

BARROW Neurological Institute

at **PHOENIX CHILDREN'S Hospital**

Vol. 3 | Issue 1

100% for Cash



Five-year-old Cash Davis was born with congenital central hypoventilation syndrome (CCHS), otherwise known as Ondine's Curse, an extremely rare condition. Essentially, his brain fails to send a signal to the lungs to breathe. When Cash falls asleep his body just "forgets" to breathe. As a result, Cash has a tracheostomy and has spent his entire life plugged into a ventilator, leaving him vulnerable to infections.

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Epilepsy: What You Should Know

Epilepsy is a neurological disorder that causes recurrent seizures. Nerve cells (neurons) in the brain fire uncontrolled signals, resulting in an excess of neuron activity that causes a seizure. This chronic illness can be caused by a variety of brain injuries or congenital problems, trauma, stroke, and malformations of brain development.

Seizures are commonly divided into two types depending on which part of the brain is affected: generalized seizures, and partial (or focal) seizures. More than 60 percent of children with epilepsy experience partial seizures. Partial seizures arise from one region of the brain, with symptoms that correspond to the function of that area. For example, a seizure beginning in the occipital lobes may cause visual symptoms. Generalized seizures result when both sides of the brain are affected. With generalized seizures, a child may fall, lose consciousness, or their muscles may jerk and twitch.

Epilepsy affects the entire family. Not only are there physical symptoms to overcome children may often exhibit cognitive and emotional symptoms. Children with epilepsy may have related neurological conditions and developmental disabilities. Stress and frustration caused by having uncontrolled seizures may result in emotional or behavioral symptoms. Children with recurring seizures may feel isolated from their peers and experience a loss of self-esteem. Creating a support system and talking to others who face similar issues may help with the emotional side of epilepsy. Children with epilepsy and their parents may benefit in joining a support group.

Our Treatment Plan

The epilepsy team at Barrow Neurological Institute at Phoenix Children's Hospital includes some of the most respected pediatric epilepsy specialists in the country. The comprehensive approach to treating epilepsy usually begins with an office visit for a careful review of the child's history and prior diagnostic studies as well as

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"Our goal is to deliver the best patient- and family-centered care to each child who comes to us."

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P. David Adelson, MD
 Director, Barrow
 Neurological Institute at
 Phoenix Children's
 Hospital
 Chief, Pediatric
 Neurosurgery/
 Children's Neurosciences

From the Director continued from cover...

From the Director

As the new year begins we reflect on what it means to build a solid foundation and be part of a larger community. An important aspect of our vision here at Barrow Neurological Institute at Phoenix Children's Hospital is to provide community education, outreach, and injury prevention. We demonstrate our commitment to this by providing opportunities throughout the year that help to educate faculty, staff, community members and parents to be the most knowledgeable in the care of and best advocates for our children.

In this issue, we focus on children with epilepsy. Epilepsy affects five out of every 1,000 children. Although common, it is not a very well understood neurological condition. Children with epilepsy face physical symptoms coupled with feelings of social and emotional isolation. It is important as a physician to treat the whole child, not just the condition. As we see on a daily basis and personal level, epilepsy can have a significant impact on a child's short-and long-term development and the ability to participate in the typical activities of childhood. Caring for a child with a chronic neurological condition such as epilepsy may lead to financial and personal stressors for families as well.

As part of our mission to improve the health and quality of life of children with neurological disorders, our Comprehensive Epilepsy Program consists of a multidisciplinary team of specialists that have come together to provide the necessary patient and family-centered, high-quality care children with epilepsy need. This allows for a better experience for both the family and patient. Aside from providing state-of-the-art care for these children, our team participates in and helps drive clinical and translational laboratory research that will ultimately lead to new and more effective treatments.

We know it is important to educate other physicians, staff, healthcare providers, parents and anyone else who cares about children with epilepsy or

other neurological problems so they can be educated advocates for their child's care. On April 12, 2014, Barrow at Phoenix Children's will again join with the Epilepsy Foundation of Arizona to present a free educational conference that provides support, education, and resources for parents to better care and advocate for their child.

As part of our educational vision, each year our physicians and staff show their support by participating at community events such as the Down Syndrome, Epilepsy, Hydrocephalus and Autism Speaks Walks. Barrow at Phoenix Children's has also continued to build its support of and collaboration with several community resources and local health organizations in the Valley and will continue to build and improve our relationships with these important organizations and events.

We hope you enjoy our newsletter. As you may have noticed, topics change from issues to issue because we listen and our responsive to your suggestions for improving it and providing topics of interest to you. Please continue to send me suggestions and comments about improving this publication and more importantly, how we can enhance our care your children and service to you and the community. Thank you!

I also encourage you to visit our new website at <http://barrow.phoenixchildrens.org>, to learn more about our programs and accomplishments or like us on Facebook.

Epilepsy: What You Should Know continued from cover...



examinations. Further evaluation often includes admission to the Pediatric Epilepsy Monitoring Unit (PEMU) to record the seizures with video-EEG technology. This often reveals the type of seizure, including whether the seizures are generalized or partial. This is important in determining the best action plan for treatment.

The PEMU is a state-of-the-art unit with eight patient rooms designed

for children and their families. Each room is outfitted with video equipment to capture seizure activity while the child's brainwaves are recorded. The feedback received during an actual seizure leads to a more accurate diagnosis. The PEMU enables doctors to see if seizures are coming from a particular area of the brain and, if so, determine if it is an area that can be investigated further with more detailed MRI, PET scans, or placement of intracranial electrodes. Presented with this information, the epilepsy team collaborates to provide a comprehensive treatment plan, which may include medications, diet, and surgery.

Epilepsy Treatment Options

Among children with epilepsy, 60 percent achieve seizure control after taking one or more anti-epileptic drugs (AEDs). Medications must be monitored by a neurologist for effectiveness. Doctors may order blood tests, urine tests, and EEG brain wave studies to monitor treatment with AEDs. There are more than a dozen commonly used AEDs. The medications are chosen based upon seizures type, but also upon other factors, including age and the unique medical history of each patient. The specialist chooses the single best medication after the initial evaluation, but the effectiveness in each child is monitored and sometimes a second medication is best.

There are some alternative treatments instead of or in addition to the use of AEDs. Your epilepsy specialist

may suggest the ketogenic diet to reduce the number or severity of seizures. The ketogenic diet is high in fat and low in carbohydrate content, which shifts the body's metabolism in the state of ketosis. For reasons that are not entirely clear, ketosis can decrease the number of seizures for some children with epilepsy. The diet requires careful monitoring to ensure proper nutrition and growth. A ketogenic diet is demanding upon the family routine and not suitable for all patients; however, it can be used to treat many different types of seizures, and may be effective for those with difficult-to-control conditions, such as Lennox-Gastaut syndrome.

Children with difficult-to-control seizures may also be candidates for treatment with vagus nerve stimulation (VNS) treatment. VNS surgery is an outpatient surgery where a small electrical generator, about the size of a silver dollar, is implanted under the skin in the region below the collarbone.

The device sends an electrical signal to the vagus nerve that can reduce the number of seizures in roughly 50 percent of those treated. It offers the advantage of avoiding possible side effects associated with AEDs.

Epilepsy surgery is also a treatment option for many children and teenagers who have uncontrolled seizures. Surgical treatment is possible if the region of the brain where the seizures begin can be identified and is safe to remove. While all parts of the brain are important, some regions are more important than others. For successful candidates, seizures may be completely controlled and their level of functioning may be the same or even better than prior to surgery. The success rate for surgery depends upon the exact operation, but up to 80 to 90 percent of patients can be helped by some procedures.

If you suspect your child may have epilepsy, have your child seen by a medical provider trained in evaluation and management of epilepsy as soon as possible.

The Comprehensive Epilepsy Program includes the Pediatric Epilepsy Monitoring Unit (PEMU). The PEMU is staffed by a team of experienced, compassionate EEG technologists who will place the EEG leads and maintain them for 24 hours of recording. Children usually stay in the PEMU from two to five days, but the length of stay is individualized for each patient and the clinical concern that needs to be addressed.

During the stay, Child Life specialists provide fun activities for patients such as arts and crafts, toys, books, and games. These specialists also will be on hand to answer your questions, talk about what to expect, and help with coping and support.



Symptoms of epilepsy can vary from child to child depending on the cause and the affected region of the brain. A single seizure does not indicate epilepsy; however, children with the following symptoms should be evaluated by a neurologist:

- Seizure activity (convulsions)
- Strange sensations such as tingling
- Memory difficulties
- Unsteady gait or slurred speech
- Unusual or repetitious behavior
- Staring spells
- Changes in how awake or interactive the individual is

Epilepsy Center at Barrow at Phoenix Children's Hospital

The Comprehensive Pediatric Epilepsy Center at Barrow at Phoenix Children's is dedicated solely to the diagnosis, treatment, and management of infants, children, and teenagers with epilepsy.

Under the leadership of John F. Kerrigan, MD, physicians from the Divisions of Neurology, Neurosurgery, Neuropsychology, Psychiatry, and Neuroradiology collaborate to provide comprehensive, evidence based care that is individualized for each patient. Our team includes dedicated nurses, EEG technologist, social workers, and dietitians with special training and expertise in treating children

with epilepsy. The Pediatric Epilepsy Program utilizes state-of-the-art technology and the latest developments in treatment protocols to create management plans that strive for the best possible outcome for each of our patients and families.

Our mission is to provide the best possible clinical care, educate future providers, and make a substantive contribution to new learning and research for children and adolescents with epilepsy, within an environment that is supportive and family centered.

Leadership Epilepsy Program Team

Epilepsy Specialists (Neurologists)



John Kerrigan, MD
Medical Director



Randa Jarrar, MD



Matthew Troester, DO



Korwyn Williams, MD, PhD

How to Refer: By Phone : (602)-933-0970

Neurosurgeons



P. David Adelson, MD,
Director, Barrow Neurological
Institute at Phoenix
Children's Hospital



Ruth Bristol, MD



Ratan Bhardwaj, MD, PhD



John Fulton, PhD

Neuropsychology

Nurse Coordinator, Hypothalamic Hamartoma Program

Maggie Bobrowitz, RN

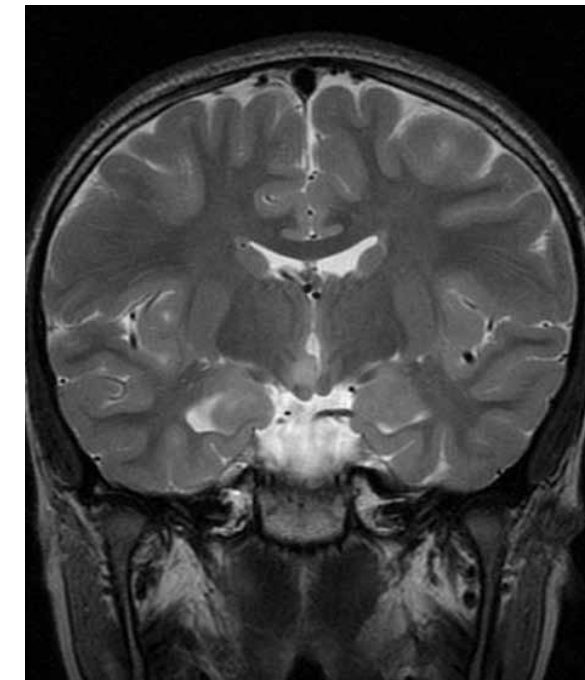
Ketogenic Diet

Lisa Vanatta, RD

Epilepsy Research at Barrow at Phoenix Children's Hospital

The National Institute of Health (NIH) - Childhood Absence Epilepsy (CAE) study is the United States' largest, controlled head-to-head comparison of anticonvulsant treatment for a particular epilepsy syndrome (childhood absence epilepsy). The findings have changed management of this particular type of epilepsy and the continuation phase continues to provide information about long-term outcomes, psychiatric and learning comorbidities associated with the epilepsy and medications used to treat it. This study has been possible through the financial support of the federal government, collaboration between multiple clinical sites, and the willingness of hundreds of patients and their families to participate.

The Hypothalamic Hamartoma (HH) Tissue Research Laboratory (Principal Investigator John F. Kerrigan, MD) focuses on the study of surgically resected HH with the aim of understanding the basic cellular mechanisms responsible for seizure activity arising from this human epileptic tissue. Our lab utilizes traditional neuroanatomical techniques to study HH, including immunohistochemistry, western-blot analysis, Golgi staining, and confocal imaging of micro-injected neurons. We work in collaboration with other research laboratories at Barrow Neurological Institute and elsewhere. In collaboration with the Wu Laboratory at Barrow, our current funding includes a three-year \$300,000 grant from the Arizona Biomedical Research Commission (ABRC) to study trans-membrane currents in HH neurons relating to gap junctions and pacemaker ion channels.



Research Funding Outcomes

Grants & Sponsored Projects

- MDA Application Submitted
- Harrington Discovery Institute Letter of Intent Submitted
- CIPT Letter of Intent (Jonny Lifshitz, PhD) Submitted
- T32 (P. David Adelson, MD) with Arizona State University submitted
- The Doctors Cancer Foundation (Ratan Bhardwaj, MD) Submitted \$50,000
- NIH R01 (Jorge Arango, MD/Ewa Brandys, MD) Submitted \$1,296,575
- Leadership Circle Awards- Ratan Bhardwaj, MD Awarded \$75,000, Theresa Thomas, PhD Awarded \$54,543
- U01 (P. David Adelson, MD/Robert Arceci, MD, PhD) Application submitted \$6,767,100
- MOU with MEDITECH for International Fellowship
- Year 3 ABRC "Rapid Cycle Outcomes Research to Improve clinical and Operational Outcomes" \$149,947

Presentations

Robin K. Blitz, MD, FAAP, was invited to speak about Fragile X syndrome at Scottsdale Unified School District on October 8, 2013

Jonathan Lifshitz, PhD, was invited to speak about the emergence of neurological dysfunction when the injured brain rebuilds itself, at Midwestern University in Phoenix, Arizona on October 16, 2013.

P. David Adelson, MD, was invited to speak on the importance of pediatric neuroscience institutes for improved health outcomes and quality of life for children with neurological disorders at the annual Congress of Neurological Science meeting in San Francisco in October 2013

Danni Brown, RN, was invited to speak at the Fall Trauma Nursing Conference at Oregon Health and Science University in Portland, Oregon in October 2013.

Jacob Venter, MD, CPE, was co-presenter at the annual American Public Health Association Exposition in Boston for the poster "Improving family-centered mental health care by supporting siblings of psychiatrically hospitalized youth" in November 2013



“It’s not easy being an ordinary parent raising a child with extraordinary needs. Phoenix Children’s Hospital and Cash’s amazing team...made my dreams for my son’s life a reality!”

100% for Cash continued from cover...

Through networking, Cash’s mom Tracey researched a breathing pacemaker made by Avery BioMedical. The technology consists of a surgically implanted receiver and electrodes that are paired with antennas worn over the implanted receivers. Through a small transmitter, the unit stimulates the nerves to the diaphragm, the muscle involved with breathing.

Tracy sent a request to Avery BioMedical asking for information regarding its breathing pacemaker and, with the help of the company, she found David Notrica, MD, a pediatric surgeon at Phoenix Children’s Hospital, and met with him in February 2013. This procedure had never been done on a pediatric patient before in Arizona. To prepare himself for the surgery, Notrica met with a physician from Seattle who had successfully completed the procedure several times.

It took a team of experts to treat Cash. On July 25, 2013, Dr. Notrica, along with P. David Adelson, MD director of Barrow Neurological Institute at Phoenix Children’s Hospital, conducted bilateral phrenic nerve pacing surgery. Cash’s pacers were turned on for the first time on September 4 by pulmonologists James Woodward, MD and Aparna Rao, MD at Phoenix Children’s.

“To see Cash sleeping for the first time in five years without a ventilator was amazing.” said Tracy. “For the past five years Cash’s life has depended on a ventilator that required power. His pacers are now powered by an ordinary nine-volt battery that he can carry around with him and he can fall asleep wherever he chooses. Having the ability to fall asleep on a couch for the first time in his life had Cash grinning ear to ear,” added Tracy.

“The decision to pace Cash has been remarkable and life changing. Our pacing experience has exceeded all of my expectations,” Tracy said. “Cash’s recovery from surgery was minimal; he was out of the hospital the next afternoon. We turned on his pacers and have not used his ventilator since that day.”

“It’s not easy being an ordinary parent raising a child with extraordinary needs. Phoenix Children’s Hospital and Cash’s amazing team of surgeons, nurses and pulmonologists, made my dreams for my son’s life a reality!” Tracy said. “Not only did the pacers change the quality of Cash’s life, but they have provided our entire family with a restored hope for Cash’s future; it looks bright and promising!”



News and Announcements

Neuropsychology Post-Doctoral Fellowship Accreditation

Thanks to our hard working faculty and staff, Barrow at Phoenix Children’s neuropsychology postdoctoral fellowship has been credentialed by the Association of Postdoctoral Programs in Clinical Neuropsychology (APPCN). Barrow at Phoenix Children’s has five neuropsychologists with expertise in assessing and treating concussions and expertise in performing neuropsychology work ups for epilepsy.

Child Neurology Resident

Congratulations to Brian Appavu, MD, one of our child neurology residents, was selected as one of the American Academy of Neurology Institute’s 2014 Resident Scholarship recipients! He will be traveling to Philadelphia for the Annual meeting in April.

PALS Grant Awarded

Congratulations to Beth Trevino, MD who was recently awarded a \$7,500 PALS grant. The grant will be used to outfit a room in the Heart Center for developmental pediatric evaluation. This room will serve patients in both the CCriB and 22Q clinics (Developmental Pediatrics, Cardiology and Genetics). This addition will help establish more comprehensive care with discipline collaboration for children with congenital heart disease who are at higher risk for developmental delays and disabilities.

Updated Website- New Look and Web Address

Barrow at Phoenix Children’s has launched a newly designed website and now has a different web address. Please visit us at: <http://barrow.phoenixchildrens.org>

Awards and Accomplishments

David Adelson, MD and Robin K. Blitz, MD were honored to be recently selected for Phoenix Super Doctors® 2014

Upcoming Events

2014 Annual Children’s Neuroscience Symposium

When: March 9 to March 12

Where: The Ritz-Carlton, Phoenix.

This year’s keynote speaker is Gerard Gioia, PhD, Children’s National Medical Center.

This symposium is designed to enhance the practitioner’s knowledge of common pediatric neurological disorders including presenting signs and symptoms, recommendations for specialist consultation, and recent treatment advances. Please visit our website to register and learn additional information about this event.

Register Online Today, www.phoenixchildrens.org/CNS2014

Free Community Educational Conference

Presented by Barrow Neurological Institute at Phoenix Children’s Hospital and the Epilepsy Foundation of Arizona

When: Saturday, April 12, 2014 - 8 a.m. to 12 p.m.

Where: Phoenix Children’s Hospital Rosenberg Building - Mel Cohen Conference Center

Please register online, www.phoenixchildrens.org/recent-advances-pediatric-epilepsy

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www.facebook.com/BarrowAtPhoenixChildrens



<http://barrow.phoenixchildrens.org/>

Welcome to New Faculty and Staff

Clarimar Borrero-Mejias, MD, joins Barrow at Phoenix Children’s as a pediatric neurologist. She received her medical degree at Universidad Central Del Caribe, School of Medicine in Bayamon, Puerto Rico and completed her residency training at Pediatric Hospital-University of Puerto Rico, School of Medicine in San Juan, Puerto Rico and here at Barrow at Phoenix Children’s. Before arriving in Arizona, Dr. Borrero-Mejias worked at the Tulane Lakeside Hospital in Metairie, Louisiana and the Children’s Hospital of New Orleans.

Brianne J. Butcher, PhD, joins the psychology division as a neuropsychologist. She obtained her doctorate degree at the University of Texas in Austin, Texas. Before arriving in Arizona, Dr. Butcher worked at the Miami Children’s Hospital and completed her postdoctoral fellowship in pediatric neuropsychology at the Children’s Medical Center in Dallas, Texas.

Sherrily Mulleneaux, FNP, joins the Physical Medicine and Rehabilitation team as a Family Nurse Practitioner. An Arizona native, she returned to her home state after working in pediatric neurology at Georgetown University Medical Center and in developmental pediatrics in Utah.

Sajitha Puthalath Mpharm, CCRP joins the Barrow at Phoenix Children’s team as a research coordinator. She obtained her master’s degree from Al-Ameen College of Pharmacy in India and obtained her diploma as a Clinical Research Professional after arriving in Arizona in 2009.

Reena Rastogi, MD joins the team as a pediatric neurologist. She received her medical degree at St. George’s University School of Medicine in Grenada, West Indies. Dr. Rastogi completed her pediatric residency at St. Joseph’s Hospital and Medical Center in Arizona. Her child neurology residency was completed here at Barrow at Phoenix Children’s, where she was the Chief Resident of the Child Neurology Residency Program. Before joining the team, Dr. Rastogi spent a year in private practice.

Randall Ricardi, DO was welcomed back to Psychiatry in the consultation/liaison division. He earned his medical degree at the Chicago College of Osteopathic Medicine in Chicago and completed his fellowship at Hawthorne Center in Northville, Michigan. Dr. Ricardi returns to Barrow at Phoenix Children’s with many years of experience in private practice. He is also a professor at several colleges in Arizona including Midwestern University, Arizona State University, and University of Arizona. His special areas of interest include ADHD, adolescent and child depression and OCD.

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or scan this code with your smartphone.



Supporting Children's Neurosciences

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

Recently, through the generous support of two individual donors, Barrow Neurological Institute at Phoenix Children's Hospital was able to open a new pediatric brain tumor lab in collaboration with Translational Genomics Research Institute to develop new strategies in the fight against pediatric brain cancer.

We thank our supporters as this investment into our Institute helps us in the development of new paradigms for clinical care and cures for these children. You can express your support of the Institute in ways that complement your own personal interests as you help us grow, evolve, and continue to set new standards in pediatric neurological care.

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 Bonnie Morgan at **(602) 933-2607**
or visit www.phoenixchildrens.com/DonateBarrow