

# BARROW Neurological Institute

## at PHOENIX CHILDREN'S Hospital

Winter 2016-17

### 100% for Brady



When Rebecca Dorn gave birth to her first baby, everything went according to plan. Nearly 11 months later, when her second child, Brady, was born, things were much different.

Brady arrived prematurely, and when he was born, he lost oxygen to his brain. He spent four weeks in a neonatal intensive care unit in Wisconsin, where his family lived. At first, Brady's parents weren't sure how his birth might affect his health. But it quickly became apparent that something wasn't right.

"He wasn't on track," said Rebecca. "He wasn't grasping my finger, he wasn't reaching those milestones. I had just done all of this 10 months ago with his older sister."

Doctors told Rebecca that Brady's delays could be related to his prematurity, encouraging her that he would catch up in time. But she wasn't buying it.

Brady would scream and cry all the time. He would only sleep from pure exhaustion. She knew something was wrong. Rebecca

joined discussion boards and read blogs in which mothers of children born premature discussed conditions and complications.

"They kept mentioning CP and I didn't know what the heck it was," she said. "These moms were explaining my life. I went to the United Cerebral Palsy website, when someone finally said 'cerebral palsy' and saw more upsetting news: Brady matched all the symptoms."

So she took him back to the doctor.

"I said 'I'm not leaving until you figure out what's wrong with him,'" she recalled.

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### Treating Movement Disorders

For children with movement disorders like cerebral palsy and spasticity, simple movements are difficult to do. These disorders often affect many parts of the child's body. That's why the Pediatric Movement Disorders Program (PMD) at Barrow Neurological Institute at Phoenix Children's Hospital is made up of a multidisciplinary team of neurologists, neurosurgeons, orthopedic physicians and surgeons, and rehabilitation specialists to solve the problems of normal function and movement in these children.

The team is dedicated to helping children living with movement disorders have rich, fulfilling lives. The conditions we treat include cerebral palsy, spasticity, tic disorders, tremor, ataxia, dystonia, chorea, myoclonus, gait disorders and juvenile parkinsonism.

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**P. David Adelson, MD**  
Director, Barrow Neurological Institute at Phoenix Children's Hospital  
Diane and Bruce Halle Endowed Chair in Pediatric Neuroscience

## From the Director

### Dear Barrow Neurological Institute at Phoenix Children's Hospital Supporter,

The phrase "movement disorders" is broad, encompassing many neurological conditions that cause a person's body to move involuntarily.

Among these disorders is cerebral palsy, tics and Tourette disorders, dystonia, myoclonus, spasticity, chorea, ataxia and gait disorders. While each condition differs as to its etiology and mechanism, unfortunately most do not yet have a cure. For that reason and as part of our mission, we seek a common goal for these children who have such disorders: To improve the health and quality of their lives for these children so they can have rich and fulfilling lives with less pain and improved muscle function.

The Pediatric Movement Disorders (PMD) Program at Barrow Neurological Institute at Phoenix Children's Hospital is comprised of physicians and medical professionals from many different disciplines, including neurology, neurosurgery, physical medicine and rehabilitation, orthopedics and research scientists, as well as social workers, psychologists and psychiatrists, working together to treat each patient's individual condition with customized, personalized treatment plans as part our 360-degree approach to care that is the basis of our mission.

Most important is the accurate diagnosis and assessment of these children. Using state-of-the-art technology in the Bubba Watson and PING Golf Motion Analysis Laboratory at Phoenix Children's Hospital as well as imaging, video analysis, genomic testing, and a whole gamut of comprehensive testing of these complex disorders, the lab uses advanced bioengineering techniques, 3-D and entertainment technology and medical expertise to first study a patient's movement patterns and muscle activity to develop an accurate, personalized diagnosis. The lab's highly-trained physical therapists and engineers then interpret this data to help our PMD team customize treatment plans and ultimately measure improvements and outcomes for each child.

We recognized the importance and impact of these disorders in our community and so we aggressively recruited a team to lead this effort. In 2015, Michael Krueer, MD, joined Barrow at Phoenix Children's as the director of the PMD Program as well as director of the Neurogenetics

Research Program at Barrow at Phoenix Children's, with an aim to improve the diagnosis and treatment of children with movement disorders. In 2016, Taryn Bragg, MD, joined Dr. Krueer and his team because of her specialization in the surgical treatment of movement disorders while Mohan Belthur, MD, a pediatric orthopedist, specializes in the medical and surgical treatment of the musculoskeletal issues that affect these children.

With the addition of Dr. Bragg and Dr. Belthur to the team, the PMD Program is now able to provide more comprehensive procedural and surgical options to improve the health for children with these disorders.

Additionally, even with our advances in medical and surgical care, rehabilitation and therapy are of the most important components of care. Laura Wilner, MD, who leads our division of physical medicine and rehabilitation, and her team of therapists play a key role in the PMD Program to ensure ongoing assessment and care for these children.

Together, this comprehensive PMD team works together to provide the best care possible to improve the quality of lives for these children living with movement disorders. As you will have a chance to experience in this issue of our newsletter, we will take you on the journey with Brady, a child who benefited from the expert diagnosis and treatment of our PMD Program and how our clinical and research programs work together to bring new treatment options from the lab to the patient's bedside.

We recently receive a very generous gift from an anonymous donor in support of our PMD Program in its neurogenetics work in the laboratory with translation to the clinic. As always, your support is appreciated as this allows us the continued development of cutting-edge research and clinical treatments for these children with movement disorders and all neurological diseases and disorders our young patients deal with in their daily lives.

Thank you!

P. David Adelson, MD

# Movement Disorders continued from page 1

## Our Team

Recognizing the importance of creating and developing a movement disorders program, Michael Krueer, MD, joined Barrow Neurological Institute at Phoenix Children's Hospital in 2015 to lead our multidisciplinary clinic and team of movement disorder specialists. Besides being a board-certified pediatrician, child neurologist and neurodevelopmentalist, he specializes in the neurogenetics of these disorders. He directs the Neurogenetics Research Program at Barrow at Phoenix Children's, which includes nationally-recognized clinical and laboratory research programs with an aim to improve the diagnosis and treatment of children with movement disorders. Each patient treated by Dr. Krueer and his team has the option to participate in clinical research efforts and cutting edge clinical trials.

As the medical director of the PMD Program, Dr. Krueer provides comprehensive diagnosis and management for young patients with neurodevelopmental and neurodegenerative disorders that affect movement.

In 2016, Taryn Bragg, MD, joined the Barrow at Phoenix Children's team. She is a pediatric neurosurgeon, board-certified in pediatric neurosurgery and neurological surgery, specializing in the treatment of movement disorders, spasticity, spina bifida, congenital brain and spine abnormalities, cerebral palsy and hydrocephalus. Dr. Bragg and the neurosurgical team offer a number of surgical treatment options, including botulinum toxin injections, intrathecal Baclofen pumps, selective dorsal rhizotomy and pediatric deep brain stimulation.

Mohan Belthur, MD, from the Herbert J. Louis Center for Pediatric Orthopedics at Phoenix Children's Hospital, is a board-certified pediatric orthopedist and provides the musculoskeletal expertise necessary for these children. With the addition of Dr. Bragg and Dr. Belthur to the team, the PMD Program is now able to provide more comprehensive procedural and surgical options to improve the health and quality of life for children with these disorders.

Even with medical and surgical treatments, therapy is one of the most important components of care for children with ongoing movement and functional disorders. Laura Wilner, MD, who leads our division of physical medicine and rehabilitation, is a board-certified physiatrist, specializing in the care of children with neurological problems. Along with her team of therapists, they play a key role in first assessing each patient individually and then creating personalized plans designed to optimize each child's function.

## Our Treatments

Once a diagnosis has been made, the program offers comprehensive medical and surgical options.

Patient evaluations are facilitated by the program's standardized videotape assessment protocol and the Bubba Watson and PING Golf Motion Analysis Laboratory, which is supported by the Herbert J. Louis, MD Center for Pediatric Orthopedics and the Frances H. McClelland Pediatric Rehabilitation Program, all at Phoenix Children's Hospital. These resources allow the team to use video, kinematics and surface electromyography (EMG) to create targeted, customized treatments for patients.

Barrow at Phoenix Children's has one of the few pediatric deep brain stimulation programs (DBS) in the country. The program is a collaborative effort with the Muhammed Ali Parkinson Center at Barrow Neurological Institute at Dignity St. Joseph's Hospital and Medical Center and Barrow Brain and Spine Associates.

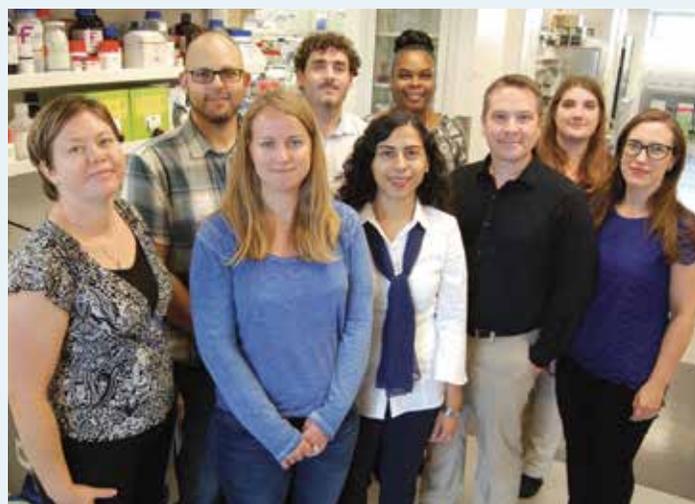
The program also has strong relationships with local and national community partners, family resources and support networks. This allows us to provide patient-centered, 360-degree care. We also offer several specialized clinics in order to provide our most challenging patients the care they deserve. This includes the comprehensive Cerebral Palsy Clinic, a program where patients are seen by specialists in neurosurgery, orthopedics, physical medicine and neurology in a single afternoon in order to develop a detailed management plan. Also offered is the Complex Tourette Syndrome Clinic, in which patients struggling with their tics and comorbidities receive detailed recommendations from specialists in psychology, neurology and psychiatry in a single visit.

## Our Research

In addition to his role as a neurologist with the PMD Program, Dr. Krueer also leads the Molecular and Cellular Neurogenetics Research Laboratory at Barrow at Phoenix Children's. In the lab, researchers study the neurogenetic basis of movement disorders. Every patient and family treated at PMD is given the opportunity to participate in our ongoing clinical or translational research projects.

Barrow at Phoenix Children's is also home to the Cerebral Palsy Genetic Research Network (CPGRN), an international collaboration dedicated to understanding the genomic landscape of spastic cerebral palsy. Once thought to be exclusively due to oxygen deprivation or prematurity, current estimates suggest about one-third of cerebral palsy cases are genetic.

The CPGRN is conducting large-scale genome sequencing studies in patients recruited from around the world in collaboration with the University of Adelaide, Australia and Yale University, in order to identify new genetic causes of cerebral palsy. Active clinical research includes multiple medication trials; studies of the genomic basis of Tourette syndrome, in collaboration with Harvard University and the University of Florida; studies of brain connectivity in genetic forms of cerebral palsy; and disease gene discovery in pediatric movement disorder patients.



## Save the Date!

Please save the date for a free community event for families of children with cerebral palsy on May 13, 2017 at Phoenix Children's Hospital. Attendees will hear from our experts in the areas of cerebral palsy and movement disorders. For more information, please visit [barrow.phoenixchildrens.org](http://barrow.phoenixchildrens.org).

## Angus Wilfong, MD, Joins Phoenix Children's Hospital as Chief of Pediatric Neurology



**Angus A. Wilfong, MD**, has joined Phoenix Children's Hospital as chief of pediatric neurology at Barrow Neurological Institute at Phoenix Children's Hospital. In this role, Dr. Wilfong will oversee all functions of the neurology practice including treatment of neurological diseases and disorders, technology, innovation and research and development. His clinical specialty is childhood epilepsy.

Prior to joining Phoenix Children's, Dr. Wilfong was the medical director of the comprehensive Epilepsy Program at Texas Children's Hospital. While there, he pioneered a minimally invasive epilepsy treatment that uses a laser to perform neurosurgery. The treatment has been effective in stopping seizures and drastically reduces the amount of time patients spend recovering in the hospital. He brings his expertise in laser ablation therapy for epilepsy and other cerebral lesions to Barrow at Phoenix Children's.

Dr. Wilfong earned his medical degree from the University of Saskatchewan. After training in pediatrics in Canada, he completed a residency in child neurology and fellowships in electromyography, clinical neurophysiology and epilepsy at Baylor College of Medicine. He has held faculty appointments at the University of Saskatchewan, Medical College of Wisconsin and for the last 15 years, at Baylor College of Medicine where he was professor of pediatrics, neurology and developmental neuroscience.

## Fraternal Order of Eagles Donates \$1,000 to Neurotrauma Research Lab

In October, the Translational Neurotrauma Research Program at Barrow Neurological Institute at Phoenix Children's Hospital received a \$1,000 donation.

The Fraternal Order of Eagles donated the funds to support the program led by **Jonathan Lifshitz, PhD** who has pioneered translational research in concussive brain injury. The organization has donated to the research program several times over the past several years. The group donated the latest gift during a tour of the facilities at the neurotrauma research lab. To arrange for a tour and to support the research program, contact Kelly Hurter at (602) 933-2675.

## Barrow at Phoenix Children's Welcomes New Administrative Director



Barrow Neurological Institute at Phoenix Children's Hospital recently welcomed **Tracy Carlisle, MBA**, as administrative director. Tracy was previously director of the Neuroscience Institute at Children's Services at John F. Kennedy Health System in New Jersey.

At Barrow at Phoenix Children's, Tracy will oversee all neuroscience service lines to create full integration of services. She will be responsible for the development and growth of the institute's services to achieve the highest levels of clinical quality outcomes, patient satisfaction and value within Barrow at Phoenix Children's.

Save  
the Date!

•  
**Free Epilepsy  
Community Conference  
April 2017**

•  
**Recent Advances in the  
Treatment of Cerebral Palsy,  
a free community conference  
May 13, 2017**

•  
**For more information, visit  
[barrow.phoenixchildrens.org](http://barrow.phoenixchildrens.org)!**

## Welcome New Faculty & Staff

**Angus A. Wilfong, MD**  
Neurology

**Tracy Carlisle, MBA**  
Administration

**Sharlene Hanlon, MBA**  
Administration

**Gena Wilson, CPNP**  
Psychology

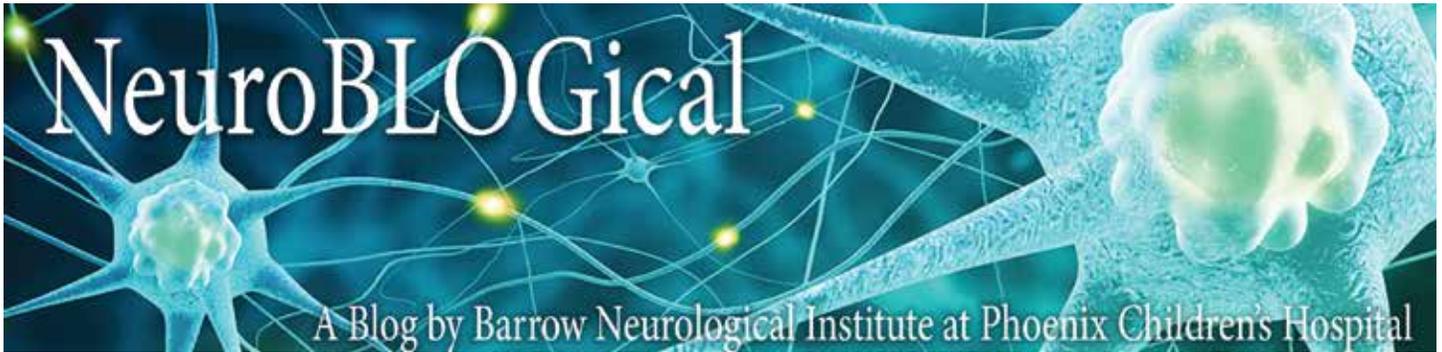
**Taylor Arnold, PhD, RD**  
Ketogenic Diet Program

**Jennifer Harper**  
Research

**Zulma Gomez, MA**  
Neurology

**Maira Escobedo, MA**  
Physical Medicine & Rehabilitation

**James Gann, MBA**  
Administration



In neuroscience, there are often many questions:

- What are the treatment options for my child's epilepsy?
- What's considered a traumatic brain injury?
- Will my child's headaches ever go away?

In an effort to address your questions and help patients and parents explore neuroscience, we created NeuroBLOGical: A Neuroscience Blog by Barrow Neurological Institute at Phoenix Children's Hospital at [barrow.phoenixchildrens.org/Neuroblogical](http://barrow.phoenixchildrens.org/Neuroblogical).

What topics do you want to see addressed? What neuroscience-related questions have you wrestled with?

Let us know at [barrow@phoenixchildrens.org](mailto:barrow@phoenixchildrens.org)!

# 100% for Brady continued from page 1



At that point, six-month-old Brady underwent a four-hour electroencephalogram (EEG), a test that monitors the electricity in the brain. His neurologist found that Rebecca was right. Brady had cerebral palsy and infantile spasms, a kind of seizure that affects children younger than one year old, which were causing the crying and screaming.

He was immediately admitted to the hospital and placed on anti-seizure medications, which calmed him. Shortly after that, Brady was prescribed oral Baclofen — a medication that calms the muscle spasms and tightness caused by his cerebral palsy.

“It was a complete 180,” Rebecca said. “He started sleeping, he was smiling. He was a happy kid.”

A few years later, at the age of six, Brady became a patient of Taryn Bragg, MD, a neurosurgeon who specializes in the treatment of children with movement disorders, including cerebral palsy. She is board-certified in neurological surgery and pediatric neurosurgery. At that time, Dr. Bragg lived and worked in Wisconsin.

When she first met Brady, Dr. Bragg suggested he would be a great candidate for a Baclofen pump, which would be placed in his brain. It took some convincing, Rebecca said, but in 2014, Dr. Bragg surgically placed a pump that automatically delivers Baclofen into his body through a catheter that runs from the pump in his abdomen to a little opening in his skull under his skin.

The new medication helped Brady, but it wasn’t an easy journey. Brady was in the hospital for 12 weeks, and it was then that doctors discovered he also had hydrocephalus, a condition that causes swelling in the brain. He had a shunt placed to reduce the pressure and swelling.

“We got to know Dr. Bragg really well at the hospital because we were there for so long,” Rebecca said. “She’s been very helpful to us in terms of getting him what he needed.”

The cold winters of Wisconsin were hard on Brady, so in 2015, the family decided to move to Phoenix.

“Dr. Bragg was the one doctor I was nervous about leaving,” Rebecca said. “How do you leave your neurosurgeon?”

In late 2015, she took Brady to Phoenix Children’s Hospital for an appointment and she heard news she couldn’t quite believe: Dr. Bragg, Brady’s neurosurgeon, was coming to Barrow at Phoenix Children’s. She joined Barrow Neurological Institute at Phoenix Children’s Hospital as a neurosurgeon in June 2016.

“Brady is very special,” Dr. Bragg said. “He is bright, engaged and is listening. As with many families, whether they have moved or I have, we will forever be connected. It is my privilege to be part of his life once again.”

Brady, who is now 10, regularly visits Phoenix Children’s where Dr. Bragg is still his neurosurgeon. He cannot speak, but when he sees Dr. Bragg, he lights up.

“Brady smiles when she comes in the room,” Rebecca said. I’m just glad she’s here.”

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## Director of Barrow at Phoenix Children's wins prestigious international award



**P. David Adelson, MD**, director of Barrow Neurological Institute at Phoenix Children's Hospital, Diane and Bruce Halle Endowed Chair in Pediatric Neurosciences and chief of pediatric neurosurgery received the 36th Herbert Olivecrona Award by the Department of Clinical Neuroscience/Neurosurgery at Karolinska Institutet in Stockholm, Sweden. Dr. Adelson was chosen for his vast clinical and research contributions to the field of pediatric

neurosurgery, his extensive and significant work in the area of pediatric neuroscience research, and in particular, pediatric traumatic brain injury.

He was recognized for his work in neurocritical care, acute care management and neuroplasticity/neuroregenerative neuroscience in both laboratory and clinical research. He has authored or co-authored more than 200 peer-reviewed publications, books and book chapters, the majority on the subject of neural injury in children.

As part of the only Level 1 Pediatric Trauma Center in Arizona, Dr. Adelson oversees and personally provides emergency neurosurgical care to patients who have suffered neurotrauma, including brain, spine and spinal cord, and peripheral nerve injuries.

Since 1976, the Olivecrona Award has recognized outstanding neurosurgeons and neuroscientists throughout the world who have contributed with excellence to the neurosurgical field, based on development of microsurgical techniques, pedagogical skills or scientific contributions. Dr. Adelson is the first pediatric neurosurgeon to win the award and is the second winner from Arizona.

## Neurological, Orthopedic Surgeons attend Mayo Clinic Spine Conference

In December, members of our collaborative spine team were featured speakers at the inaugural Mayo Clinic Spine Conference at Mayo Clinic Arizona held in Scottsdale.

This team includes orthopedic surgeons **Judson Karlen, MD**, and **Greg White, MD**, and neurosurgeons **Jamal McClendon, MD**, and **P. David Adelson, MD**. The two divisions work together to provide comprehensive diagnosis and treatment of spinal diseases and disorders through surgical and non-surgical services for our patients.



## P. David Adelson, MD, Speaks at International Conference



**P. David Adelson, MD, FACS, FAAP**, director of Barrow at Phoenix Children's, in December, was a featured speaker and delivered five lectures at The International Conference on Recent Advances in Neurotrauma (ICRAN), an international neurotrauma conference held in Bogota, Colombia.

ICRAN is a conference held every two years and brings together experts from around the world in the field of neurotrauma. Dr. Adelson spoke on different aspects of pediatric traumatic brain injury.

Barrow at Phoenix Children's was recognized at this conference for developing an international neurotrauma fellowship to provide research and clinical training for physicians in resource-poor countries. With future funding support, this fellowship will continue train clinician researchers in neurotrauma from around the world.

**Sign up** for our e-newsletter at  
[phoenixchildrens.org/enewsletter](http://phoenixchildrens.org/enewsletter).

# Supporting Children's Neurosciences

## BARROW Neurological Institute at **PHOENIX CHILDREN'S Hospital**

While you prepare for your own future, you have the opportunity to impact the future of our patients with a legacy gift or bequest to Barrow Neurological Institute at Phoenix Children's Hospital. Legacy gifts and bequests have an enduring impact on the children treated at Barrow Neurological Institute at Phoenix Children's Hospital – patients who need our specialized care. Planned giving enables you to focus your philanthropic goals, while realizing significant income and tax benefits. Your visionary gift can help us provide a brighter future for our patients as you plan for your own.

We thank our supporters whose investments help us in the development of new paradigms for clinical care and cures for children. You can express your support of the Institute in ways that complement your own personal interests.

### WHAT PHILANTHROPY SUPPORTS:

- Development, enhancement of existing and/or new clinical programs
- Funding cutting-edge programs in clinical, translational and laboratory experimental research
- Community and professional educational initiatives
- Institute's infrastructure supporting the biorepository and bioinformatics and data center.

### WAYS TO GIVE:

- Make a memorial or honor gift
- Name an Institute's Fund
- Contribute to the Director's Fund
- Provide funds for Endowed Chairs for research and program leadership

**For more information call Kelly Hurter at (602) 933-2675  
or visit [phoenixchildrens.com/DonateBarrow](http://phoenixchildrens.com/DonateBarrow)**