

BARROW Neurological Institute

at **PHOENIX CHILDREN'S Hospital**

Vol. 2 | Issue 3

100% for Monica



“Monica has always been one of our healthiest kids,” said Nannette, mother of six. “So when she started experiencing stomach pains and severe weight loss after fighting a terrible bout of pneumonia last year, we knew something was wrong.”

Nannette brought Monica to see their gastroenterologist at Phoenix Children’s who sent her to get some blood work drawn. “Monica collapsed during the blood draw and the doctors made the decision to hospitalize her,” remembers Nannette. “That was when we started the long search for a proper diagnosis.”

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From the Director

The end of summer is in sight, bringing with it the promise of cooler temperatures and the commencement of the 2013-14 academic year. This busy time also signifies the beginning of a new year for pediatric residents, fellows and medical students.

Barrow Neurological Institute at Phoenix Children’s Hospital is committed to improving the health and quality of life of children with neurological disorders by educating the physicians of tomorrow through our education programs, which include pediatric residency, pediatric-neurology residency and psychology internship training programs at Phoenix Children’s. The Institute also provides advanced learning opportunities through fellowship programs in neurosurgery, neuroradiology and neuropsychology.

These educational opportunities allow us to attract top talent and innovation while also improving health care delivery and state-of-the-art care here in the Southwest.

Back to school also signifies the beginning of football, soccer, cheerleading, and other youth sports. Unfortunately though, these activities also bring with them the risk of sports-related traumatic brain injury (TBI), more popularly known as a concussion.

Trauma, particularly TBI, remains the leading cause of death and disability in

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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
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Chief, Pediatric
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From the Director continued from cover...

children and occurs in sports, automobile accidents, and a variety of other ways. According to the Centers for Disease Control, 1.5 million people -600,000 of them children-suffer a TBI each year, with many resulting in death or long-term disability. While there is often a focus on the more severe cases of TBI, concussions are growing into a silent epidemic. Something that still surprises me today is some do not understand concussions are indeed brain injuries! And even when mild, can result in permanent damage!

Concussions represent the majority of brain injuries resulting in emergency room visits or hospital admissions, yet these injured children are the least likely to be followed over the course of their recovery. While most do well, many children experience post-concussive syndrome that may include severe headaches; disturbances of vision or balance; sensitivity to light or sound; or nausea. Oftentimes, symptoms are ignored because it's only a concussion.

One of the biggest shockers for parents following a concussion is they find their children often have significant and prolonged difficulties returning to the activities they enjoyed before the injury. Many children require treatment to get them back on track with school and other areas of life. While those who suffer moderate to severe TBI are at greatest risk, children who suffer even a mild concussion are not immune. Mounting evidence shows permanent impairments in concentration, focus, and quality of life even after a mild TBI. Pediatric patients at greatest risk are those with evidence of post-concussive symptoms. We are currently focusing our research efforts on these patients, which may improve our assessment of risk and aid in directing care.

Fortunately, with the media attention on the long-term effects of TBI on players from the NFL and NCAA, there is more awareness of the potential for brain injury in the scholastic and recreational athlete. This has led to increased scrutiny and care for children to ensure they are not put at risk in the acute period, and have access to adequate follow up, assessment, and diagnostic work. It has become increasingly clear that simple follow up with a primary

care physician is not enough to be approved for return to play. A child who has suffered even a mild TBI and remains symptomatic should be followed by an experienced multidisciplinary team to ensure safety and improve long-term outcomes.

We have designed a program and multidisciplinary clinic located in convenient locations across the Valley to assess and care for these children. This allows for a better experience for both the family and patient.

As part of our mission to improve the health and quality of life of children with neurological disorders, our Concussion Neurotrauma Program demonstrates how a multidisciplinary team provides the necessary comprehensive, high-quality, patient- and family-centered care children need. Aside from providing the very best for these children, our team participates in and helps drive research that will ultimately lead to new and more effective treatments.

I hope you continue to find our newsletters helpful and informative. Please, feel free to contact me or the staff if you have any suggestions for improving our newsletter, other topics of interest, or improving our care of children and service to you or the community. Thank you!

I also encourage you to visit our website at www.phoenixchildrens.com/Barrow, to learn more about our programs and accomplishments or like us on Facebook.

Concussion Neurotrauma Program

The Concussion Neurotrauma Program at Barrow Neurological Institute at Phoenix Children's Hospital is a multidisciplinary clinic dedicated solely to the care of pediatric patients who have suffered a traumatic brain injury. A collaboration of specialists representing neurosurgery, neurology, sports medicine, neuropsychology, neuroimaging, injury prevention, and rehabilitation, the program provides improved communication, clinical care, research, education, and most importantly, patient- and family- centered care.

The program, which includes a clinic dedicated to the care of young athletes who have suffered sports concussions, offers improved patient care by ensuring access to the variety of subspecialty programs neurotrauma patients require for evaluation, diagnosis, management, and treatment. This model ensures a patient-focused approach to the care and well being of children and also includes a dedicated focus on family-support needs. The program's goal is for children and their families to get one-stop care, where standardized treatment protocols are researched, evaluated, and consistently improved as new data comes available.

This model ensures a patient-focused approach to the care and well being of children and also includes a dedicated focus on family-support needs.

Leadership



P. David Adelson, MD,
Co-Director, Neurosurgery



Kristina Wilson, MD,
CAQSM, FAAP, Co-Director,
Sports Medicine



Michael Lavoie, PhD,
Neuropsychology



Melanie Alarcio, MD,
Neurology



Katie Klas, CPNP-AC/PC,
Neurosurgery

Who to Refer:

- Any child who has suffered a closed head injury within the last six weeks
- A child who has been seen through the Emergency Department for a closed head injury

How to Refer:

By Phone: (602)-933-0196 or (602)-933-0440

Additional Information:

Patients who have had a concussion more than six weeks ago and whose ONLY symptom is chronic headaches should be referred to one of our designated neurology providers: Kara Lewis, MD; Robert Little, MD; Marcy Yonker, MD; or Carolyn Hickman, CPNP.

Pediatric Concussion: What You Should Know



A concussion is a brain injury resulting from trauma to the head and can vary in severity. All concussions must be treated with the same initial caution to allow the brain time to heal.

Concussion symptoms are commonly divided into four groups: physical, cognitive, emotional, and sleep.

Headaches are the most common physical symptom of a concussion. Other physical signs may include nausea, fatigue and loss of balance. The cognitive symptoms are most often noticed by teachers as children who suffer concussion typically respond slowly and need more time to complete assignments in the classroom. Emotional symptoms are apparent to parents and friends. Lastly, children may have significant problems with sleep. They can either be drowsy despite sleeping more than normal or they can be sleeping less and have difficulty falling asleep. These symptoms are the brain's way of showing it has been injured and should be taken seriously.

Children should have complete cognitive and physical rest until all symptoms have fully resolved. During the school year, it is not uncommon for children even with a minor concussion to miss a few days of school to allow their brain to heal. Complete cognitive rest, which is the most important part of recovery, includes no television, computer work, or texting. Modifications to school attendance and workload are also required. With physician and neuropsychologist guidance, most school counselors can work personally with the students to assist them during the healing process.

With more severe concussions, further accommodations in school may be necessary. Most young children recover in seven to 10 days from a first concussion. Teens and collegiate athletes may recover in as little as five to seven days, but in all children who are still developing and growing, a conservative approach is best. Additional concussions generally increase the amount of time required for the child to recover; in those cases, doubling the amount of rest needed is often necessary. Child athletes should not return to a sports-related activity until they are able to return to school and participate in other cognitive tasks without any return of symptoms.

In addition, there are risks that can lead to death, including second-impact syndrome, which can occur if a child returns to sport and sustains another injury to the brain prior to completely recovering from the first injury. The long-term effects of concussion, especially multiple concussions in pediatric and adolescent athletes, are unknown. Permanent deficits, however, are seen in as many as 15 percent of children who suffer even one mild concussion.

Concussions are often initially unrecognized by coaches, families, and the athletes themselves due to a lack of education and awareness. Many people believe concussions are associated with a loss of consciousness. In reality, only about 10 percent of concussions are associated with blacking out.

A concussion is a brain injury resulting from trauma to the head and can vary in severity. All concussions must be treated with the same initial caution to allow the brain time to heal. Any head injury associated with the following symptoms should be evaluated in the emergency department:

- Repeated vomiting
- Loss of consciousness (blacking out) longer than a few seconds
- Neck pain
- Severe headache that gets worse over time
- Memory difficulties
- Seizure activity (convulsions)
- Unsteady gait or slurred speech
- Weakness or numbness in extremities
- Unusual behavior
- Concerns for a skull fracture
- Changes in how awake or interactive the individual is

Most other head injuries without these symptoms may be evaluated as soon as possible by a physician trained in the diagnosis and management of pediatric concussion. This may be your son's or daughter's primary care physician, neurologist, neurosurgeon, or a primary care sports medicine physician who specializes in the care of athletes. If it is a sports-related injury, and trained medical personnel are on-site, they may provide an immediate assessment.



Common Symptoms:

Physical Symptoms

- Headache*
- Nausea
- Vomiting
- Balance problems
- Fatigue
- Sensitivity to light or noise

Common cognitive symptoms include:

- Feeling foggy or slowed down
- Problems concentrating or remembering
- Feeling confused
- Emotional Symptoms:
- Irritable
- Anxious
- Nervous
- More emotional than normal

*The most common concussion symptom

This past spring, legislation was passed in Arizona requiring all athletes and parents who participate in government-funded athletic programs to receive concussion education at the start of the sports season. Student athletes and parents are now required to sign a statement indicating they have received education on concussions and understand the risk of head injury in sports participation. In addition, when children are taken out of a game by a parent, coach, referee, or team physician for a concussion, they are not allowed to return to any athletic activity until cleared by a doctor, nurse practitioner, or physician's assistant.

Concussions are brain injuries and should be taken seriously. Clearance to return to play should be given by a medical professional with specialized training in the diagnosis and treatment of brain injuries.

Young athletes should never be cleared to return the same day and generally it is recommended they rest at least a week from sports-related activity. If they are continuing to have symptoms at a week, continued rest is necessary. But if they are free of all symptoms and not taking any medications they are often ready to begin a gradual return to sports-related activity.

All children are at risk of sustaining a concussion. Currently, there is no way to prevent a concussive injury. As a parent of a child who may sustain a concussion, you can help minimize injury to the brain by quickly identifying the signs and symptoms. If you suspect a concussion, have your child seen by a medical provider trained in the evaluation and management of concussion as soon as possible. In addition, rest the brain by minimizing all cognitive and physical demands until all symptoms resolve.

Residents and Fellows

Barrow Neurological Institute at Phoenix Children's Hospital provides full-time, educational experiences in the neurosciences. Medical and research education are core strategic priorities of the Hospital. We have a strong commitment to attract top talent and provide training to the health care leaders of tomorrow. Our residency and fellowship programs provide doctors exposure to comprehensive and multidisciplinary management of patients, and advanced operative techniques in the fields of pediatric neurology, neuroradiology, and research.



This year we are happy to welcome neurosurgery fellow Krystal Tomei, MD; neuropsychology fellow Marika Maris, PhD; and neuroradiology fellow Patricia Cornejo, MD.



We would also like to welcome this year's neurology residents (photo left to right): Natalie Guido-Estrada, MD; Tara Mangum, DO; Brian Appavu, MD; Nadia Dominguez-Molina, MD; and Judy Li, DO.



The Division of Psychology is excited to welcome Ashley Whitaker and Harpreet Kaur to the pre-doctoral internship program.



When Puffenberger started daily visits with Monica during her in-patient stay, the psychology intern immediately started teaching her vital tools to deal with her anxieties and fears. Monica felt very comfortable with Synthia, and really appreciated her calm and compassionate demeanor. She appreciated how Synthia related to her as a young lady and not a child.

As treatment began, which involved nutrition support through an NG tube with night feeds and also meals and snacks by mouth during the day, Monica quickly realized this was going to be a difficult journey back to health. After so much time being malnourished, Monica's stomach needed to re-learn how to take on normal amounts of food. This was going to cause a sort of stretching of her stomach and even involve discomfort. Synthia helped Monica understand how she needed to push through the pain, and eat in order to get better. Her treatment continued even after discharge, and Monica came home with a Nasojejunal (NJ) Tube that would continue to deliver nightly supplemental nutrition until she reached a healthy and stable weight.

Nannette remembers Monica's relief when Synthia explained they could continue weekly visits even after discharge from the hospital.

"Even at home the anxiety that came with meal times was overwhelming," Nannette said. She described feeling helpless knowing she could not force her child to eat, and yet breathed a sigh of relief when she realized that Monica would really listen to Synthia's counsel.

Monica did not return to school during the months of treatment, and continued to thrive and get better with the wonderful encouragement and counseling she received from Synthia. The day finally came when Shauna Rae Schroeder, MD was going to remove the NJ Tube. Monica was grateful that Synthia was present to coach her through the process, and was thrilled to hear that Dr. Schroeder wanted to empower her by allowing her to pull out the tube on her own!

Monica was already inspired by her little sister's challenges with spina bifida and the comprehensive medical care she receives at Phoenix Children's Hospital. Now her own battle with SMA syndrome, allowed her to experience firsthand the compassionate nurses, experienced doctors, and the incredible support of Child Life.

Monica and Nannette agree the biggest help was the amazing compassion and counsel she received from the Psychology Department.

100% for Monica

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Nannette and her husband, Ched, were no strangers to Phoenix Children's Hospital, but things were different this time. "This hospitalization was very scary for us," said Nannette. "With everything we have experienced with Annie, Ched and I consider ourselves experts on spina bifida and all the health issues that come with it. When Monica's weight dropped dangerously low and began to affect her heart function, we were terrified and did not have the security of experience and knowledge to fall back on. We had no idea what was making our normally very healthy daughter so sick and felt helpless as we saw her wasting away before our eyes."

Eventually the diagnosis came: superior mesenteric artery (SMA) syndrome, an extremely rare disorder that causes upper gastrointestinal obstruction and is often difficult to diagnose. "This was the cause of Monica's severe stomach pain, inability to eat and drink, and spiral downward into severe weight loss," said Nannette. "This condition is very rare and often overlooked as an eating disorder."

Monica was hospitalized for 15 days, it was during this time she met Synthia Puffenberger, an intern with the Psychology Department at Barrow Neurological Institute at Phoenix Children's Hospital.

Nannette welcomed the doctor's suggestion to involve psychology and give Monica a thorough evaluation. The nutritionist also explained how patients commonly develop a strong fear of eating over time due to the pain and discomfort they experience. Monica also dealt with high anxiety and panic attacks resulting from nausea and a paralyzing fear of vomiting.

"This condition is very rare and often overlooked as an eating disorder."



Upcoming Events

Autism Speaks Walk

Sunday, October 27, 2013

8 a.m. to 12 p.m.

Tempe Beach Park, Tempe, AZ

Join us at the annual Walk Now For Autism Speaks to support Autism research and awareness.

2014 Neuroscience Symposium

March 9-12, 2014

The Ritz Carlton, Phoenix, AZ

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

The targeted audience of this symposium includes: primary care providers, nurse practitioners, physician assistants, nurses, allied health, athletic trainers and coaches.

Recognizing neurological problems in children is challenging. 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.

Awards and Accomplishments

Sleep Laboratory Fully Accredited by American Academy of Sleep Medicine

Thanks to the dedication of Rupali Drewek, MD, and Matthew Troester, DO along with the hard working Hospital staff, Phoenix Children's now has the only pediatric American Academy of Sleep Medicine (AASM) accredited sleep laboratory in the Southwest! This accomplishment makes us one of just seven accredited pediatric sleep centers in the entire western U.S.

The Sleep Medicine Program is dedicated to treating a variety of problems that compromise healthy sleeping habits and keep children and their parents from having a comfortable night's rest.

U.S. News & World Report Recognition

The Hospital's divisions of Neurosurgery and Neurology are ranked 32 nationally, in the 2013-14 U.S. News & World Report Best Children's Hospitals list.

Seven physicians from Barrow at Phoenix Children's were named on the U.S. News & World Report 2013-14 Top Doctor List. Congratulations to P. David Adelson, MD; Robin Blitz, MD; Saunder Bernes, MD; Beth Ann Haynes, MD; Randa Jarrar, MD; Urszula Kotlow, MD; and John F Kerrigan, MD.

Five physicians from Barrow at Phoenix Children's were named Top Doctors in Phoenix Magazine, 2013. Congratulations to Saunder Bernes, MD; Robin Blitz, MD; John Condie, MD; Kara Lewis, MD; and Laura Sweetman, MD.

P. David Adelson, MD is ranked in the top 1% nationally for a Neurosurgery/Pediatric Neurosurgeon

Welcome to New Faculty and Staff



Jacob Venter, MD, CPE; Psychiatrist

Jacob Venter, MD, CPE, has joined Barrow Neurological Institute at Phoenix Children's Hospital as the Division Chief of Psychiatry. He is board certified in psychiatry, child and adolescent psychiatry and in medical management. Dr. Venter joins the team with more than 22 years of experience in his field. He holds a medical license to practice in South Africa, Massachusetts and Arizona. Dr. Venter received his medical degree from the University of the Orange Free State, Bloemfontein, South Africa and completed residency at the University of Stellenbosch in Stellenbosch, South Africa. He also obtained residency training at Maricopa Integrated Health System in Phoenix, Arizona and Harvard Medical School in Cambridge, Massachusetts. After his residency in Massachusetts, Dr. Venter completed his Child and Adolescent Neuropsychiatry Research Fellowship at Harvard Medical School, McLean Massachusetts General Hospital. He joins us from Cambridge Health Alliance.

Larry Maese, Director of Ambulatory Satellite Offices

Amber Gorichs, Communication and Marketing Liaison (Neuroscience)

Meredith Williams, Lead Scheduler (Neurology)

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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