



Kids Count!

News from Goryeb Children's Hospital

Spring 2009

A Letter of Gratitude

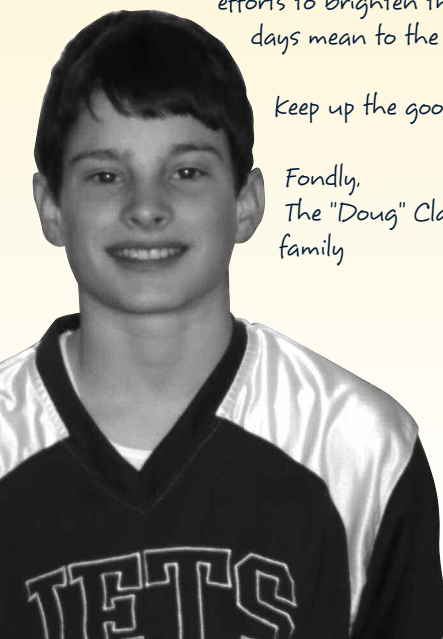
Dear Amy and Child Life Staff,

Thank you all so very much for your kindness over the past week. Douglas was released today and he is very happy to be home. We are in awe of the Goryeb Children's Hospital operation. From your department through to the doctors to housekeeping; the high level of professionalism is outstanding. While I hope to never be there again with any of my children, it was a perfectly wonderful place to be when circumstances forced it. The visit by the Jets was truly the highlight of Doug's day/week/year! His Dad gave him a Jet's jersey as a welcome home present and he is wearing it proudly.

You will never know how much your team's efforts to brighten the kids' days mean to the families.

Keep up the good work.

Fondly,
The "Doug" Clarkson
family



Epilepsy Care with Kids in Mind

In the realm of pediatric epilepsy care, one would assume that hospital programs would employ physicians specializing in seizure disorders *and* pediatrics. Surprisingly, some facilities, including most nearby regional medical centers, do not.

The exception: the pediatric epilepsy program at Morristown Memorial and Overlook hospitals.

"Most adult epilepsy programs see children, but they don't recognize the unique aspects of managing childhood epilepsy," says Harvey Bennett, MD, director of child neurology at Atlantic Health.



Goryeb now has an EEG machine dedicated solely to pediatrics

This program stands out, he says, because its collaborative staff includes child neurologists with clinical experience in treating seizures. For example, Lorraine Lazar,

MD, PhD, director of the pediatric epilepsy program at Atlantic Health,

is board certified in pediatric neurology and epilepsy. In addition, all physicians and staff are kid-friendly, including a pediatric neurosurgeon, a pediatric nurse practitioner, a dedicated electroencephalogram (EEG) technician and child life specialists.

Patients are also offered evaluations with the latest technology, including 24-hour inpatient video EEG monitoring, no-waiting EEG monitoring for emergency cases and routine EEGs and MRIs. Thanks to the Tina and Richard V. Carolan Foundation, Goryeb Children's Hospital now has an EEG machine dedicated solely to pediatrics (see story page 2).

Epilepsy affects one to three percent of all children. Each year, 150,000 children and adolescents in the United States will have a newly occurring single seizure; approximately 20 percent of them will be diagnosed with epilepsy or recurrent, unprovoked seizures. The child neurology program at Atlantic Health has grown continuously over the past three years, with over 4,000 patient encounters in 2008 alone.

To meet the needs of the rising patient load, the program is seeking funds for wireless monitoring at Morristown Memorial and Overlook hospitals, another pediatric EEG machine and the creation of a dedicated, family-friendly space at Goryeb. If you can help, please call Gerri Kling at 973-593-2414.

Pictured above: Pediatric EEG technician Lakeisha Robinson calms a young patient with bubbles

INSPIRING COMMUNITY PHILANTHROPY

Pediatric Ambassador Program



Kaleigh Levoyer, 19, is a go-getter. Even as a patient at Valerie Fund Children's Center at Goryeb Children's Hospital, she's getting things done.

It all started two years ago, when the Parsippany

Kayleigh Levoyer

teen was diagnosed with type 1 non-Hodgkin's large b-cell lymphoma and underwent chemotherapy.

While waiting around for various procedures, Ms. Levoyer noticed that many of the activities offered

to pass the time were geared to small children.

Taking action, she addressed the deficit last year through her Girl Scout Gold Award service project. A long-time fan of Manga, she sought contributions from local businesses and donated 50 Japanese comic books to the center. To accompany each book, she wrote

summaries and included drawing instructions for the characters and housed them in portable crates she painted blue.

"I read Manga mostly for the stories, but I also like the illustrations of the characters and scenes," she says. "Because of them, I can understand more of what the author is trying to portray in the story and I get an idea of what the characters look like."

A first-year student at the College of New Jersey, Ms. Levoyer

spends much of her free time delving into fantasy worlds, through weekly Anime Club meetings, action video games and her poetry for Ink, a creative writing club. Like any co-ed, she's focusing on finishing the semester and

looking for a job to earn extra cash over the summer.

Her health, as well as her prognosis, is good: "Doctors said that, with other patients, after five to 10 years, 95 percent were cancer-free." She returns to the center every three months for check-ups.

Ms. Levoyer has nothing but praise for the center. The medical staff, she says, always pays particular attention to her emotional needs, like when she underwent a spinal tap. "They talked me through it," she says. "They made sure I was comfortable and kept my parents with me until I had to be knocked out."

Now, thanks to Ms. Levoyer, teens waiting for procedures like this one can escape the medical scene by grabbing a Manga book and lose themselves in feudal fairy tales, paranormal activity and science fiction thrillers.

It's fortunate for Morristown Memorial that Richard Carolan and his family moved back to New Jersey. As executive director of the Tina and Richard V. Carolan Foundation, he favors supporting medical research and hospital projects close to home.

"I took a tour of the children's hospital and said, 'Wow, look at this place; I want in,'" recalls Mr. Carolan, a Bernardsville resident.

The foundation recently donated \$88,000 to Goryeb for the purchase of a VeinViewer, an electroencephalogram (EEG) and a Touch Wall.

When drawing a child's blood, it can be difficult for nurses to locate a vein. To prevent painful, multiple jabs, the VeinViewer locates a child's vein with an imaging system that uses infrared light and a digital camera to create an image

of the vascular structure. The device, which projects that image onto the child's skin, will be used primarily in the Edward and Joan Foley Pediatric Intensive Care Unit.

Thanks to the new EEG, care for pediatric patients with seizure disorders, such as epilepsy, has become more convenient. Approximately 20 children a week come to Goryeb for an EEG, a test used to detect abnormalities related to electrical activity of the brain. Now these young patients no longer face extended waits and scheduling conflicts. The EEG is also used for patients with developmental delays and autism.

To help combat childhood and adolescent obesity, the Touch Wall will provide pediatric patients with a fun cardio work out while enhancing endurance and flexibility. The interactive climbing wall is comprised of touch surfaces, on which red signals flare in various sequences and speeds. Participants scramble to deactivate the light with a quick touch as soon as it appears.

The Tina and Richard V. Carolan Foundation was established in 1990 by the Carolan family.

Carolan Gift a Triple Blessing

'One Stop Shopping' in Pediatrics

At a recent Craniofacial Center team meeting at Goryeb Children's Hospital, about 20 pediatric subspecialists, from geneticists to neurosurgeons, engaged with a parade of pediatric patients and their parents, giving feedback and medical advice in the cases brought before them.

The parents of a 1-year-old girl with craniosynostosis answered a host of questions as physicians studied their daughter's MRI, blazing across a large screen. One plastic surgeon noted that the girl's long, narrow head could be rounded surgically, but added that it's a significant operation for cosmetic reasons. Yet another warned that if left untreated, the girl's condition could worsen, possibly causing brain damage. The parents weighed the input and told the group they had already decided on surgery.

"We see children as a team; it's fantastic for parents. It can be intimidating to sit in front of 20 doctors, but parents hear every opinion at once and leave with a game plan."

— Catherine Mazzola, MD

The team leader then described the operation and recovery process and gave them a referral for the surgeon.

In another case, a 20-year-old college student showed doctors her malformed left ear, the result of Goldenhar Syndrome, a congenital birth defect that involves deformities, usually on one side of the face. Her problems affect her left side: hearing loss, blindness and facial nerve palsy as well as asymmetrical facial features.

"Can you fix my smile?" she asked the team. The doctors examined her ear, her jaw, inside her mouth. To reshape the ear, plastic surgeons suggested a prosthetic or a reconstruction using harvested tissue. To improve her hearing, the ear doctor recommended either a bone-anchored hearing aid or reconstructive surgery. An oral surgeon

then suggested braces, reconstructive jaw surgery and cheek implants.

Although no final decisions were made that day, the young woman and her mother gathered a collection of referrals to various specialists, including a child psychologist for social and psychological stress.

"This is one-stop shopping," says Catherine Mazzola, MD, medical director of the Craniofacial Center and a neurosurgeon. "We see children as a team; it's fantastic for parents. It can be intimidating to sit in front of 20 doctors, but parents hear every opinion at once and leave with a game plan."

Dr. Mazzola founded the center two years ago to help infants, children and adolescents with congenital or acquired craniofacial abnormalities by providing innovative, cross-disciplinary care. These patients often experience complex medical problems involving feeding and swallowing, hearing, speech, breathing, dental formation and psychosocial development. The team, which meets once a month, is comprised of board-certified pediatric experts in a host of subspecialties. Based on The American Cleft Palate – Craniofacial Association guidelines, the center strives to improve the health and appearance of patients, while lending educational and emotional support.

To operate as effectively as possible, the center is seeking funding for a full-time coordinator and a part-time therapist who specializes in speech, swallowing and language. Financing for a dedicated Craniofacial Center space inside Goryeb is also needed.

If you would like to help, please contact Gerri Kling, major gifts officer, at 973-593-2414.



New Posts to ENHANCE CARE

As patient volumes rise, Goryeb Children's Hospital remains committed to providing stellar care and improving services, despite the challenging economic times. While some institutions are cutting services, Goryeb

is hiring another hospitalist and hopes to add two key positions – nurse navigator and staff psychologist.

"The new team would improve the experience of pediatric patients and their families by providing support, information, advocacy and guidance," says Walter Rosenfeld, MD, chair of pediatrics at Goryeb Children's Hospital. "Because being hospitalized or diagnosed with a chronic condition can be overwhelming and anxiety producing for both the child and family, we're committed to making the experience as painless and worry-free as possible."

As the children's hospital draws patients from an ever-expanding geographic region, the hospitalist has become crucial as fewer general physicians make hospital visits. An on-site physician, the hospitalist serves as a liaison between the patient and the family's general doctor. The new hospitalist, who will join two already on staff, will be involved with every aspect of pediatric medical care, including quality improvement, education, patient advocacy, outreach and research.

One of two new funding priorities, the nurse navigator would assist patients and their families during treatment, offering clinical medical expertise on everything from diagnosis to drugs. Many patients, especially those with chronic conditions, require the services of several different subspecialists. To that end, the nurse navigator would collaborate between care providers and treatment settings.

The staff psychologist would provide a supportive environment for patients and their families to share concerns and learn coping skills in dealing with chronic conditions, long hospital stays and surgery.

The aim of all the positions is to foster the best outcomes for patients in a family-centered environment.

GIFTS *Heart* from the



raffle The car enthusiasts at **Driving Impressions' Winter Retreat** may have been eying the revved up Rutgers Formula Society of Automotive Engineers 2008 team car and its vegetable oil-powered tow truck, but their hearts were with the young patients at Goryeb Children's Hospital. A raffle filled with various motorsport prizes drew \$350 to benefit the children's hospital. The event, held on Dec. 13, 2008, at the Dover-based manufacturer of motorsports apparel, was co-hosted by Paul Miller Porsche and the Sports Club of America – Northern New Jersey Region.



To cheer up pediatric patients over the holidays, the **Sussex County Bit-by-Bit 4 H Club** donated 45 teddy bears, dogs and horses they stuffed themselves to Goryeb's patient outreach program. "We got a lot of satisfaction knowing we brought joy to children over the holidays," says Mary O'Connor, 17, club president, who lives in Newton. The group chose the children's hospital as the recipient of its service project thanks to Frelinghuysen resident Grace Ackerson, 11, who was treated at Goryeb for a broken arm after a go-cart accident.

toys



music The **Spring Brook Twig** gave the gift of music to pediatric patients at Goryeb. The group hosted a family event featuring a concert by the musical group Music for Aardvarks, on Feb. 7, 2009, at Malcolm Forbes Amphitheatre. The little guests clapped along to the songs and then created a St. Valentine's Day craft. Proceeds from the event financed a musical concert by the band later in the day for the youngsters at the children's hospital.



Zach Olsen (pictured with Child Life Manager Lisa Ciarrocca) never forgot the excellent care he received at Goryeb when he broke his femur in a sledding accident

as a second grader. In a full-body cast, the boy stayed in the hospital for a week and spent another 10 weeks at home confined to a hospital bed. The 13 year old's Bar Mitzvah gave him the perfect opportunity to show his gratitude. As part of his "Mitzvah project," he purchased a Nintendo Wii™ game system for Goryeb, along with 10 games and 14 Playstation®2 games (his mother, **Amy Olsen**, contributed the Playstation®2 system). The former patient hopes to volunteer at the hospital as soon as he's old enough.

games

gifts



In lieu of birthday presents, **Madison Doherty** (pictured with younger siblings Meaghan and Matthew) requested that fellow second graders attending her gymnastics party bring art kits and fleece blankets for patients at Goryeb Children's Hospital. Thanks to the generosity of the 28 attendees, the Lafayette resident donated 26 blankets and 29 art kits to the hospital, where she and her sister, Meaghan, were once patients.

"We hold the hospital in high regard — their lives were saved there," says Maryann Doherty, Madison's mother. "We still have the tea set, stuffed animals and blankets my daughters received as patients."