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Danielle Navidi pours a delicious smoothie that contains the types of nutrients young cancer patients need. **Photo by Tom Lander**

Cooking for Cancer: A Mother's Determination to Nourish Her Child Helps Hundreds

By Lynn Cantwell

Inspiration comes in many forms. An act of beauty can inspire a song. An injustice can inspire a legal career. For Danielle Navidi, inspiration for a new career came from a simple need: to find something her 11-year-old son, Fabien, would eat during his treatment for Hodgkin's lymphoma at MedStar Georgetown University Hospital.

Today, Fabien is a healthy college junior, and Danielle directs a program on cancer nutrition called "Cooking for Cancer" at MedStar Georgetown. She has even authored a recipe book filled with cancer-fighting foods that are appetizing to children whose appetites and preferences are continually evolving because of their treatments.

Danielle's journey began eight years ago. Fabien wasn't feeling well. His throat and chest felt tight, and he had a lump on his neck. One weekend, the lump became very large and the usually healthy child told his mother that it felt like he was breathing through a straw.

After a trip to the family pediatrician and a chest X-ray, Fabien's diagnosis was Stage III Hodgkin's lymphoma, a

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Mother's Intuition Leads to Accurate Brain Tumor Diagnosis

By Leslie Whitlinger

While most parents believe their children are extraordinary, Jessica Lovelace and her husband, Chris Clarke, have scientific proof. Their daughter, Kyla, is one of the very few children in the United States diagnosed each year with a rare brain tumor lodged in an even rarer – and dangerous – location.

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After surgery to remove a dangerous tumor from her brain, Kyla is back to being her playful self again.
Photo courtesy of Lovelace-Clarke Family

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Message From the Chairman

Safety Focus and Community Support Improve Outcomes

Dear Friends,

At MedStar Georgetown's Department of Pediatrics, we know we have a tremendous responsibility – caring for your child. Our entire focus is centered on this mission: bringing the best possible care to the children and families we serve.

Crucial to the health of any patient is providing care in the safest manner possible. This commitment has been, and will always be, a major focus at MedStar Georgetown University Hospital. One critical area where we have focused our patient safety efforts has been protecting our children from serious infections that result from intravenous catheters. While these catheters are essential to providing medications and nutrition to children who are seriously ill, they can result in serious blood infections. We are extremely proud that our Department of Pediatrics has not experienced a blood infection caused by a central line catheter for three years, placing us in the upper echelons of patient safety nationally. This kind of careful attention to detail is present in all we do at MedStar Georgetown.

While the health of your child is our central focus, we long ago recognized that a child cannot be cured without the involvement of their family. We know that it takes more than expert physicians, highly technical procedures and the latest medications to cure a child. It also requires care of the emotional and spiritual needs

Photo by Andrea Grego

of the child and family, none of which can be done in isolation. Our family-centered and inclusive approach reflects our belief in the Jesuit tradition of *cura personalis* – caring for the whole person.

We are finding increasing commitment from our neighbors to help make family-centered care a reality. We are thankful for amazing programs like:

- H.O.M.E., run by Ozzy Ramos, a big-hearted retired U.S. Marine, donating tremendous holiday toys and gifts to children in our Pediatric HIV Program.
- Our MedStar Georgetown Jingle, raising $259,000 this past December to build and sustain our Pediatric Bone Marrow Transplant Unit and our Pediatric Survivorship and Palliative Care Programs.
- JUST T**RYAN** IT, raising $125,000 at its annual triathlon for kids this year to support our Pediatric Hematology-Oncology Patient Assistance Fund.
- GO BO GO, founded by the Johns Family, providing $39,000 this year to the Pediatric Hematology-Oncology Family Emergency Relief Fund.
- The Katelyn Hall Foundation Golf Tournament, donating approximately $40,000 to support our Division of Neonatology and Neonatal Intensive Care Unit.

There are so many gifts, I simply cannot recognize them all here. We feel blessed by these donations that help children and their families grow stronger.

Safety is paramount to all of us in the Department of Pediatrics. And we know it takes more than providing a safe environment and the best clinical care possible to help families through injury and illness. That's why we work so hard to provide family-centered care with programs like Child Life (see stories on pages 6 and 7) and other initiatives that support families through it all.

I hope you find inspiration in these pages and are able to find a way to help us continue our focus on safety and family-centered care at MedStar Georgetown's Department of Pediatrics.

Warmest regards,

David B. Nelson, MD, MSc
Chair, Department of Pediatrics,
MedStar Georgetown University Hospital

Thinking About Zebras Leads to a Rare Diagnosis and Accurate Treatment

By Maritza Matheus

While some people believe in the patter of reindeer on roofs at Christmas, a doctor at Medstar Georgetown's Pediatric Intensive Care Unit (PICU) imagined zebras. Her quick thinking led her to a startling, rare and accurate diagnosis.

Last December 24, Dr. Raquel Farias-Moeller, a second-year resident at the PICU, examined Izabella, a newly admitted 10-year-old patient. While many children and families were home preparing for holiday festivities and opening gifts, Izabella was in the hospital because of seizures. Her parents and extended family were at her bedside worried and heartsick.

MELAS is a very rare condition that can occur during childhood with symptoms sometimes resembling the flu.

Two days prior, Izabella was her typical self, excited with anticipation about the holidays and the break from school. Suddenly, Izabella experienced typical flu-like symptoms, a persistent cough and a fever. Her pediatrician prescribed antibiotics and cough medicine. Soon after, Izabella became very dizzy, had blurry vision and was bumping into furniture. "It just was not the typical flu," described Rosa, Izabella's mother. When Izabella fell in the bathroom, Rosa took her to the local hospital's emergency department. While there, Izabella began convulsing; and the staff immediately transferred her to the pediatric unit at MedStar Georgetown.

The pediatric team performed an electroencephalogram (EEG), a common diagnostic test for people suspected of having seizures. The results were puzzling since Izabella appeared to be in "status epilepticus" or a life-threatening prolonged state of seizure. Then, she was transferred to the PICU where an MRI was performed. Meanwhile, Izabella was developing dangerous levels of lactic acid in her cells – a common bodily reaction to trauma such as seizures. Her kidneys were failing and she had a tube inserted into her mouth to help her breathe. Izabella's fast-declining health couldn't be diagnosed by the test results.

"It was a stressful time for all," recalls Dr. Farias-Moeller. "The family, originally from Guatemala, is not fluent in English. It was Christmas, they expected to be home, and they anxiously wanted a diagnosis. Still, the camaraderie among the patient and MedStar Georgetown staff was amazing. Everyone pulled together, which yielded quick results."

While reviewing the case on December 25, Dr. Farias-Moeller thought about the expression "when you hear hooves, think of horses and not zebras." The saying prompts physicians to consider the most likely causes before jumping to unusual and rare conditions. However, Dr. Farias-Moeller thought of the unusual: MELAS, which is mitochondrial encephalomyopathy, lactic acidosis

With a team approach to providing care, Drs. Santos and Farias-Moeller were able to accurately diagnose Izabella.
Photo by Laura Brickley

and stroke-like episodes. MELAS is a very rare, chronic condition that affects 16 out of every 100,000 people and it often goes undetected. It affects many of the body's systems, particularly the brain and nervous system (encephalo) and muscles (myopathy). Often, the signs of this disorder appear in childhood following a period of normal development and correlate with the description of Izabella's symptoms and recent behavior.

Cesar Santos, MD, chief, Division of Pediatric Neurology and his team took Dr. Farias-Moeller's lead and ordered the corresponding diagnostic tests. The results were conclusive: Izabella's illness was MELAS.

Such teamwork and compassion were not surprising for this multidisciplinary and collaborative team which included a pediatric neurologist, nephrologist (kidney disease physician), an infectious disease specialist, intensive care doctors and nurses, various diagnostic clinicians, interpreters and physician residents. As Dr. Farias-

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Young Athletes and Concussions — What You Need to Know

By Tamara Katy, MD, Emergency Department Pediatrician

As parents, we understand that sports help children stay active, build coordination and learn important life skills like teamwork and discipline. However, playing sports can be risky. With sports participation by children on the rise, so are sports-related injuries.

Beyond sprains and strains, a more serious and potentially catastrophic risk of participation in certain sports is head injury. What you may find surprising is that head injuries, specifically concussions, are not limited to contact sports such as football, hockey and lacrosse. Concussions can occur in almost every sport. As such, it is important that coaches and parents are vigilant about the use of protective equipment and aware of the important steps to take when children hit their heads.

Correct use of safety equipment and other preventive measures helps keep sports injuries to a minimum.

Emergency Department Pediatrician Tamara Katy, MD, offers her perspective on sports and concussions.
Photo by Leslie E. Kossoff/LK Photos

A concussion is a disruption in normal brain function due to a blow or jolt to the head, as defined by the Centers for Disease Control and Prevention (CDC). When a concussion occurs, brain cells are injured and the brain's delicate chemical balance becomes disrupted. Since a concussion is a traumatic brain injury, it needs to be taken seriously.

Although most concussions in young athletes occur when they hit their heads, an impact is not required for them to have a concussion. Sometimes, a severe jolt that results in the rapid movement of the head can cause a concussion as the brain hits the inside of the skull.

In fact, concussions were discussed in last spring's issue of the *American Journal of Sports Medicine*. A published study conducted by MedStar Health Research Institute's Sports Medicine Research Center examined trends in concussions that occurred during participation in high school athletics during an 11-year period. The study revealed that collision sports like football and lacrosse had the highest number of concussions overall; however, concussion rates (concussions per 1,000 exposures) in girls' soccer were second only to boys' football. Additionally, girls' concussion rates were similar to or higher than those experienced by boys who participated in similar sports: basketball, soccer and baseball/softball.

Recognizing a Concussion

One of the most important things to remember is that while loss of consciousness is a symptom of concussion, most people with a concussion do not lose consciousness. Following a blow or jolt to the head, it is important to watch your child for symptoms. Have a pediatrician or emergency department physician evaluate your child if one or more of the following symptoms is present:

- Severe headache
- Nausea and vomiting
- Sleepiness
- Irritability or change in personality
- Loss of memory
- Confusion
- Slower movement
- Visual changes
- Weakness
- Numbness.

Young athletes should be encouraged to notify their coaches and parents about hits to the head. If they lose consciousness, experience severe confusion or have a seizure following a head injury, call 911 immediately.

A MedStar Health Research Institute study found concussion rates in girls' soccer was second only to boys' football.

Treating a Concussion

Once we learn how the child was injured, we take an extensive medical history and perform physical and neurological examinations. If the circumstances and symptoms suggest that the child may have a concussion, we perform brain imaging, such as a CT scan, to rule out internal bleeding, swelling or skull fractures.

The most important treatments for a concussion include rest and close monitoring. While we may suggest pain relievers to treat a resulting headache, it is critical that children or young adults rest their brains – both physically and cognitively – with the exact time frame based on the severity of the concussion. Such "time-off" restrictions include temporarily restricting:

- Participating in sports, recreational and other physical activities
- Reading or completing school work
- Viewing screens on television, smartphone devices, computers, video games, etc.
- Driving, if applicable.

If the physician recommends follow-up care by a neurologist, MedStar Georgetown has a team of pediatric neurologists who specialize in brain injury.

Preventing Future Brain Injuries and Concussions

Preventing repeat brain injury, especially when the brain is vulnerable during the recovery phase, is of utmost importance. While a concussion is healing, a second head injury can have devastating consequences.

Once children have experienced and recovered from a concussion, precautions should be taken to avoid future head trauma. Studies show that the brain takes longer to heal following repeat concussions and multiple concussions can lead to learning and psychiatric problems. ✦

For more information about concussions, visit medstargeorgetown.org/concussions.

To schedule an appointment, call MedStar Georgetown M.D. at 202-342-2400.

MedStar Health Research Institute (MHRI)

MHRI is the research division of MedStar Health. As part of this multi-hospital academic medical system spanning the Baltimore, Md., and Washington, D.C., region, MHRI ranks in the top 20 percent of all U.S. institutions in total funding received from the National Institutes of Health and other federal agencies.

In the last year, MHRI's nearly 900 active studies involved thousands of patients and resulted in more than 550 peer-reviewed medical publications.

Concussion Prevention

The Centers for Disease Control and Prevention's website provides a wealth of information about concussions and youth sports including these tips:

- Teach and practice safe playing techniques.
- Encourage athletes to follow the rules of play and to practice good sportsmanship.
- Make sure athletes wear the right protective equipment – helmets, padding, shin guards, and eye and mouth guards. Protective equipment should fit properly, be well maintained and be worn consistently and correctly.
- Teach athletes it's dangerous to play with a concussion. Rest is key after a concussion. Discourage others from pressuring injured athletes to play. Don't let your athletes convince you that they're "just fine."
- After a concussion, the brain needs time to heal. Don't let athletes return to play the day of the injury and until a healthcare professional, experienced in evaluating for concussion, says it's OK.
- Work closely with league or school officials. Be sure that appropriate individuals are available for injury assessments and referrals for further medical care.

Source: Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. CDC.gov.

Donors Make Family-Centered Care Possible at MedStar Georgetown

By Sarah Markel

When a child is sick, the whole family hurts. MedStar Georgetown recognizes that when it comes to caring for children, offering world-class medical and surgical care is just the beginning. "We firmly believe that addressing the emotional and social needs of the entire family is crucial to the well-being of every child," says David B. Nelson, MD, chair, Department of Pediatrics.

Our team of physicians; nurse practitioners; nurses; social workers; physical, occupational and art therapists; chaplains; child life specialists and other staff provide children with "family-centered care" in which families get the emotional and practical support they need during a medical crisis. That high level of care includes helping children cope with the challenges of illness and being away from home at a hospital.

"Some of our programs help parents get the support, nutrition and rest they need to be there for their children," adds Dr. Nelson. Many of these services are funded through the kindness and generosity of family members and friends of former pediatric patients. Some of the funding comes from businesses demonstrating what it means to be a good corporate citizen for the Washington, D.C., community.

MedStar Georgetown Pediatrics Takes Care on the Road

MedStar Georgetown's "blanket of care" approach extends to children and families who do not have access to medical care. The KIDS Mobile Medical Clinic/Ronald McDonald Care Mobile has been rolling into some of Washington, D.C.'s, underserved neighborhoods on weekdays since 1992. CareFirst BlueCross BlueShield (CareFirst) recently awarded the Mobile Clinic/Care Mobile a gift of $225,000 over three years, which will enable more children to visit the van for their pediatric and adolescent care. This gift follows a previous donation of $150,000 from CareFirst to this program. The Mobile Clinic/Care Mobile maintains electronic medical records for each child. Social workers and mental health professionals work on site to ensure that kids and their parents have the knowledge and tools to manage their health.

"It's because of our donors, from corporations such as CareFirst, right down to grassroots events, like the MedStar Georgetown Pediatrics Gala, that thousands of Washington, D.C.'s, most vulnerable children have a medical home where their doctors not only know and care about them, but understand the world in which they live," notes Matthew D. Levy, MD, medical director, Community Pediatrics.

Mobile Clinic Provides "Blanket of Care"

The KIDS Mobile Medical Clinic/Ronald McDonald Care Mobile was founded on the belief that every child, regardless of financial means, deserves high-quality, community-based, comprehensive care. Children are surrounded with a "blanket of care" within the scope of the program's key areas including:

- Comprehensive pediatric and adolescent health care
- Child advocacy and mental health
- Social services
- Education and outreach
- D.C. HOYA Clinic.

C. Rae Montilla, RN, BSN, CCRN, performs a physical exam on Savonte Gunn in the KIDS Mobile Medical Clinic. **Photo courtesy of Verizon**

Waikia Williams brings her daughter, Airyana Copeland to the KIDS Mobile Medical Clinic for a checkup.
Photo courtesy of Verizon

The comprehensive healthcare model offers children the following services:

- School, sports and summer camp physicals
- Well and sick visits
- Immunizations
- Tuberculosis screenings
- Hearing and vision screenings
- Gynecologic services
- Referrals to specialists as needed
- Medical management for chronic illnesses such as asthma, diabetes and HIV/AIDS.

For general information and eligibility criteria, call 202-444-8888. ✦

To support family-centered care at MedStar Georgetown, contact Timothy Mooney at 703-558-1375 or mooneyt1@gunet.georgetown.edu.

You can also give online at medstargeorgetown.org/giving.

Generous Donors Expand Child Life Program

By Sarah Markel

Child Life Program specialists help children cope with the stress and uncertainty of illness and hospitalization. Since 2003, Hope for Henry has been improving the lives of children who have cancer and other serious illnesses by providing carefully chosen gifts and specially designed programs to entertain and promote comfort, care and recovery. With their help, the Child Life Program staff bring more smiles and laughter, hope and magic into the lives of hospitalized children and their families.

Hope for Henry was founded to honor the legacy of Henry Strongin Goldberg, a Washington, D.C., resident who had received care at MedStar Georgetown for Fanconi's Anemia, a rare disease that mainly affects the bone marrow.

Another source of support, the Mattie Miracle Cancer Foundation, provided funding to MedStar Georgetown for an additional Child Life specialist last year.

When Mattie, the son of founders Vicki and Peter Brown, was hospitalized at MedStar Georgetown for osteosarcoma, a very aggressive bone cancer, the Child Life team made a huge difference in the quality and well-being of his day-to-day life. The experience prompted his parents to found the Mattie Miracle Cancer Foundation in his honor. "Our mission is to address the psychosocial and emotional needs of families battling cancer," says Vicki.

"Beyond the great clinical care Mattie received at Georgetown, the contributions of the therapists, social workers and chaplains who were part of our team were equally important during that difficult time for our family," Vicki says.

"Our job is to help hospitalized children feel comfortable and safe," explains Linda Kim, director, Child Life Program, MedStar Georgetown. "Thanks to the generosity of these two groups and the many others who donate to Child Life, we are able to give more children the support they need."

Learn more at mattiemiracle.com and hopeforhenry.org. ✦

Child Life Specialist Linda Kim helps Whitney Smallwood understand what her chemotherapy treatments will involve by using a doll and "medical play."

Cooking for Cancer: A Mother's Determination to Nourish Her Child Helps Hundreds *continued from page one*

cancer of the lymph nodes and lymphatic tissue. Hodgkin's is considered one of the most curable forms of cancer with a survival rate of 95 percent of patients five years after treatment, according to the National Library of Medicine.

> ***Fabien's positive outcome can be attributed not only to the multidisciplinary team's commitment to the treatment of childhood cancer, but to his mother's tenacity with respect to his nutrition.***
>
> **✦ Amal Abu-Ghosh, MD, oncologist**

Fabien's six-month treatment protocol included four, 28-day cycles of chemotherapy followed by eight weeks of radiation.

As grateful as Fabien's family was that his cancer diagnosis came with an encouraging prognosis, it was difficult for them – especially Danielle – to watch him go through the rigors of his treatment. "The toxicity of chemotherapy is so severe," says Danielle. "I wish I could have traded places with him, but I couldn't." The one area in which Danielle believed she could help was Fabien's nutrition.

Danielle was raised in Europe by American expatriates. She embraced the European style of shopping and meal preparation of her upbringing: shopping often, cooking with the freshest, most healthful ingredients, and typically avoiding fast food. She was a good cook, too. Her lasagna and her spaghetti and meatballs were among Fabien's favorites.

However, Danielle soon learned that once Fabien was in the throes of his treatment, the approaches to meals that had always worked were no longer effective. Once he had regained his appetite after his first chemotherapy cycle, Danielle prepared lasagna for Fabien, but he couldn't tolerate it. "His tastes had changed because of the treatment. At that point, my motherly instincts, my European upbringing, were useless for him," says Danielle.

The ability to feed one's child – to meet a child's most basic needs – is vital to every parent. "When a child has cancer, his or her parents lose control of everything," says Aziza Shad, MD, director, Pediatric Oncology at MedStar Georgetown. "Their schedule is based on their child's treatment, they cannot control the outcome. The only thing parents can control is their ability to feed their child. When that doesn't work well, it can be devastating."

According to Dr. Shad, chemotherapy affects the appetite in a number of ways:

- Sores in the mouth and gastrointestinal tract cause discomfort during chewing and swallowing
- Changes in the lining of the mouth cause foods to taste metallic
- Changes in appetite cause new food preferences and aversions.

Additionally, there are certain foods that children receiving chemotherapy cannot have because of their compromised immune systems. Doctors generally recommend avoiding salads and other fresh, raw fruits and vegetables that cannot be peeled. When white blood cell counts are low, the body's ability to fight potential bacteria present in the raw foods can be compromised. However, many children actually crave these foods during chemotherapy. These complexities led Danielle to make it her mission to find foods that worked for Fabien. "The challenge was enormous. I was constantly trying different things – trial and error on my part to see which foods were going to soothe and strengthen him," she says. "Some days his

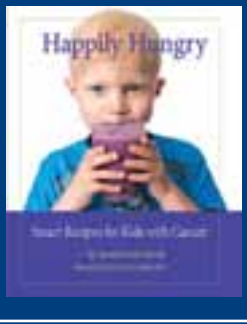
Though Fabien is all grown up, the nutritional lessons his mother learned during his cancer treatment are now helping other patients.
Photo courtesy of Fabien Navidi-Kasmai and Danielle Cook Navidi

A nutritious recipe from Danielle Navidi's new book: *Happily Hungry*

Tropical Smoothie

Ingredients:

- 1 cup fresh or frozen mango chunks (if using fresh, freeze the chunks over night)
- ½ cup silken tofu
- ½ cup pineapple-orange juice
- ¼ cup plain soy milk
- 1-2 tbs. fresh squeezed lime juice
- Agave nectar to taste (optional)



Process all ingredients in a blender until smooth. Serve immediately. Makes one 15-ounce smoothie.

To order *Happily Hungry*, call 202-444-3852 or e-mail laneme@gunet.georgetown.edu.

Funded by the Bryce Foundation, the Lane family, the Bosch family and Enterprise Holdings Foundation, all proceeds help the Pediatric Cancer Nutrition Program at MedStar Georgetown University Hospital.

preferences would change from morning to night. There were days that water tasted weird."

"Fabian is an outstanding young person," says his MedStar Georgetown oncologist, Amal Abu-Ghosh, MD. "Fabien's positive outcome can be attributed not only to the multidisciplinary team's commitment to the treatment of childhood cancer, but to his mother's tenacity with respect to his nutrition."

Danielle's experience inspired her to learn more about food and its effect on the body. Soon she will complete a master's degree in holistic nutrition. Meanwhile, she has incorporated her education with her culinary skills into the work she is doing at MedStar Georgetown. She started the Cooking for Cancer Program, available only at MedStar Georgetown.

Funded by a Hyundai Hope on Wheels grant, the program includes nutritional assessments of patients at the beginning and end of treatment, cooking demonstrations for families in treatment and nutrition consultations for cancer survivors and their families to help them live a healthful lifestyle. Danielle also brings samples of cancer-fighting foods and develops a recipe of the month for the families of pediatric hematology and oncology patients.

"Danielle's food is absolutely delicious. It isn't just good for children with cancer, but for anyone, because it is based on sound nutritional principles," says Mary Lane, MSW, social worker, MedStar Georgetown. "The program has been a tremendous success. In some cases, entire families have changed their eating habits for the better, and parents are relieved that they can prepare food that their children can eat."

"There are two times in the life of a child with cancer when nutrition is important," says Dr. Shad. "During their treatment and then – as cancer survivors – for the rest of their lives."

Children who eat adequate amounts of nutritious foods tolerate their treatment better. Poor nutritional status results in more complications and side effects from treatment. Dr. Shad adds: "Extreme weight loss or weight gain requires us to modify a child's treatment," which is not ideal.

Once children have completed cancer treatment, it is important that they make lifestyle choices that may help prevent future cancers and other late effects such as heart disease. "We teach cancer survivors not to smoke and encourage them to eat foods that are low in sodium and fat and rich in fruits and vegetables. Cancer treatment puts children at greater risk for lifestyle-related problems later in life, so it makes sense to intervene early if you can," says Dr. Shad. "We are so fortunate that the Navidis brought Fabien to us for treatment. The nutrition program Danielle has brought to MedStar Georgetown patients is invaluable." ✦

For more information about the Cooking for Cancer Program, call MedStar Georgetown M.D. at 202-342-2400.

Thinking About Zebras *continued from page three*

Moeller says: "The more brain power goes into a case, the better for the patient and the family." In addition, Dr. Farias-Moeller's ability to speak Spanish to the family provided them with tremendous comfort.

Although Izabella and her family have a long medical path to follow and will need to learn how to manage the continuous effects of MELAS, they finally have the peace of mind that comes from receiving an accurate diagnosis.

As Dr. Farias-Moeller proved, sometimes there is no harm in thinking of zebras and for this, Izabella's family is very grateful. ✦

To schedule a neurologic evaluation, call MedStar Georgetown M.D. at 202-342-2400. medstargeorgetown.org/pedsneurology

Mother's Intuition Leads to Accurate Brain Tumor Diagnosis *continued from page one*

Fortunately, Jessica and Chris' determination to "get the best" for Kyla led them to MedStar Georgetown where the right diagnosis and surgery stopped this dangerous brain tumor from destroying the little girl's life.

It all started with a series of seemingly random events. Kyla was born with torticollis – a muscle imbalance in the neck – which was corrected using gentle exercises. But when she was three, her mother noticed that Kyla was having some difficulty with her balance, not being able to stand on one foot and getting extremely dizzy after only one or two twirls. Suspecting it might be related to the torticollis, Jessica raised her concerns with the pediatrician who referred Kyla to physical and occupational therapists. That team determined that Kyla's problems were mild enough to be treated with basic therapeutic exercises to resolve the physical difficulties.

Kyla's recovery from open brain surgery has her back at school and playing with friends. **Photo courtesy of Lovelace-Clarke Family**

> ***Chris and I knew Georgetown was the best place for Kyla, and they proved us right.***
>
> ✦ **Jessica Lovelace**

But an even more troubling problem surfaced at Kyla's four-year checkup when she failed her right ear hearing test. Advanced studies revealed an uncommon condition called "auditory neuropathy" that arises when the nerves in the inner ear can't transmit signals to the brain.

Kyla's growing constellation of conditions prompted the family to consult a neurologist.

"We wanted to get to the bottom of Kyla's problems and needed the best to get us there," Jessica says. "So we went online, did the research and picked Georgetown."

MedStar Georgetown University Hospital is home to one of the most highly rated neuroscience programs in the nation. Its comprehensive pediatric services offer a full range of dedicated specialty programs from an advanced pediatric critical care unit to expert neurologists. Working together, these specialists provide the best possible care for children who have the most complex brain conditions.

Kyla and her parents soon became very familiar with – and thankful for – MedStar Georgetown's capabilities and compassion.

Within days, Kyla was undergoing evaluations by Cesar Santos, MD, chief, Division of Pediatric Neurology, and other specialists. As Kyla was being prepared for a series of MRIs, the hospital's pediatric sedation team calmed and played with her to minimize her fears while she waited.

"Kyla had a large brain tumor – juvenile pilocytic astrocytoma (JPA) – in an extremely sensitive location where all the major nerves converge," explains MedStar Georgetown neurosurgeon, M. Nathan Nair, MD. "It was a very serious situation. We admitted her on the spot and scheduled open brain surgery for the next day."

When To Seek a Specialist

Regular pediatric checkups are essential to monitor your child's development and catch problems early when they are most treatable. In addition, both Jessica Lovelace and Dr. Nair recognize the role of a parent's intuition in bringing subtle concerns to the doctor's attention.

"As a parent, you know your child better than anyone else," Jessica says. "If your gut tells you something is wrong, you need to be his or her advocate and push for the next level of care."

Symptoms like Kyla's – difficulty with balance and standing on one foot – are indicators for any parent that something might be wrong. Adds Dr. Nair: "Talk first to your pediatrician about any slight problems with hearing or balance that weren't there before, or any other indications that your child might be falling behind." Depending on the diagnosis, there are treatment options that can resolve many balance-related disorders.

During the five-hour procedure, Dr. Nair was able to remove most of the growth, leaving only trace amounts too risky to tackle. But he also discovered that the tumor had crushed one of Kyla's two auditory nerves, effectively eliminating her ability to hear on the right side. If the tumor had not been removed when it was, the outcome could have been devastating. Kyla may have lost the ability to move the muscles in her face, including swallowing and opening or closing her eyes. In the worst-case scenario, she could have needed a tracheotomy, feeding tubes and life-long care.

But thanks to the MedStar Georgetown team's efforts and expertise, Kyla was home again less than two weeks later, and progressed the next week. Today, she is doing well and improving. While her hearing in her right ear is gone, she's back in school and facing a bright future.

"With the help of aggressive physical, occupational, and speech therapies, Kyla has made tremendous improvements in her movements and her verbal skills," says MedStar Georgetown pediatric oncologist Najat Bouchkouj, MD, who is following Kyla's care closely. "Kyla's tumor, although benign, can grow slowly. With regular physical exams and brain MRI studies, we will continue to keep a close eye on her progress. Her prognosis is excellent."

"It's a miracle that the tumor hadn't damaged more critical functions," says a grateful Jessica, "but Drs. Santos, Nair, Bouchkouj and the other MedStar Georgetown specialists caught it early and continue to provide the care she needs. Chris and I knew Georgetown was the best place for Kyla and they proved us right." ✦

To schedule an appointment with a pediatric neurologist, call MedStar Georgetown M.D. at 202-342-2400. medstargeorgetown.org/pedsneurology

Expert Pediatric Neurologists. Exceptional Epilepsy Care.

MedStar Georgetown University Hospital is Washington, D.C.'s, only level-four epilepsy center as designated by the National Association of Epilepsy Centers. This distinction means that we have the professional expertise and facilities to provide the highest level of medical and surgical evaluation as well as treatment for those who have complex epilepsy.

If your child is living with seizures – even if he/she had treatment in the past – call us today to schedule an epilepsy evaluation or to request a free epilepsy brochure and DVD. ✦

Call MedStar Georgetown M.D. at 202-342-2400. medstargeorgetown.org/epilepsy

Cesar Santos, MD, chief, Division of Pediatric Neurology, provides neurologic examinations as part of epilepsy evaluations and treatment.

First in D.C. to Earn "Baby-Friendly" Award

By Meggie Davis

MedStar Georgetown joined an elite group of birth facilities by obtaining a "Baby-Friendly" designation. In fact, MedStar Georgetown is the first and only hospital in the Washington, D.C., metropolitan area to earn this coveted award. Only 134 of 31,000 medical facilities in the U.S. have received this distinction.

This achievement is awarded by Baby-Friendly USA – the United States' accrediting organization for the Baby-Friendly Hospital Initiative, a global program sponsored by the World Health Organization (WHO) and the United Nations Children's Fund (UNICEF). The initiative encourages and recognizes birthing facilities that provide an optimal level of care and best practices for breastfeeding mothers and their babies.

To earn this award, MedStar Georgetown successfully and consistently demonstrated the WHO/UNICEF "Ten Steps to Successful Breastfeeding," from revamping policies to providing perinatal staff with intensive education.

"We are thrilled to have received this award from Baby-Friendly USA. It's an incredibly valuable distinction," says Carol Ryan, MSN, RN, IBCLC, FILCA, clinical manager, Perinatal Education and Lactation Services. "It boils down to public health – improving the health of our women and our children. No matter how women choose to feed their babies, we give everyone 100 percent of our professional care." ✦

For information about the "Ten Steps to Successful Breastfeeding," call MedStar Georgetown M.D. at 202-342-2400. medstargeorgetown.org/breastfeeding

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Common Questions Answered in Our Ask-a-Doc Online Library

Visit MedStar Georgetown's Ask-a-Doc library and watch videos of our knowledgeable and compassionate doctors who answer questions about various healthcare topics.

For example, you can watch a series of videos of Dr. Siva Subramanian who answers commonly asked questions about the Neonatal Intensive Care Unit (NICU). Some of the questions answered include:

- What is a NICU?
- What kind of babies do you care for in the NICU?
- What kind of health issues do some premature babies have?
- What are late-premature babies?
- What types of "high-touch" therapies are available at MedStar Georgetown?

To view our Ask-a-Doc videos, visit medstargeorgetown.org/askadoc.

Siva Subramanian, MD, chief, Division of Neonatology, answers questions about the neonatal intensive care unit.

Photo by Rachel Christoferson

Welcome New Physicians

We are pleased to introduce doctors who have recently joined the MedStar Georgetown Pediatrics team.

Domestic and International Adoptions
Nina Scribanu, MD

Pediatric Infectious Diseases
Susan K. Wollersheim, MD

To schedule an appointment, call MedStar Georgetown M.D. at 202-342-2400. medstargeorgetown.org/findadoc

Visit us on medstargeorgetown.org/pediatrics

To start or stop receiving this newsletter, call **202-444-6815**.

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