



## A Year of Firsts at Children's National: Breaking New Ground in Pediatrics



2015 ANNUAL REPORT



**I**t's a pleasure to present the Children's National Health System 2015 Annual Report. Our report this year is all about breaking new ground in pediatric medicine. The pages to follow are filled with impressive accomplishments, and Children's National is the first and only pediatric hospital in the nation to achieve many of them. In the practice of pediatric medicine, new discoveries and advancements in care are invaluable and important. Pushing boundaries means saving lives, improving futures, and knowing that every accomplishment opens the door to even greater discoveries.

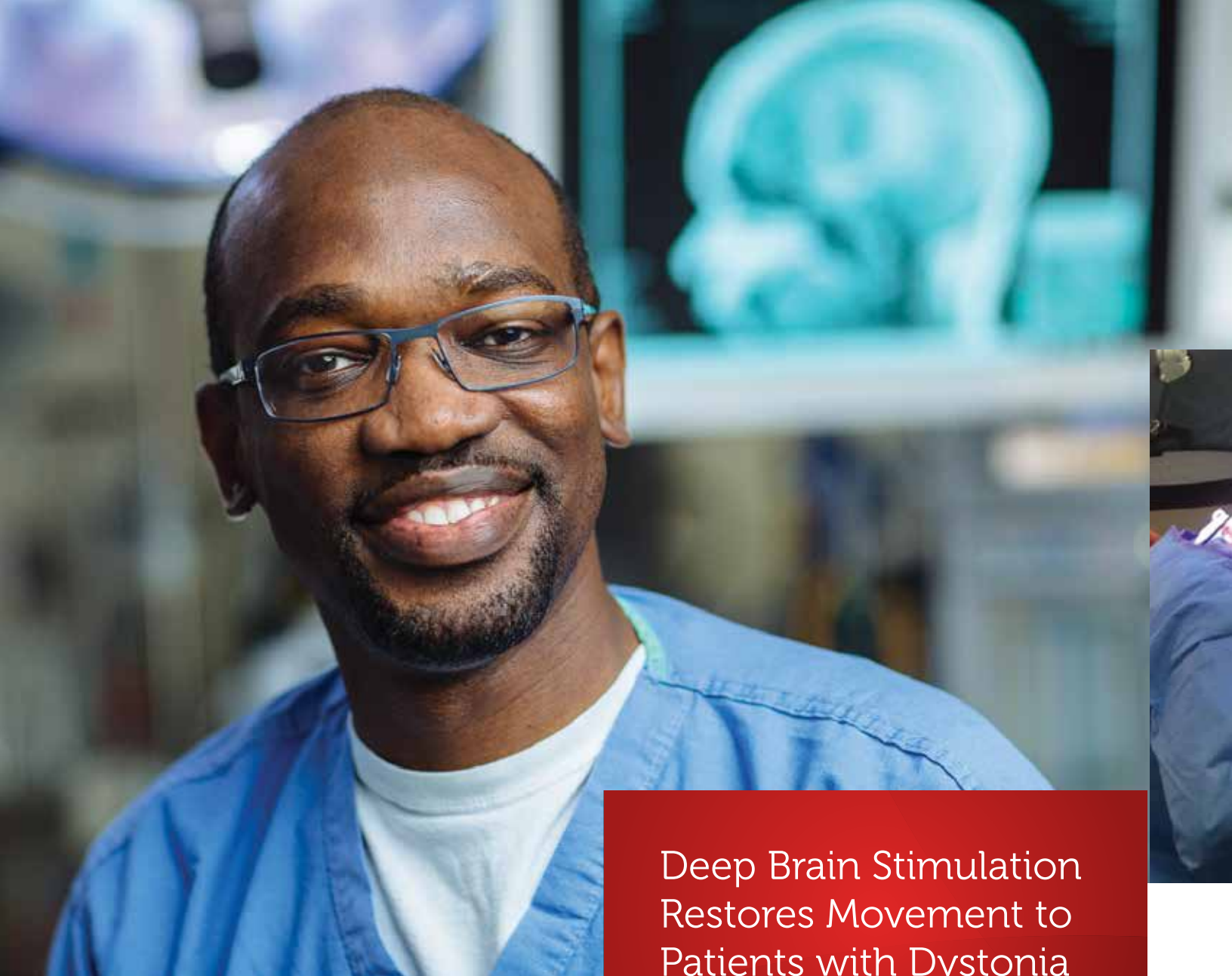
This annual report highlights the expert providers at Children's National who have gone above and beyond to take significant steps forward in their respective specialties. These advances are essential in our quest to provide the highest level of care to our patients – no matter how complex their conditions may be. “Impossible” is not a word in any of our vocabularies, and our accomplishments are evidence of our commitment to provide the best care possible to the children we serve. The dedication and determination of the faculty and staff at Children's National to find solutions to even the most complex cases is worthy of great praise and celebration.

As President and CEO of Children's National, I can attest that our physicians and researchers have made important breakthroughs that have enriched our practices and raised expectations across the field of pediatric medicine. Rightly, I am proud and honored to work alongside them and all the staff and faculty at Children's National. I can safely speak for all of us when I say that every day, every one of us is motivated and humbled by our patients and families. Our patients inspire us to reach higher, think bigger, and never accept the status quo. Likewise, we are thankful for the support of our partners in research, philanthropy, and business. Their confidence in us allows us to continue improving health outcomes for children in the region, across the country, and around the world.

The magnitude and ripple effect of new discoveries and advancements in pediatric medicine are hard to capture within the limits of an annual report. But, like all we do at Children's National, we will give it our very best.



Kurt Newman, MD, President and CEO



## Deep Brain Stimulation Restores Movement to Patients with Dystonia

Through the use of an implant that provides deep brain stimulation, Children's National is offering hope to patients with movement disorders, such as dystonia. Led by pediatric neurosurgeon, Chima Oluigbo, MD, the Division of Neurosurgery is pioneering the use of this technique to help children restore lost function.

**P**atients with movement disorders experience difficulties due to neurological dysfunction that impact the speed, fluency, quality, and ease in which they move. In these cases, neurons in the brain's motor circuits misfire. Through the use of deep brain stimulation, neurosurgeons at Children's National are able to synchronize neuronal firing and accomplish the previously impossible: restoring muscle control to patients with these disorders. The team at



Children's National also is currently engaged in clinical trials seeking to expand the use of this procedure to patients with cerebral palsy, one of the most common dystonias.

Prior to the development of deep brain stimulation techniques, there was no effective



treatment for patients with movement disorders. Deep brain stimulation does not directly repair the brain, however it does allow physicians to restore movement to their patients. "We are finding ways to improve function and deep brain stimulation is one of them" asserts Dr. Oluigbo.

Statistically, movement disorders are quite common in children. But "it's not just numbers; it's also about impact," Dr. Oluigbo explains. "Think about the potential of a child who is very intelligent and can contribute to society. When that child is not able to contribute because he or she is disabled by a movement disorder, the lost potential is very significant. It has an impact."

The effective use of deep brain stimulation requires ongoing attention from the Children's National team. When considering this technique, the multidisciplinary team evaluates the patient, assessing the appropriateness of the technique in treating his or her specific condition.

If deep brain stimulation is appropriate, physicians may request and then evaluate MRI imaging. By studying these images, they can identify the specific areas of the brain on which treatment should be focused.

The effects of deep brain stimulation are often dramatic, reports Dr. Oluigbo. He states that "90 percent of children with primary dystonia show up to 90 percent symptom improvement."

Looking forward, there is evidence to suggest that this technique could be used to aid people with memory disorders, patients in minimally conscious states, as well as patients with incurable epilepsies.

Dr. Oluigbo believes that his journey to improve the lives of individuals with movement disorders isn't finished. "The near future also will include things that restore function", says Oluigbo. Through the use of stem cell therapies and nerve regeneration, Dr. Oluigbo hopes medical professionals will be able to truly and permanently restore function.



Children's National Leads a Global  
Taskforce to Fight Leukodystrophies



Children's National is leading the research into a collection of devastating genetic disorders—leukodystrophies. For over a decade, Adeline Vanderver, MD, has led a team of researchers, exploring the causes of and treatments for these disorders. Much work has already been done, including clinical trials in the diagnosis of unsolved leukodystrophies.

**T**he team at Children's National is working to explore previously unsolved leukodystrophy cases. In addition to seeking a cure for these disorders, the clinicians at Children's National hope to achieve faster diagnosis and produce a bioregistry, or comprehensive catalog, of disorder-associated genes.

Leukodystrophies are a collection of approximately 30 genetic disorders affecting one in 7,000 live births. Children born with one of these disorders exhibit deficiencies in the insulation of axons, through which electrical currents travel in the brain. When these currents are disrupted, patients exhibit significantly delayed reactions or an inability to perform certain actions, such as walking or speaking. These conditions lead to a substantially shorter life span, with 34 percent of all patients failing to reach their ninth birthday.

Partnership is a key component of the team's approach to leukodystrophy research. Dr. Vanderver is an internationally recognized leader in research and treatment for patients with leukodystrophy. Her research team has joined forces with some of the most experienced and educated practitioners worldwide working to advance care for patients with these debilitating and deadly disorders. "We're hosting meetings of the Global Leukodystrophy Initiative to establish standards of care in collaboration with a patient advocacy group," says Dr. Vanderver.

To treat confirmed or suspected cases of leukodystrophy, Children's National operates a weekly multidisciplinary clinic. At this clinic, patients are seen by leukodystrophy specialists and practitioners, including pediatric neurology, hearing and speech, and rehabilitation. Nearly 400 patients benefited from this clinic in 2014.

Dr. Vanderver and her team are applying a multi-faceted approach to improving the quality of life for patients with a leukodystrophy. Along with refining diagnostic procedures, the team has outlined future plans of implementing genome sequencing clinical trials for potential therapies. The team continues to inform treatment of these disorders globally and define a clear standard of care.

Children's National also works as a clearinghouse of information for parents whose children are impacted by some form of leukodystrophy. By educating parents on this complex condition and advocating for them and their children, Children's National paves the way toward a promising future in which treatments are better tested and defined, and diagnostic protocols are more effective.

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## Children's National Pioneers Incisionless Surgery for Bone Tumor Treatment

Children's National Interventional Radiologist, Karun Sharma, MD, PhD, states that when treating pediatric patients, using minimally invasive treatments is critical. With Dr. Sharma at the helm, the team at Children's National is working to hone a new technique that promises to treat osteoid osteomas with a minimally invasive procedure, using MRI-guided High Intensity Focused Ultrasound (MRI-guided HIFU).

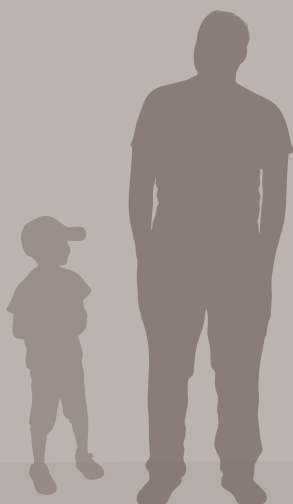
**T**he Image-Guided Non-Invasive Therapeutic Energy (IGNITE) program is a collaboration between the clinical and research teams at Children's National to develop and introduce minimally invasive and non-invasive surgical technologies. Through this FDA-approved research program, Children's National identifies and treats candidates with conditions that can be successfully remediated with MRI-guided HIFU—specifically, osteoid osteoma, a condition in which patients develop benign tumors.

In the recent past, orthopaedic surgeons' only course of treatment for osteoid osteomas was to surgically excise the tumors. Because the tumor is often difficult to distinguish from surrounding bone





Osteoid osteoma is primarily a pediatric concern, it is most common among those between the ages of 4 and 25.



matter, fragments of bone would often be removed unintentionally, adding to the pain of the procedure and sometimes resulting in bone weakening.

MRI-guided HIFU can be completed more quickly than previously utilized methods, for example Radiofrequency Ablation (RFA), and results in shorter recovery times. This treatment also reduces risks of related complications, including infections and fractures.

“We’re hoping that HIFU will eventually replace traditional treatments,” says Dr. Sharma.

MRI-guided HIFU focuses sound waves to destroy tumors from outside the body with precision. The sound waves heat the target area, allowing surgeons to remove the tumor without breaking the skin.

Along with guiding staff in applying ultrasound waves to the appropriate area, MRI technology also allows clinicians to measure the temperature of the target area throughout the procedure to ensure that just the right amount of heat is applied.

The physicians at Children’s National are currently working with the National Institutes of Health to expand the use of this treatment. Incredible possibilities are on the horizon to use this method in treating other conditions as well. Dr. Sharma and his team hope to use HIFU to improve chemotherapy delivery in patients who suffer from malignant tumors. Future plans include exploring this procedure as a method of treatment for patients whose tumors are inoperable, as well as those who have exhausted their chemotherapy treatment options.

Not only is Children’s National the first pediatric hospital in the United States to use MRI-guided HIFU to treat osteoid osteomas, they also are home to the first FDA-approved clinical trial studying the use of this treatment, the IGNITE Program.

# Children's National Provides a Cure for Sickle Cell Disease

Children's National is one of the first pediatric hospitals to offer patients living with sickle cell disease a chance at a cure with Haploidentical Hematopoietic Stem Cell Transplantation. Through this process of bone marrow transplantation, Children's physicians can effectively cure this often-debilitating disease.

**C**hildren's National is one of the first pediatric hospitals to offer patients with sickle cell disease a chance at a cure with haploidentical hematopoietic stem cell transplantation. Through this process of blood and marrow transplantation, physicians at Children's can effectively cure this often debilitating disease.

Without the option of bone marrow transplantation (BMT), sickle cell disease is a chronic condition where patients must learn to manage the symptoms and have no alternative cure. Physician follow-up, pain relieving medication, and oral or intravenous fluids are required during periods of intense pain caused by a sickle cell crisis.



Children's National has long been a nationally recognized leader in pediatric blood and marrow transplantation. Since 1988, specialists have performed more than 1,000 bone marrow transplants as treatment or curative procedures for a variety of disorders and diseases, including sickle cell disease.

Historically, patients required a 100 percent Human Leukocyte Antigen (HLA) match with their bone marrow donor in order to receive a transplant. However, in January 2015, Children's National researchers began a clinical trial using haploidentical-related donors (a half-matched donor, for example a living parent or sibling) as a method for curing sickle cell disease. If successful,

the pilot project could expand the pool of eligible patients for transplantation, and increase the chance for a cure.

While researchers at other institutions have undertaken similar studies, efforts at Children's are enhanced by the team's ability to treat viral infections, a common complication with bone marrow transplants, with an infusion of cytotoxic T-cells. The combination of expanded availability, due to haploidentical-related donors, and advanced care to treat complications using T-cells, makes the sickle cell BMT program at Children's National unique.

donor options for the more than 75 percent of patients is the basis of the haploidentical hematopoietic stem cell transplant treatment at Children's National.

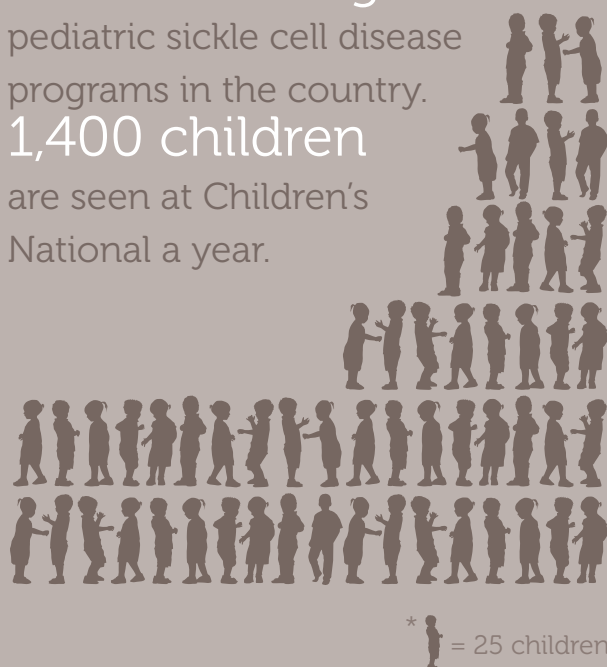
David Jacobsohn, MD, leads the Children's National team as the Division Chief of Blood and Marrow Transplantation. Under his guidance, researchers employ BMT as a treatment for sickle cell disease when there are eligible patients with qualified donors. Dr. Jacobsohn's team continues to gather data on treatment implementation to advance the practice of using BMT to cure sickle cell disease. The goal is to expand the treatment to patients that previously lacked a suitable donor. "Use of a haploidentical donor exponentially expands the number of patients that can be considered for BMT," said Dr. Jacobsohn. "More people have a haploidentical, such as a living parent, than have a full match."



Alistair Abraham, MD, Director  
of Sickle Cell Transplant  
Program at Children's National

Bone marrow transplantation is more than a treatment option for sickle cell sufferers; it is a cure. Data from small samples of patients who have undergone the procedure indicates an impressive success rate. Ninety percent of patients with identical match sibling donors who utilize the treatment experience a curative outcome. However, less than 25 percent of patients have an identical-match sibling who also does not have sickle cell disease. Finding alternative

Children's National has  
one of the largest  
pediatric sickle cell disease  
programs in the country.  
1,400 children  
are seen at Children's  
National a year.







## Minimally Invasive Procedures Improve Outcomes for Neonates

When newborns enter the world with serious medical conditions, surgery is sometimes imperative. Waiting until their bodies grow and mature is not an option. However, performing surgery on neonates is delicate and challenging. An elite cohort of surgeons at Children's National possesses the skills necessary to perform minimally invasive procedures on neonates.



One of the minimally invasive interventions that Children's National specializes in is esophageal atresia.

In babies born with this condition, the esophagus is not connected appropriately to the stomach. While specific deformities vary, the esophagus is often either discontinuous and exists as two blind pouches or, in more serious cases, it connects to the airway. Esophageal atresia is relatively common, occurring in approximately one in 3,500 babies.

Prior to the development of minimally invasive techniques for the treatment of esophageal atresia, repair required the completion of a thoracotomy, a large incision down the infant's side. The lasting impacts of such a

long incision were substantial. Along with creating an unavoidable and sizable scar, many thoracotomy procedures required the breaking of ribs. When ribs are broken in infants, patients are at an increased risk of later suffering from scoliosis, chest wall asymmetries, or other defects of the chest wall.



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Since 2010, surgeons at Children's National have performed this surgery thoracoscopically. When performing a thoracoscopic repair of esophageal atresia, surgeons make three small incisions. Through these small slits, surgeons insert the scopes and surgical tools necessary to repair the malformation, leaving a small scar and no broken ribs.

The use of this minimally invasive surgery technique improves recovery time and quality of life for patients suffering from this condition.

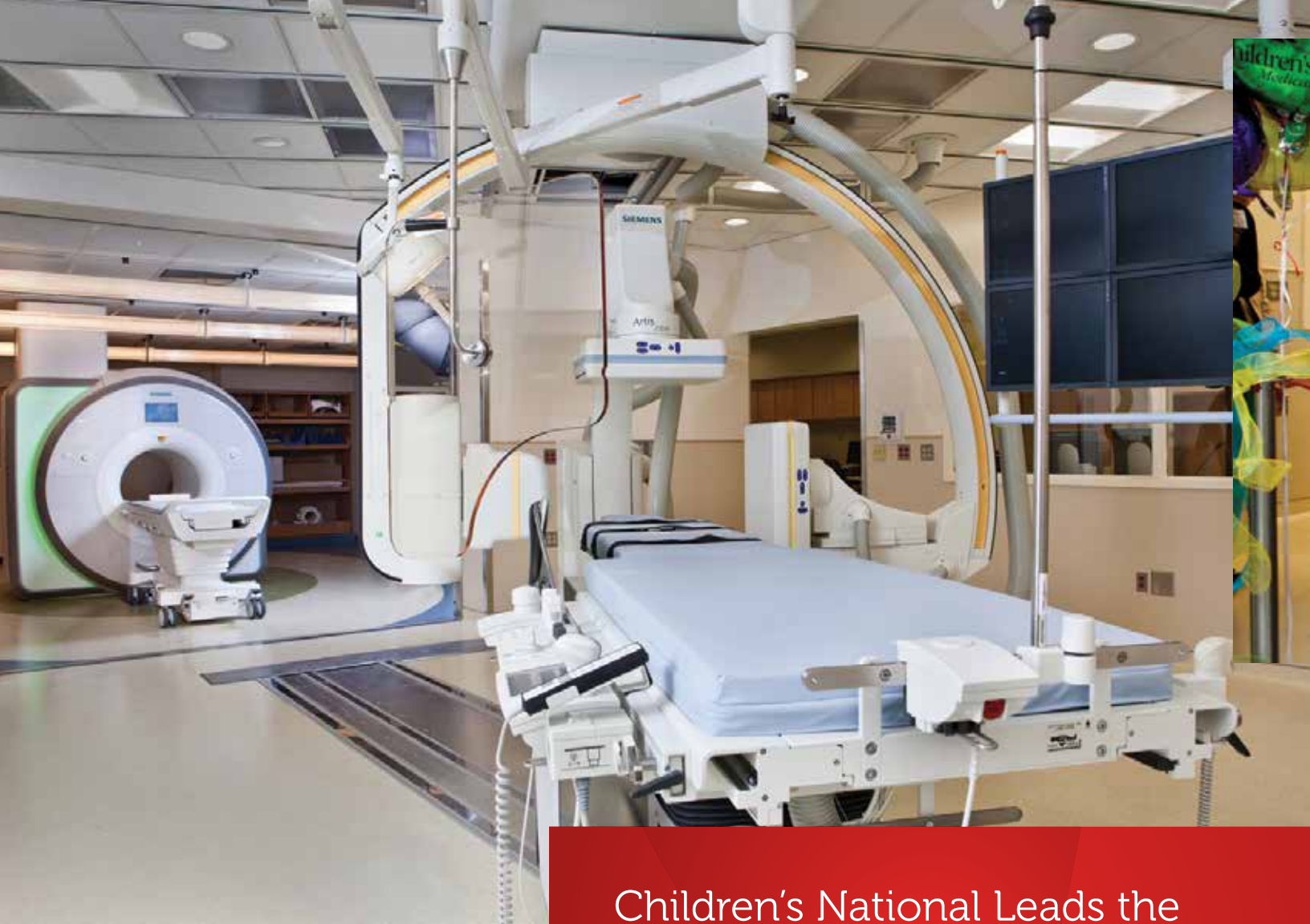
Division Chief of General and Thoracic Surgery, Timothy Kane, MD is an international leader in the practice of minimally invasive surgical procedures and actively collaborates with



physicians and researchers with a similar focus through participation in the International Pediatric Endosurgery Group (IPEG)-made up of more than 600 medical professionals from 52 different countries.

As advocates for minimally invasive surgery, Dr. Kane and his colleagues train pediatric surgical fellows in these procedures. As those fellows move on to attending positions and train more fellows, the number of surgeons qualified to perform these procedures multiplies.

Not only is the number of practitioners increasing, but the number of cases where MIS surgery is possible is also increasing. The team at Children's National has begun exploring the use of MIS procedures in the treatment of congenital diaphragmatic hernias.



## Children's National Leads the Way in Pediatric MRI-Guided Heart Catheterization

Pediatric heart catheterization experienced advancement this year. In March 2015, Kanishka Ratnayaka, MD, performed the first MRI-guided right heart catheterization on a pediatric patient in the United States.

**W**hen a child's heart isn't functioning properly, it's vital that clinicians image the heart and gather specifics regarding the malfunction. Physicians commonly utilize heart catheterization to glimpse inside the patient's beating heart. With catheterization, surgeons can see where the deformity or malfunction is located and create a specific course of treatment prior to surgery, improving the likelihood of a positive patient outcome.





As of September 2015, specialists at Children's National performed 853 MRI-guided heart catheterizations.

With the development of MRI-guided right heart catheterization, a first in the realm of pediatrics, the cardiology team at Children's National has facilitated a major enhancement to the process of catheterization for pediatric patients. With MRI, physicians can capture more detailed pictures of the heart, allowing for increased accuracy in diagnosis and enhanced pre-surgery planning.

An MRI-guided procedure also reduces sedation time, which can have undesirable side effects on young patients. The MRI scanner currently in use, provided by the National Institutes of Health (NIH), has decreased scanning time from one hour to 40-45 minutes. This reduction in time brings the team closer to the ultimate goal of accomplishing the procedure sedation-free.

When using MRI-guidance for this procedure, physicians can

simultaneously gather information on the hemodynamics and the function of the heart. When using this guidance method instead of the traditional radiographic fluoroscopic guidance, neither physicians nor their patients receive any radiation exposure.

Though MRI-guided heart catheterization is new, heart catheterization with alternative forms of guidance has been a specialty at Children's National since 2013. Physicians at Children's National have honed their skills through the sheer quantity of procedures they perform annually.

Moving forward, the team will continue to advance the heart catheterization process with the ultimate goal of providing effective and painless diagnosis, evaluation, and intervention to newborns and children with congenital heart disease.

# Philanthropy Empowers a Year of Firsts

Fiscal year 2015 was a special year for philanthropy at Children's National, and hospitals throughout North America, as we hosted the Woodmark Children's Forum to celebrate the impact of donations to pediatric care and research. Attended by more than 450 executives, faculty, and donors representing pediatric hospitals from the U.S. and Canada, the event featured a luncheon with First Lady Michelle Obama, during which she cited the role of philanthropy in improving survival rates and transforming pediatric care. Kurt Newman, MD, President and CEO of Children's National, echoed her sentiments, saying, "The expert care and cutting-edge research at children's hospitals like ours simply would not be possible without the generous support of our donors."

Throughout the year, our generous donors made possible a number of firsts, including several endowed positions -- the A. James Clark Distinguished Professor of Molecular Genetics (Eric Hoffman, PhD), the Van Metre Companies Professor of Cardiology (Charles Berul, MD), the Foglia-Hills Professor of Pediatric Cardiac Research (Nobuyuki Ishibashi, MD), and the Diane and Norman Bernstein Professor of Community Pediatrics (Mark Weissman, MD).







It was a record-breaking year for many Children's National fundraising events – including the Heroes Gala (\$726,000), the Race for Every Child (\$1.05 million in 2014 and more than \$1.2 million in 2015), and the White Hat Gala (\$400,000). Community support for our mission was strong: the El Zol Radiothon broke the national record for Spanish-language radiothons by raising \$858,794, and the University of Maryland's Terp Thon set a national record for a sixth-year dance marathon, raising \$604,318. The Children's Ball, chaired by Norma and Russ Ramsey, had another successful year, topping \$4.1 million.

Children's Ball



Philanthropy also allowed us to improve our programs, services, and facilities for children and families. In November 2014, we officially opened the Dream Clinic, an area that was transformed into a convenient, child-friendly space for children battling cancer. This was made possible by the proceeds from the 2013 Heroes Gala, chaired by Elizabeth Kaufman. In June 2015, we opened the Elsie & Marvin Dekelboum Family Foundation PULSE Center. "PULSE" stands for "pediatric ultrasound scanning excellence," and the center enables physicians to provide safer and more precise imaging for children.

In the coming year, children and families at Children's National will see the powerful impact of philanthropy through several exciting initiatives. We recently opened the Seacrest Studios at Children's National, in partnership with the Ryan Seacrest Foundation, which will provide programming for children right from our main atrium. Later in the year, we will open our first-ever Healing Garden, which will be dedicated to the First Ladies of the United States. That project is the result of the generosity and leadership of Heather and Andy Florance, and will give children safe and convenient access to the outdoors to experience the healing power of nature.

We are grateful to all of our donors and partners, who have helped advance our mission through their passion and generosity.



Elsie & Marvin  
Dekelboum Family  
Foundation PULSE Center



# Children's National in the News



## August, 2014

### Children's National Sleep Experts Guide Policy on School Start Times and Effect Change

Children's National was featured in nationwide coverage of an American Academy of Pediatrics policy regarding school start times. Children's National experts, Judith Owens, MD, and Danny Lewin, MD, conducted research that informed the policy, which recommended later school start times to combat chronic sleep loss and the erratic sleep patterns among the nation's teens. As a result of this policy statement, two of the area's largest school districts, Fairfax and Montgomery counties, have pushed school start times later.



## September, 2014

### Conjoined Twins Separated at Children's National Celebrate their First Birthday

Tyler and Tyson Proctor, conjoined twins that were separated at Children's National in 2013, celebrated a special first birthday event at the hospital with their family and the doctors and nurses who helped save their lives. Tyler and Tyson were born conjoined, attached at their chests and bellies. The boys shared a liver, and Tyson needed heart surgery. At 2 months old, Tyler and Tyson were separated in a complicated surgery that was aided by a plastic model of the boys' entire midsection made with a 3-D printer. Their birthday party was a celebratory reunion with the Children's National faculty and staff.

## December, 2014

### Toddler Receives Long-Awaited Heart Transplant on Christmas Day

Toddler Teresa Perez spent nearly 10 months in the Children's National Cardiac ICU waiting for a new heart. She was diagnosed with cardiomyopathy, which meant that her enlarged heart lost its ability to pump blood effectively and was the main reason she needed a heart transplant. Teresa was placed on a Berlin Heart EXCOR® Pediatric Ventricular Assist Device (VAD) while she waited for a heart, which she received on Christmas Day. Several staff members throughout Children's National left their own families on Christmas Day to assist in the procedure. Teresa's surgery went well, and she did not experience any complications. She was happily discharged less than two weeks after surgery, and will be followed closely for the rest of her life to monitor her new heart.

## December, 2014

### Children's National on the Front Lines of the Ebola Crisis

As the Ebola crisis evolved in the United States, the CDC took action and organized a network of pre-approved healthcare institutions, vetted and sanctioned to care for Ebola patients. Children's National was at the forefront of that preparation and was designated among 35 medical institutions to serve as an Ebola-ready treatment center. Children's National was one of only five freestanding pediatric institutions selected.

## June, 2015

### *U.S. News & World Report* Ranks Children's National Among the Best Children's Hospitals in the Nation

Children's National Health System was named to the prestigious Honor Roll of the *U.S. News & World Report* 2015-16 Best Children's Hospitals, ranking among the top 10 pediatric hospitals in the nation. Children's National was ranked in each of the 10 specialties for the fifth year in a row. Three specialties-Neonatology, Neurology/Neurosurgery, and Gastroenterology/GI Surgery-were ranked among the top 10 in the country, while all 10 specialties ranked in the top 25 nationally.



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# Fiscal Year 2015 Financial Highlights

## ASSETS

As of June 30, 2015 in Thousands

Cash and short-term investments on hand	\$116,582
Amounts owed by insurance companies, government agencies, patients, and other entities	184,078
Inventory on hand to meet the needs of our patients	9,092
Net value of property, plant, and equipment	499,958
Investments to be held longer than one year	437,722
Proceeds from the sale of bonds to pay for capital expansion, renovation, and equipment	29,949
Funds contributed over the years by our friends in the community to pay for specific projects	150,434
Other assets	187,096
<b>Total assets, the strong financial base that ensures our ability to continue to care for sick children</b>	<b>\$1,614,911</b>

## LIABILITIES

As of June 30, 2015 in Thousands

Amounts owed to vendors, employees, and other third parties	\$321,328
Amounts borrowed to fund the projects and purchase the equipment needed to serve our patients, payments due within a year	5,581
Amounts borrowed to fund the projects and purchase the equipment needed to serve our patients, payments due in the future	458,487
The difference between what we own (our assets) and what we owe (our liabilities), representing the community's interest in Children's National Medical Center	829,515
<b>Our current liabilities, plus the community's interest, equals our total assets</b>	<b>\$1,614,911</b>

## SOURCES OF INCOME FOR DELIVERING QUALITY HEALTHCARE SERVICES TO OUR COMMUNITY COME FROM

As of June 30, 2015 in Thousands

Services provided for inpatients and outpatients, including physician care, diagnostic and therapeutic procedures, nursing care, and room and board	\$2,191,006
Because government and other insurance carriers do not pay the total charges on the care delivered, we did not collect	(1,246,827)
Because we provide care to the indigent and children with families unable to pay their full bill, we did not collect	(30,249)
We received additional income from other sources, including research grants and other programs sponsored by outside support	119,483
The use of restricted charitable gifts to support operations	30,249
Contributions from our friends in the community who understand and support our mission to care for children	26,692
<b>Total revenues and support to care for the children who need our special services</b>	<b>\$1,090,354</b>

## FROM OUR INCOME WE PAID FOR

As of June 30, 2015 in Thousands

Salary and benefits for our medical, professional, and support staffs	\$639,407
Operating supplies and services	298,545
Depreciation and interest on plant and equipment	81,237
Professional liability protection	9,168
<b>Total expenses required to meet the needs to support our patients and mission</b>	<b>\$1,028,357</b>
Excess of revenues from operations to support our mission	61,997
<b>Total Philanthropic Support</b>	<b>63,439</b>



## **Children's National Medical Center**

### **Corporate Entities**

Children's Hospital

Children's Hospital Foundation

Children's National Advocacy and Public Policy, Inc.

Children's National Health Network

Children's National Specialists of Northern Virginia, LLC

Children's Pediatricians and Associates, LLC

Children's Research Institute

Children's School Services

Safe Kids Worldwide

**We would like to thank our donors, volunteers, employees, parents, and children who graciously give their time in support of our organization and our mission.**

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