Kids Count!

SPOTLIGHT ON
Valerie Fund Children’s Center

For one young patient, visiting the Valerie Fund Children’s Center (VFCC) at Goryeb Children’s Hospital isn’t something to dread. For him, it’s all about the video games, the toy box crammed with stuffed animals and the caring nurses. In fact, he keeps pestering his mother that it might be time for another check up.

This fondness is exactly what Hazem Mahmoud, MD, medical director of the VFCC, wants his young patients and their parents to feel. “Our mission is for this center to be a home away from home; when a child is a patient here, we’re an extension of that child’s family and their house,” he says.

The VFCC treats children, adolescents and young adults with cancer and diverse blood disorders, such as Sickle Cell Anemia, Hemophilia, white blood cell and/or platelet abnormalities and bleeding conditions. The second largest children’s cancer center in Northern New Jersey, the VFCC at Atlantic Health cares for approximately 35 new cancer patients and 300 new hematology patients each year.

“Coming here is different than taking your child to the ER with a broken arm, where you stay briefly and then go home,” he says. “This is recurring, with each stay lasting three to four days in the hospital. It can be a hardship on families. Who will take care of the kids at home? How will the family pay for a babysitter? What if the heat gets shut off because a family cannot pay their bills? How to deal with the sibling at home who is jealous and thinks his parents love the other child more?”

For many families, these questions are answered by the VFCC. In addition to providing excellent medical care for young patients, the center caters to a patient’s family, extending a much-needed safety net through psycho-social services.

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A Note from Pediatrics Chairman
Walter Rosenfeld, MD

Goryeb Children’s Hospital is poised to enter a new era. We’ve defined a strategic plan that builds on our excellent clinical care and identifies high-priority initiatives, including the creation of four Centers of Excellence in Gastroenterology/Inflammatory Bowel Disease, Respiratory/Asthma, Diabetes and Epilepsy. While we are already a leader in these areas, we intend to move to an even higher level by increasing research, measuring outcomes data, and bolstering our family support services.

We’re committed to creating and improving our psychosocial programs because we know this approach actually results in improved outcomes and better satisfaction. Through our Child Life Program, patients learn relaxation techniques to reduce pain, talk therapy to lessen anxieties and music therapy to soothe nerves during procedures. We want this program to reach more patients in the Emergency Department and our outpatient areas.

Throughout Goryeb, doctors are seeing the value of holistic healing. Our team includes professionals at the Atlantic Rehabilitation Institute where meditation, guided imagery and massage are employed to help control chronic pain. Psychologists are also used to help young people and their families learn to live with chronic diseases. Yet many psychosocial services that are so crucial in treating the “whole” child are frequently not covered by insurance.

We would like these complementary programs to be integrated with routine medical care for our patients and their families. For Goryeb to achieve its bold agenda, we need the community’s support. Please help us make Goryeb a recognized national leader in children’s health care.

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While many teens are preoccupied with friends, schoolwork and sports, two Basking Ridge students are filling their free time helping others. Last summer, Emily Weber, 15, and Katie Curtin, 16, both sophomores at Ridge High School, started Kids4Kids, a committee that supports Goryeb Children’s Hospital.

For their first project, the teens are collecting “comfort cart” items, travel size toiletries given to parents and patients who forget necessities like shampoo and toothpaste when staying overnight at Goryeb. The sophomores enlisted the help of four local elementary schools as well as 80 Girl Scout troops to gather the supplies.

“Their goal is to get more teens involved with the hospital,” says Ms. Curtin. She and Ms. Weber hope to attract an enthusiastic crowd at a spring fundraiser at the Bernardsville Cinema. Proceeds will go toward the purchase of 35 flat screen televisions for Goryeb. Kids4Kids works closely with the Child Life Department to determine funding needs.

“We want to help as many kids as possible, either indirectly by giving their parents comfort carts or by making the children more comfortable by providing TVs or video games,” says Ms. Weber. “We want to give help wherever it’s needed.”
many cases, a much-needed safety net through psycho-social services offered by two social workers. Yet these comforts come at a cost and are not covered by insurance. Dr. Mahmoud is seeking outside funds to strengthen already existing programs, hire new staff and develop new initiatives.

When a child is chronically ill, the financial strain on a family can be tremendous. One parent is often out of work to care for the sick child, and even families with good insurance can feel the pinch, says Dr. Mahmoud. Through the Good Neighbor Fund, families are given assistance to offset daily living expenses, such as mortgage payments, water and electric bills, babysitting costs and medicine, to ensure that a patient’s care is not disrupted.

“If a patient is sick and the parents can’t bring the child in because they don’t have gas in their car, we have funds available to assist them with transportation through various organizations, including Atlantic Health Car Service,” says Dr. Mahmoud.

Another non-medical but necessary component of the VFCC is the school re-entry program for children with cancer, which serves to smooth a patient’s transition back to the classroom after an extended absence. Before the patient’s return, the center’s social workers, nurse practitioner and child life specialist visit with the child and his or her class to teach about cancer and to dispel any myths. Armed with visual props, such as a doll wearing a wig and wood blocks representing blood cells, the social worker discusses what it’s like to get chemotherapy, to wear a wig or to have mouth sores, says Cathy Cerutti, VFCC social worker.

“The kids ask a lot of questions, like what if the cancer comes back,” she says. “Our goal is to be honest: We work hard at the center to help gain a child’s trust about their diagnosis, their treatment and managing day to day.” Mrs. Cerutti also negotiates with the school any issues that should arise, such as learning lags from treatment or medication side effects. To expand this advocacy program, Dr. Mahmoud wants to secure funds to hire a full time social worker.

Also on Dr. Mahmoud’s wish list is the expansion of a data manager position so that patients’ illnesses, treatment and outcomes could be tracked into adulthood. This process will enable doctors to compare treatments, outcomes and medication side effects.

Through the generosity of donors, Dr. Mahmoud also wants to fund a palliative care doctor to treat dying patients and prescribe pain medications and a nurse practitioner to serve as a liaison between the patient and hospice or home care.

From Dr. Mahmoud’s perspective, these supplemental programs are not optional; they will help ensure that the VFCC remains a premier children’s treatment center, one that its young patients look forward to visiting.

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**Riggio Memorial Draws Record Sum**

In her 20 short years, Melissa Riggio accomplished much and inspired many, and she continues to do so even after her death. Daughter of Steve and Laura Riggio of Bernardsville, Ms. Riggio had Down syndrome and succumbed to leukemia on April 7, 2008. To honor her, the family established the Melissa Riggio Memorial Fund to benefit the Valerie Fund Children’s Center at Morristown Memorial, where she was a patient.

Since then, over 427 people have given $168,000 from across the country, many never having met the young woman. Some contributed because they were moved by her story and other parents of special needs children were awed by her many accomplishments.

“Our family is enormously grateful to those who contributed to the Melissa Riggio Fund,” says Mr. Riggio, CEO of Barnes & Noble. “It says so much about the inspiring life Melissa led. We plan to add to these contributions with a substantial family donation, enabling the fund to provide support to families whose children are undergoing treatment for leukemia.”

A 2007 graduate of Bernards High School, Ms. Riggio was crowned prom queen. She fulfilled a personal goal her senior year by being placed in a “mainstream” English class. An office worker at the Somerset Hills YMCA, she aspired to become a counselor. In 2003, she was honored with the Self Advocate Award from the National Down Syndrome Society.

Ms. Riggio’s birth influenced the availability of material on special needs children at bookstores nationwide. Mr. Riggio, then executive vice president of Barnes & Noble, dedicated a specific section for children with special needs at Barnes & Noble bookstores. Since then, this section has flourished.

Through writing, Ms. Riggio shared her feelings about having Down syndrome. A poet, her words were set to music and recorded by pop artist Rachel Fuller and produced by rock musician Pete Townshend. Her thoughts were published in the National Geographic Kids and included in Chicken Soup for the Soul: Children with Special Needs. She writes: “Sometimes all I see — all I think other people see — is the outside of me, not the inside. And I really want people to go in there and see what I’m all about.”

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**Sam’s NICU WOWS Donors**

On Sept. 18, 2008 over 125 donors flocked to the private preview of Sam’s Neonatal Intensive Care Unit (NICU), named in memory of Samantha Marie Salzberg, the daughter of lead donor Steve Salzberg. The costs of the $15 million project were offset by the $5.1 million raised from the community, with Steve and Doris Salzberg pledging $1.5 million. As benefactors toured the relocated and expanded facility, they marveled at the 34 private and semi-private rooms complete with family-friendly touches like soft lighting and comfortable convertible couches and high-tech equipment such as Giraffe® OmniBeds® and Giraffe® warmers and incubators.

“This is a chance to memorialize Sam,” said Mr. Salzberg as he addressed the guests. “Twenty-one years ago my daughter couldn’t be treated here, and now Morristown Memorial’s NICU will stand against any in the country.”

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**GIFTS from the Heart**

The Women’s Association of Morristown Memorial (WAMMH) raised $63,000 toward the purchase of new equipment that will test infant pulmonary function for the Pediatric Pulmonary Program. The service, offered at only a few hospitals in the nation, will identify various types of lung diseases and assess responsiveness to certain medications. The funds were raised through the Babies Alumni, an infant photography and birthday enrollment program run by WAMMH. These monies, along with contributions from WAMMH general funds, were used to purchase the $88,000 equipment.

The Newcomers Club of Morristown held a wine and cheese party on Oct. 11, 2008, at the 112-year-old Victorian home of Dawne and Larry Drake of Convent Station, raising over $675 to benefit Gagnon Children’s Emergency Department and the Department of Child Life. Over 50 guests listened to Amy Humphreys, child life specialist, discuss her role in the Emergency Department. Susan Lamberton of Convent Station co-chaired the event with Mrs. Drake.