healing, self-expression, and/or self exploration."

Rusk Pediatrics Program Update (\$15,000)

We have completed our first three month session with ArtWorks (Beat Box & Graffiti Art). The second session is about to begin. The upcoming teaching artist is, amongst other things, an Upcycling Artist and will be helping the patients and family members to be creating various art pieces/collages with "found items". ArtWorks has been hired for three different 12 week sessions of programming.

The third of which will begin upon completion of the Upcycling Collage Program. In addition, ten changeable "swing frames" have been purchased, and mounted in the 8 South hallways. This has allowed the patients to display their art and has created an increased child friendly atmosphere. In addition, it is our intent to have an actual art exhibit at the end of this year's ArtWorks programs.

Music Therapy Program at Tisch Hospital: \$15,000

Project HUG's generosity also helps fund music therapy programming at Tisch Hospital. This integrative therapy enhances self-expression and positive coping with the healthcare experience.

Thanks in part to HUG support towards a music therapy position, this program is able to reach more patients and families seven days a week.

One of the most successful programs recently initiated by our music therapists includes the production of therapeutic music videos by patients on the inpatient pediatrics units. These videos have become a popular and engaging tool for patient expression of the feelings and experiences they face in the hospital. Patients are able to create an original song, or may choose a favorite familiar tune to record, often incorporating choreography and props. Healthcare team members may be recruited to participate too, all controlled and directed by the patient, thus adding to the therapeutic value of the video production. Once complete, the video is burned to a DVD to take home, often including an original cover design created by the patient.

These types of recordings are an amazing example of how we are able to integrate current and innovative technology together with a therapeutic process of creative expression. Our music therapists provide services both individually at the bedside as well as in a group setting. From rhythm groups to Friday night karaoke, bedside drumming to personalized

song writing, patients of all ages and their family members continue to benefit greatly from this diverse music therapy program.

Music Therapy also strongly supports pain management interventions with children and young adults. Pain management is a common challenge for many of our young patients, and music therapy is often offered to alleviate both the physical and emotional effects of pain through carefully chosen interventions tailored to each particular patient.

A "Music from Around the World" program has been offered in both the group setting as well as for individual patients restricted to their rooms. This program includes an extensive collection of popular music from around the world. The music therapist has learned to sing many of these songs in their original language in order to sing or play along with the child. Imagine coming to the hospital and speaking only Chinese, and being able to actively participate in a sing along in your native language? What a fantastic way to break down some of those boundaries that can create an even more challenging hospital experience for a young person and their family.



Rusk Fit Kids: \$20,000

Rusk Fit Kids serves patients at risk of or struggling with obesity and sub-optimal levels of physical activity. The program is led by an interdisciplinary team including a physical therapist, social worker, and dietician. Participants are assessed for current health risks, and assisted with individualized exercise recommendations. Education is provided to children and parents on nutrition and healthy living habits. Community resources are incorporated to facilitate active lifestyles and family fitness activities.

The program incorporates a series of educational projects and activities led by each team member. Each program serves a small group (6–8 children), but the program can be repeated once developed. Program effectiveness will be evaluated by knowledge questionnaire pre and post program, as well as PedsQL to determine quality of life as perceived by participants—50 children per year.

In 2016, Rusk Fit Kids held four cooking classes for current and past patients and their families. The children learned cooking skills such as

chopping, grating, and whisking. They created delicious, healthy recipes like Spinach Black Bean Empanadas and Strawberry Rhubarb Yogurt Parfaits.

Rusk Fit Kids also hosted a six-week yoga session run by a Rusk physical therapist and speech therapist. They learned about breathing, meditation, flexibility, and balance. The participants are looking forward to more programs in 2017!



Recreational Trips for Patients and Families: \$20,000

Project HUG's support for recreational trips included charter bus rental; admission cost for 15 patients; 10 chaperones/staff; and 10 parents. For the trip to see the Brooklyn Cyclones, this included food, souvenirs, and tickets for both inpatients and outpatients and four of their family members. Community activities included art and music classes for children who have sustained brain injuries.

We have taken several community excursions during this past year:

- **5/2016 NYC Ballet Midsummer Night's Dream:** This was for inpatients only. Each participant was able to bring 1 family member. Souvenirs were purchased for all patients on the unit even if they were unable to attend the event.
- **6/16 NY Liberty Game:** (Tickets were donated): Trip was for inpatients and 1 family member.
- **7/16 Brooklyn Cyclones Game:** rooftop tickets, catering, and transportation. This excursion was open to both inpatients, outpatients, and recently discharged patients (and their family members).
- **10/16 Matilda on Broadway:** This was open to inpatients and recently discharged patients and family members. Tickets, lunch, bus, and souvenirs for participants and inpatients unable to attend were provided.
- **11/16 NYC Ballet** (Tickets were donated): This excursion was for inpatients and 1 family member. Transportation and souvenirs for all patients were provided.
- **11/16 Disney on Ice:** Open to inpatients and recently discharged patients and their families. Tickets, dinner, souvenirs, and transportation were provided.



Wheelchair Mobility Community Training Day: \$20,000

Project HUG's generosity funded Rusk's pediatric Wheelchair Mobility Program. The program serves two purposes. The first is to host a series of "Wheelchair Community Days" that provide patients and their families with opportunities to learn and practice wheelchair skills, review wheelchair parts and maintenance, and get exposure to other types of adaptive mobility equipment. Second, the Wheelchair Mobility program provides financial assistance for adaptive mobility equipment to our patients and families in need.

Two Wheelchair Mobility community day events were held in 2016, Saturday, June 18th and Saturday, November 5th; both were great successes. At each event, seven children participated ranging from 7-18 years old. Several staff members from Wheeling Forward/Axis Project, including owner and founder Alex Elegud and physical therapist Lawrence Harding, presented and provided training to Rusk patients and their families. Exercise trainers and current wheelchair users who are members of the Axis Project were present, sharing their experiences and interacting with both the parents and children throughout the day. At the June event, Christopher Noel from the NYC Parks Department stopped by to provide information on community resources available. Each Wheelchair Mobility Day consisted of education on wheelchair parts and maintenance, practicing wheelchair skills, and a community outing to Central Park in the afternoon to practice their newly learned wheelchair skills and ride hand cycles. In addition, the November event included a hand cycle spin class, hosted by one of the Axis Project exercise trainers. Following the event, one mother commented that "this was the best event I could have wanted for [my daughter]," and another remarked "it was such a great idea to have an event like this, I learned so much."

Following the event in June, an outcomes questionnaire was sent to the participants and we received four out of seven responses. The feedback was overwhelmingly positive. Parents reported feeling their child learned important skills to become more independent in his or her wheelchair. They also reported that they are very likely to return for another Wheelchair Mobility Day event in the future, and are very likely to recommend participation to others. One parent commented, "Thank you so much for this training...We really enjoyed it and can't wait to come back again and learn more...We absolutely loved it."

At future events, we hope to increase the number of participants, as well as the number of physical and occupational therapists in attendance. In addition, the funds were used to assist families with transportation costs to and from the event, and provide patients with financial assistance to purchase adaptive mobility equipment such as sport wheelchairs and hand cycles.



Feel Your Food— An Intensive Feeding Program: \$20,000

Thanks to Project HUG, we were able to run the Second Annual Feel Your Food Group this past summer. The grant funding enabled us to purchase oral sensory and oral motor tools, utensils, food items, sensory activities and games, and it also permitted us to hire a per diem SLP to cover the regular caseload of the 2 SLP clinicians involved in the program.

Feel Your Food, an intensive sensory-motor feeding program, was a 2.5-hour program from Monday–Friday (for a total of 10 days) consisting of at least two food related activities intended to improve sensory stimulation, oral motor stimulation, behavioral intervention, and caregiver observation and training.

During non-food activities, the six children participated in fine and gross motor activities to facilitate stimulation of the five senses and improve sensory integration skills. The sensory food activities were related to food preparation in order to facilitate exposure to novel foods—their smell, texture, color, and odor. For example, participants engaged in making pancakes, waffles, fruit salads, and cooking eggs in different ways.

The group included six children, ages 3–5 years old, with sensory-based feeding difficulties, resulting in limited oral intake, delayed oral

motor skills, and restricted diets (picky eaters). All six of the children who attended the program engaged in sensory oral exploration of novel foods in at least 6/10 sessions and all six participants accepted and swallowed a novel food in at least 3/10 sessions.

Parents were interviewed—2 months following completion of the program and the feedback we received was very positive. All of the parents reported that the education provided by the treating clinicians was very helpful, including how they appreciated the home exercises given to them to facilitate carryover and generalization of skills learned during the program. We are hoping to make the Feel Your Food Group a twice yearly group.



Voice Program: \$10,000

Pediatric patients who need voice therapy are often referred out for therapy due to a lack of instrumentation to perform appropriate assessments to evaluate the quality and degree of hoarseness in young children, 100 children per year. The grant from Project HUG enabled us to purchase a Phonatory Aerodynamic System, ADSV Software, and Voice games (software).

The Phonatory Aerodynamic System, a state of the art device for measuring a child's voice quality and function, has been purchased and installed. This will allow for baseline measures and outcome data for children who have voice problems stemming from both congenital and acquired diagnoses. Being able to quantify how much better a child's voice gets from therapy is critical to developing programs that work and with the least financial and emotional expense for the family. Currently, voice problems often go untreated primarily as it is wrongly believed that they resolve spontaneously. Unfortunately, statistics show us that children with hoarseness not only experience limitations in social and academic engagement and development, but also become adults with intractable hoarseness. Rusk Pediatrics currently has several medically fragile children in therapy who will be the first beneficiaries of the Phonatory Aerodynamic System. Following intensive voice therapy, we will re-measure their voices to gain

insight into how the function of their voices has improved. Specifically, we can gauge the amount of work a child must use in order to generate sound. A voice that is easy to use should reflect in lower measures of breath pressure while speaking. In the real world, this also means a child is more likely to socialize, speak up in class, and feel empowered and confident that others can hear and understand them.

As Rusk Rehabilitation continues to spearhead cutting edge programs directed toward pediatric rehabilitation, quantitative measurement and documentation becomes crucial to advancing diagnostic and therapy techniques. The Phonatory Aerodynamic System is part of this initiative and will certainly have an enormous impact on the quality and success of our pediatric care.

Downtime Diversion Kits: \$5,000

The Down Time Diversion Kit program was successfully established last year to provide age appropriate diversionary activities for the children to play with either alone or with their peers without the presence of an adult to structure activities for them.

Examples include floor mats for the toddlers so they can safely get out of bed and play on the floor like typical toddlers would. Teenagers play card games and use word game books that they can play with visitors and other children on the floor or alone if they wish.

The use of the Down Time kits has proven most beneficial in the preschool population. There have also been a consistently increasing

number of requests for use of iPads by patients and family members during "Down Time." Six new iPads and cases were purchased. Two iPads will remain at the nurse's station for nursing to use with patients who need constant supervision while waiting for their parents. The remaining four will be available for patients and parents to borrow. Two will be designated as "E-Library" tablets.



Functional Electrical Stimulation (FES) Intensive Program: \$50,000

Patient access to FES equipment is limited because it is extremely costly and not consistently covered by insurance.

Additionally, many rehab facilities in the New York area do not have the pediatric versions of FES equipment, further limiting access. We plan to create a structured program to assist families in obtaining this equipment for home use.

While we have two candidates for this program, we have held off on purchasing due to their

changing circumstances. Since these devices are so costly and technology changes so quickly, we want to be sure to purchase at the right time. We are also investigating expansion into the brachial plexus population. These children are born without full use of an arm due to their nerves being stretched or partially detached during birth.

Neurodevelopmental Treatment (NDT) Intensive: \$5,000

This is a weeklong intensive programming using NDT techniques, similar model to Camp High Five but shorter in duration, 24 children per year

We have done the NDT intensive twice now, with three different children. We have adjusted our program from one week, five days with two hours total therapy per day to two weeks, ten days with 90 minutes of therapy per day. We have had great results with two out of the three patients, with OT improvements noted in lower body dressing for both patients, PT improvements with standing balance, ambulating stairs (for one patient), and overall for both disciplines there were improvements in

strength and endurance as well as coordination. The families have been happy with the progress and it has been helpful communicating with them using our goals worksheet to list their top three areas to improve upon. We are going to expand the program now from twice a year to three times a year, capturing more patients and eventually decreasing their need from weekly therapy throughout the year to intensive bursts where they can participate in more extracurricular and community activities.

**Thank you Project HUG
for all you do for our
pediatric patients!**

