On her third birthday, Zoe Rothschild, now 7, was diagnosed with Rett syndrome, a disease on the autism spectrum that causes severe neurological impairment in girls. She received her diagnosis one day after her baby brother was born. “Needless to say, I was overwhelmed,” recalls her mother, Rachel Rothschild. “No one around me had ever heard of Rett. I envisioned having to fly all over the country for specialists—only to find there’s an amazing place 45 minutes from home.”

Among the highly specialized services offered by The Children’s Hospital at Montefiore (CHAM) is the Rett Syndrome Center, the only one of its kind in the United States. Caused by a genetic mutation called Methyl-CpG binding protein 2 (MeCP2), Rett syndrome often manifests after a girl undergoes initial normal development. When she is between 6 and 18 months, in the first stages of the disease, her growth slows, and she loses the previously acquired ability to use hands, play and communicate.

Starting during the toddler years, girls with Rett syndrome often regress, losing speech and motor skills. Most develop repetitive hand movements, irregular breathing patterns, seizures and extreme motor control problems. Rett syndrome patients struggle with multiple debilitating symptoms,

continued...
Montefiore was built by philanthropists in the late 1800s. The cornerstone of New York philanthropy—including such names as Guggenheim, Bloomingdale, Sulzberger and Lehman—graced the boardroom and gave the founding gifts. Over time, many generous individuals, families and organizations believed in and supported Montefiore. Their spirit, passion and imagination enabled us to become a world-class academic medical center, committed to excellence in medicine and caring for the health of the community at large.

Today’s philanthropists—our partners who give at any level—will help Montefiore ascend to new levels of excellence. To help forge and sustain ties to this generous community, we are launching Motivations as a way to share Montefiore’s story…throughout New York, across the country and around the world.

We hope that Motivations will inform and inspire your imagination. Our vision of philanthropy is collaborative, and we invite you to join us and to get involved. We are truly grateful for your support and partnership with Montefiore.

“The Center’s main areas of focus are:

• Providing multidisciplinary care for patients.
• Conducting pre-clinical and clinical research to advance knowledge of and treatment for Rett syndrome. Preclinical studies suggest that restoring levels of the altered MeCP2 protein can undo neurological damage, but more research is needed to determine how these findings can translate to better treatment.

• Promoting education and support for caregivers, family members, healthcare providers and the community. “Through education and outreach we hope to end the perception that those with Rett syndrome cannot learn,” says Dr. Djukic.

“We’re here to help families help their children achieve their full potential,” says Dr. Djukic, who directs the Center. “There is strong scientific evidence suggesting that severe symptoms may be fully reversed even in advanced stages of the disease. We are committed to furthering clinical investigation because we believe these studies will translate into successful treatments for our patients.”

Generous contributions from patients, families and friends enable the Center to develop and maintain programs, classes, research and symposia that contribute to a deeper understanding of the disease and a better quality of life for patients. The Rothschilds co-chair an annual New York City gala (this year’s will be held on November 8 at the Broad Street Ballroom) that raises funds for research; 15 percent of the proceeds goes to the Center, to increase staff and advance treatment and research. “As a parent, your hands feel tied,” says Mrs. Rothschild. “Through this fundraiser, I feel like I am doing something to make a difference for Zoe. And by giving to Montefiore, it allows [Dr. Djukic] to do more of what she’s doing. She’s truly one of a kind.”

CHAM’s Rett Center is also the driving force behind Blue Sky Girls, an international organization that hosts an annual multi-site event—around the country and around the world—inviting girls with Rett, their families and community members to walk up the steps of a central civic building. “Climbing stairs is a symbolic gesture, because climbing takes you upwards and forward, no matter how difficult it may be,” says Dr. Djukic.

Cover Story continued

including reflux, poor nutrient absorption, growth retardation, difficulty swallowing, scoliosis, dental problems, trouble sleeping, irritability and anxiety. “She knows she’s loved, and she is a happy little girl,” Mrs. Rothschild says of Zoe, whom she describes as spunky, wild and very social. “But she knows she’s different and it makes her frustrated.”

The key to treatments at CHAM’s Rett Syndrome Center is interdisciplinary care encompassing epilepsy, physical rehabilitation, critical care, developmental pediatrics, behavioral neurology, endocrinology, genetics, gastrointestinal disorders, cardiology, pulmonary medicine, orthopedic surgery, physical medicine and rehabilitation, and dentistry. “We ensure that each patient has continuity of care from infancy through adolescence and adulthood,” says Aleksandra Djukic, MD, PhD. “Knowing that all the doctors understand and are versed in Rett makes a huge difference to my family,” says Mrs. Rothschild. “We had a few tests done elsewhere, and I felt like I had a lot of explaining to do. At the Center, we never have to apologize for anything.”

The Center’s main areas of focus are:

• Providing multidisciplinary care for patients.
• Conducting pre-clinical and clinical research
There are only four kinds of people in the world. Those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.”

— Rosalyn Carter

Some 65 million Americans care for a loved one—a physically and emotionally demanding role that too often goes unrecognized. Studies show that supporting the caregiver translates to better health not only for the caregiver but also for the patient. The Arthur D. Emil Caregiver Support Center (CSC) was established in 2011 with a grant from the United Hospital Fund and named with a gift from Oded Abboodi and the Emil family. Since it opened, the Center—the only one of its kind in a New York City academic medical center—has served more than 1,100 caregivers.

Working under a social worker’s supervision, trained volunteers like Mr. Alan Epstein provide individual attention to caregivers as they cope with meeting the needs of their loved one. “I truly find my volunteerism at the CSC to be one of the most rewarding experiences in my life,” Mr. Epstein says. “There are such tremendous pressures and fears that go along with caring for a sick loved one, whether in the hospital or at home. We provide the supportive glue that helps the caregiver to keep on going. We quickly determine what the caregiver seems to need the most at the time and find ways to meet that need. From empathetic listening, which is very powerful, to helping them access pertinent information on our computers or within the medical center, or post discharge care, to encouraging the much-needed rest when exhaustion is evident, we try to help the caregiver feel a little less alone in what is often an overwhelming and frightening situation.”

“It has been incredible to see this volunteer-driven program become such a vital part of our community in just one year,” says Paula Marcus, MD, Director of the Psychosocial Service to the Transplant Programs at Montefiore. “The families of our patients have come to rely upon the CSC.”

“The minute you walk in the door, you’re stepping out of the hospital environment into this peaceful, serene place,” says Phyllis Cobb, whose husband underwent a liver transplant at Montefiore. “I know as a caregiver how important it is to take care of myself. I can’t be any good to my husband if I’m falling apart myself. This is really a blessing.”

In keeping with Montefiore’s commitment to family- and patient-centered care, the Center’s space and resources have helped multidisciplinary teams embrace both patient and family as active members of the care team. “The CSC gives the medical center a human touch. It shows people that we really do care, and we really do care about the caregiver,” says Mr. Epstein.

HOW CAN YOU HELP?

Your support can make a significant difference in helping us sustain this exemplary caregiver program and expanding it to Montefiore’s other campuses. By adding our caregiver services to other areas of our organization, we can reach more families in need. Every contribution counts, so please contact Montefiore’s Office of Development at 718-920-6656 or visit givetomontefiore.org to find out how you can get involved. To learn more about the Center, visit www.montefiore.org/caregiversupport.
Four years ago, the CDM Group, a healthcare communications company, masterminded the creation of a battle-of-the-bands fundraiser to support the Phoebe H. Stein Child Life Program at The Children’s Hospital at Montefiore (CHAM). Featuring bands from about a dozen healthcare advertising agencies, the event, known as Pharmapalooza, has raised nearly $400,000 for CHAM since its inception. “A good time for a good cause,” is how Ed Wise, CEO of the healthcare communications company The CDM Group, describes the event.

The partnership began in 2007, when CDM sought to streamline its volunteer work and philanthropy. The agency chose to partner with CHAM because of its mission to serve the community’s most vulnerable young patients, its commitment to excellence, and its embrace of CDM’s desire to donate time in addition to money, welcoming CDM employees as volunteers in the Child Life Program. “There were many things about CHAM that resonated with us, including the thoughtful, creative environment of the hospital itself,” says Mr. Wise. “We know the power of creativity, and we saw it in action at the hospital.”

Each November, Pharmapalooza rocks B.B. King’s in New York City, featuring talented bands—made up of healthcare advertising employees—and music-industry judges. The most recent Pharmapalooza, in 2011, raised almost $100,000 to support CHAM and the Child Life Program.

The Child Life Program provides education, recreational opportunities and coordinated support for children and families to ease their stay at the hospital. Trained to care for children ranging from newborns to young adults, child life specialists create a comfortable environment for young patients, help children understand their medical procedures, address common fears, and develop age-appropriate recreational activities in the hospital.

Many CDM employees serve as Child Life volunteers, reading books, creating art and joining in on music therapy sessions with pediatric patients. CDM employee Laura Cruz vividly recalls helping a young CHAM patient who suffered from a debilitating neuromuscular condition create a colorful, jewel-studded princess box. When the difficult project was done, the young girl was clearly sapped of energy but refused entreaties to return to her bed. “I want to do another one,” she said.

“We’re blown away by the healing power of creativity and how important the Child Life program is to these kids,” says Mr. Wise.

To learn more about starting your own fundraising event or about volunteering opportunities for CHAM, please contact Christy O’Keefe at 718-920-8985 or cokeefe@montefiore.org.
Recognizing that a day at the park can mean the world to children with cancer and their families, the Gaynes support an annual family fun day at Playland Amusement Park. Each year, Mr. Gaynes is amazed at just how much this day can matter. “[One boy] came up to me and hugged me, and said ‘I want to thank you. I look forward to this day every year,’” Mr. Gaynes recalls. “I had to excuse myself, because I felt like I was going to cry. It’s a privilege to be able to give these kids such a special day.”

Mr. Gaynes and his wife Arlene sponsor the annual outing, along with other programs vital to the care and comfort of sick children, through Chillin’ with Adam: The Adam Gaynes Foundation. They established the foundation in memory of their son Adam, who died of brain cancer in 2004. With a nod to Adam’s signature expression, Chillin’ with Adam creates supportive experiences for children and their families during incredibly trying, and often isolating, times in their lives.

“It’s a great feeling to be able to assist these kids, because we know what they are going through,” says Mr. Gaynes, noting that he and his wife worked in partnership with Adam’s doctor, Rick Abbott, MD, now Attending Physician at The Children’s Hospital at Montefiore and Professor of Neurosurgery at Albert Einstein College of Medicine, to ensure that their contributions would be most meaningful to patients and their families.

The family’s donations have been used to underwrite the salary of a child life specialist, renovate the parents’ lounge, purchase a cinema-vision MRI machine to let kids watch videos while undergoing magnetic resonance imaging testing, establish emergency funds for babysitting, and set up closed-circuit televisions to observe children in isolation, among other enhancements.

“Every family deserves to be treated at a place like Montefiore, which provides cutting-edge medical care and also unwavering compassion and emotional support for families,” says Mr. Gaynes. “It’s a tough economy, and the money is not out there. It gives us a ton of satisfaction to make these kids’ lives better.”

By giving in Adam’s name, the Gaynes family feels connected to their son and maintains his legacy. “Montefiore makes it easy for us to support the care of children with brain tumors,” says Mr. Gaynes. “The medical center is very passionate about helping kids, and they’re great partners in this endeavor.”
Grace, a 44-year-old single mother of two teenagers, had two kidney transplants—in 1989 and 2008—but her life-saving care did not end there. As with all transplant patients, a lifetime of follow-up care is as vital to long-term success as the highly complex surgical procedure itself. Thanks to Montefiore’s donor-funded Helping Hands program, Grace got the help she needed to survive and thrive, even during periods when she was without insurance coverage. Helping Hands worked one-on-one with Grace to ensure she received her prescriptions at no cost, enabling her to comply with her postoperative treatment plan and maintain proper kidney function.

“I will always be grateful for the help that Montefiore provided with my medications over the years,” says Grace, who is now in stable health and has resumed full-time employment. “Without assistance, I would have had trouble paying for very necessary and expensive medications, and I would have risked my transplants. My kidney continues to work well, in large part due to this vital program.”}

Helping Hands helps patients and their families navigate the often overwhelming pre- and postoperative care surrounding transplantation. For patients and families who travel to receive a life-saving transplant at Montefiore, Helping Hands lightens the emotional and financial burden by providing support, including temporary housing, transportation to medical appointments, assistance managing medications and treatment recommendations, and help with daily activities. The program also connects patients and families to a network of community resources, helping them build a reliable support network—for life.

Interested in supporting the Helping Hands program?
Please contact Christy O’Keefe at 718-920-8985 or cokeefe@montefiore.org or visit giving.montefiore.org/helpinghands.

COMING OUT SWINGING

A fundraiser was held in Spring 2012 at Yankee Stadium for the J.E. and Z.B. Butler Child Advocacy Center at The Children’s Hospital at Montefiore. From left to right: Steven M. Safyer, MD, President and CEO; Philip O. Ozuah, MD, PhD, Executive Vice President, Chief Operating Officer, and Physician-in-Chief, The Children’s Hospital at Montefiore; David Tanner, Chairman of the Montefiore Board of Trustees; Joseph W. Bartlett, Montefiore Trustee; Bruce Doniger, Montefiore Trustee, and President of the J.E. & Z.B. Butler Foundation.
MONTEFIORE: A History of Giving Back

Montefiore was founded on the very idea of giving back—a spirit that continues today with every patient we treat, every scientific discovery we make, every community partnership we advance.

More than 125 years ago, a group of New York’s most influential philanthropists harnessed their energies and resources to build a hospital with a social mission—to help those doubly burdened by poverty and illness. The Jewish philanthropists named the institution to honor Sir Moses Montefiore, the former sheriff of London and leading Jewish philanthropist of the 19th century.

As the industrial age shifted the focus of care from individual house calls to institutional-based medicine, the Montefiore Home for Chronic Invalids opened in 1884, marking Sir Moses Montefiore’s 100th birthday. The charitable organization cared for so-called incurables—those who suffered from chronic diseases like arthritis and cancer, could not afford home care, and had nowhere else to go for clean accommodations and nursing. They quickly filled 26 beds in a modest house on Manhattan’s Upper East Side. The first patient, admitted on October 19, was Louis Spanier, a 30-year-old painter with lead poisoning, which had been previously diagnosed as “painter’s colic.”

Support for the urgently needed institution came from all corners. Montefiore’s founding members sent potential supporters a return-addressed postcard printed with annual pledge options—$10 a year to be named a member, $25 for patrons and $250 for a lifetime membership. Donors who pledged $1,000 or more could name a bed in their honor. By the end of the first year, the Montefiore Home for Chronic Invalids had 750 members and 170 patrons—the robust beginnings of what would become a 125-year-long partnership with the community to bring excellent care to those in need.

Montefiore’s philanthropic heritage—people working together with a commitment to the greater good—makes the organization the special place it is today. From humble beginnings in 1884, Montefiore now occupies four hospitals with 1,491 beds and employs more than 1,750 physicians, providing care to hundreds of thousands of patients throughout the Bronx, Westchester and beyond. It remains an institution that cares deeply for its community, providing a safe, comforting haven along with groundbreaking treatment and renowned patient care.

Montefiore still relies on the support of those who believe in our mission and vision to ensure excellence while reaching all those who need our care. With your help, we will continue meeting the needs of today’s patients and anticipating tomorrow’s healthcare challenges. Join a vibrant philanthropic tradition—and help Montefiore continue to advance a better future.

In the 19th century, people with conditions from arthritis to cancer stayed at the Montefiore Home for Chronic Invalids, a 26-bed house on the Upper East Side. Today, Montefiore is a 1,491-bed academic medical center with four hospitals across several campuses in the Bronx.
"Montefiore is a humanistic institution with a social conscience. The institution keeps on changing, but still that heritage continues."

— Wilma Bulkin-Siegel, MD, Retired Oncologist and Educator at Montefiore and Einstein

Ways to GIVE

Please help Montefiore drive forward its mission of providing high-quality, compassionate care, innovative research, premier medical education and an unparalleled commitment to the community — delivering one standard of excellence for all.

There are countless ways to give. Support the annual fund, which provides critical resources where they are most needed to advance strategic priorities and meet urgent health needs. Or make a gift in honor or memory of a loved one, doctor or nurse. You may also support specific programs, such as Pediatric Oncology, Rett Syndrome, the Arthur D. Emil Caregiver Support Center or our Helping Hands program described in this newsletter.

Additionally, we suggest donors consider gifts of stock and estate planning, which allocate cash, a percentage of an estate, or a retirement plan to the hospital, to maximize your gift — and your legacy.

There are many ways to give. Contact us to find the one that’s right for you.

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