100% Adlette, Edith & Izabelle

A diagnosis of Chiari malformation in a child often means countless visits to the doctor’s office, numerous diagnostic imaging tests and, sometimes, several surgeries. Having triplets with this neurological malformation is all that multiplied by three.

That’s the reality for Izabelle, Edith and Adlette, five-year-old triplets who all have Chiari malformation, and their parents Isabel and Julio.

Chiari malformations are congenital structural defects in the brain and spinal cord. Symptoms can include severe head and neck pain, loss of muscle strength, dizziness and balance problems, vision issues and swallowing or breathing problems. However, some individuals with Chiari don’t have any symptoms.

Chiari Malformations in Adults and Children: Diagnosis and Treatment

Chiari malformations are congenital structural defects of the hindbrain that most commonly affect the cerebellum and upper spinal cord. These malformations often develop before birth and cause symptoms due to the cerebellum having too little room, causing the lower part of the brain to dip down through the normal opening at the bottom of the skull. This can cause an obstruction of the flow of cerebrospinal fluid (CSF) and then pressure can build up on the brainstem and spinal cord affecting motor, visual, sensory, nausea and vomiting and other functions controlled by this area of the brain.

There are four types of Chiari malformations. The Chiari Type I (CM-I) is the most common type. The exact cause of this type of Chiari is not known and most of the time is found incidentally because the adult or child was being evaluated for something else like headaches or concussion, and never experienced any symptoms related to their Chiari.

To treat a complex condition like Chiari malformation, an interdisciplinary team of specialists working together is necessary to give the child relief from symptoms and the best quality of life.

At Barrow Neurological Institute at Phoenix Children’s Hospital, neurologists, neurosurgeons and physical therapists work together with a number of other specialty providers to do just that.

Because the symptoms of Chiari vary widely, it can be difficult to accurately diagnose the condition. Symptoms can include head and neck pain, loss of sensation and muscle strength, dizziness and balance problems, vision issues, sensitivity to light, breathing difficulties, sleep apnea, along with trouble speaking and/or swallowing. In patients with and without symptoms, Chiari is most often diagnosed with imaging tests like CT and MRI scans.

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

100% for Adlette, Edith & Izabelle continued on page 6...
Dear Barrow Neurological Institute at Phoenix Children’s Hospital Supporter,

A diagnosis of Chiari malformation is life-changing. For parents of children with the brain abnormality, and many times with the associated other related disorders, it can mean weekly trips to clinics and hospitals to treat all of the different issues, symptoms and related problems.

For the parents of triplets with Chiari, those responsibilities are multiplied. In this issue of our newsletter, you’ll read about these triplets — Edith, Adlette and Izabelle — who have each been diagnosed with Chiari malformation. They have undergone multiple neurosurgery and other treatments at Barrow at Phoenix Children’s to improve their health and quality of their lives.

A pediatric multidisciplinary approach is necessary to understand all of these issues and problems, especially the nuances to provide the optimal care for these children. Because of the diversity of care we provide for a large population of children affected by this condition, we recognize the complexities that accompany a Chiari malformation diagnosis, and can diagnose and recommend the best treatments. All of our specialists work closely to determine the best treatment options and management for each Chiari patient that is unique to that patient. Despite being triplets, each of these children had unique issues that differed from their siblings.

Research is also an important component to our approach to treating Chiari malformations. At Barrow at Phoenix Children’s, we have three Chiari-related research studies currently underway to develop more efficient ways to diagnose the abnormality and intrinsic neural damage that will hopefully lead to new ways to best treat this disorder.

This issue of our newsletter provides a glimpse into how we treat Chiari malformations and their neurological comorbidities, including an overview of our services, related research studies and the story of Izabelle, Adlette and Edith, along with the specialists that provide that diagnosis and care.

Your support is appreciated in the continued development of cutting edge research and treatments for Chiari malformations and all of the neurological diseases and disorders our young patients have to deal with in their day-to-day lives.

If you haven’t yet read our 2014 Annual Report, you can find it at https://barrow.phoenixchildrens.org/annual-report/2014. It contains an overview of our comprehensive neurological services, heartwarming patient stories, along with details about our research and educational efforts to improve the health and quality of life of children with neurological and psychiatric diseases and disorders. Please continue to send me suggestions and comments about improving our newsletter and annual report, and also any way we can enhance the care and services we provide to the children here at Barrow at Phoenix Children’s.

Thank you!

P. David Adelson, MD

Director, Barrow Neurological Institute at Phoenix Children’s Hospital
Diane and Bruce Halle Endowed Chair in Pediatric Neuroscience
Chiari Research at Barrow Neurological Institute at Phoenix Children’s Hospital

At Barrow Neurological Institute at Phoenix Children’s Hospital, our research team is working toward finding cutting edge ways to treat Chiari malformations.

Currently, our researchers, led by Jorge Arango, MD, and P. David Adelson, MD, are participating in three Chiari-related research studies that look at improving diagnosis and medical management for patients. One of the studies is a national consortium that aims to learn about the natural history of Chiari malformation and its clinical course following treatment. The other two research efforts are Phoenix Children’s Hospital-led studies that identify predictors of surgical effectiveness based on clinical and radiological findings before and after surgery. Through the use of biomarkers and comparative effectiveness.

Chiari does not always cause symptoms for patients, which delays diagnosis and increases the chances for permanent neurological damage.

“Developing mechanisms to diagnose and perhaps screen for neurological distress will help clinicians intervene before damage occurs, preventing the development of any symptoms and improving the quality of life of individuals with the malformation,” Dr. Arango said.

Plans are currently underway to launch additional research efforts in the area of Chiari malformations. To learn more about how you can help, visit phoenixchildrensfoundation.org/chiari.

- As of 2016, Barrow at Phoenix Children’s has collected cerebral spinal fluid samples from 81 patients with Chiari. These samples will be used for Chiari-related research.
- 75 Chiari-related neurosurgeries performed in 2015
- 3 Chiari-related studies at Barrow at Phoenix Children’s

Chiari Malformations in Adults and Children: Diagnosis and Treatment

continued from cover…

Having Chiari Malformations does not always lead to surgery. Since most malformations are found incidentally, education of potential symptoms to watch for may be all that is needed. Patients with Chiari, though, can develop a pocket of fluid in the spinal cord or brain stem, called a syrinx. This can cause a decline in the function of the spinal cord and cause walking issues, pain in the arms and legs or incontinence.

A patient with Chiari will be considered for surgery if the symptoms are so severe that they are interfering with quality of life or if they have a syringomyelia - a condition in which the syrinx is causing damage to the spinal cord. Additionally, there are a number of conditions that may be associated with the Chiari including hydrocephalus, spina bifida, tethered spinal cord syndrome and scoliosis.

Children with Chiari malformation often suffer symptoms that are treated by a number of different specialties at Phoenix Children’s Hospital. Some of these specialties include:
- Neurosurgery
- Neurology
- Urology
- Gastroenterology
- Cardiology
- Orthopedics
- Physical Medicine
- Genetics
- Sleep Medicine
- Pulmonology
- Diagnostic Imaging

How to Refer: (602) 933-0970
Tourette and Tic Disorders Clinic Now Open

In January 2016, Barrow Neurological Institute at Phoenix Children’s Hospital opened the Tourette and Tic Disorders Clinic in partnership with the Tourette Association of America. It is led by pediatric neurologists Michael Kruer, MD, and Harpreet Kaur, PhD, along with Randall Ricardi, DO, child and adolescent psychiatrist. It will provide diagnoses and treatments for children with Tourette syndrome and related disorders. To make an appointment, call (602) 933-0940.

Concussion Team from Barrow at Phoenix Children’s Attend Premiere of the Film ‘Concussion’

Education is an important component in the treatment and prevention of concussions. On Dec. 21, members of the Concussion Clinic team at Barrow at Phoenix Children’s attended the Phoenix premiere of the 2015 movie “Concussion.” The premiere, organized by the Nick Lowery Foundation, was attended by physicians and former professional athletes. After the screening, P. David Adelson, MD, director of Barrow at Phoenix Children’s, participated in a panel discussion about concussions. Thank you to Reena Rastogi, MD, Kristina Wilson, MD, Randon Hall, MD, Michael Lavoie, PhD, P. David Adelson, MD, and Katy Klas, PNP, for participating!

Biorepository Program Receives National Accreditation

The Biospecimen Sciences Program at Phoenix Children’s Hospital received an accreditation from the College of American Pathologists (CAP), making it one of only three hospitals across the country with such an accreditation.

The CAP accreditation recognizes excellence in biorepository processes for handling and banking biospecimens. The biorepository program staff works with surgeons, pathologists and researchers across all departments at Phoenix Children’s to gather and store pediatric biospecimens for study.

The program is part of the Phoenix Children’s Hospital Research Institute, a clinical and translational research endeavor that allows patients to participate in cutting edge research, which leads to the development of new therapies, devices and treatment options.

Now Recruiting: Children with Spastic Cerebral Palsy for Intense Physiotherapies Study

Researchers with Barrow at Phoenix Children’s are currently recruiting patients for a cerebral palsy related study. They’re working in association with University of Arizona Zuckerman College of Public Health and Tucson Medical Center to evaluate the effects of intense physical and occupational therapies to improve function in children with cerebral palsy.

If your child has been diagnosed with spastic cerebral palsy and is between the ages of 12 and 36 months, he or she may be a candidate to participate in this important study. Over 48 weeks, participating children will receive a total of 96 sessions of physical and occupational therapy. All therapy and evaluations beyond what is covered by the participant’s insurance will be provided free of charge thanks to a grant awarded by the National Institutes of Health. To learn more about this opportunity, contact Kiley Bernhard, MPH, at (602) 933-1161.

Welcome New Faculty & Staff

Adrian Abrams, MA
Neurology

Anne Guthrie, PNP
Psychiatry

Harpreet Kaur, PhD
Psychiatry

Josh Kellison, PhD
Psychology

Brenda Aranda, PhD
Psychology
Upcoming Events & Publications

Free Community Epilepsy and Seizure Disorders Education Event, March 19

Please join us for a free conference for families of children with seizure disorders from 8:30 a.m. to 12:30 p.m. on Saturday, March 19, in the Melvin L. Cohen Conference Center inside the Rosenberg Children’s Medical Plaza at Phoenix Children’s Hospital, 1920 E. Cambridge Ave. Epilepsy specialists and medical professionals will be leading discussions about epilepsy and seizure disorders. Light refreshments will be served. RSVP at events.phoenixchildrens.org/events/48.

Free Down Syndrome Community Education Conference, May 7

The Eighth Annual Recent Advances in Medical Treatment for Down Syndrome, a free community event sponsored by Barrow at Phoenix Children’s, the DS Network Arizona, Sharing Down Syndrome Arizona and Raising Special Kids, will be held Saturday, May 7. Please join us for a day of education from experts in the areas of Down syndrome and developmental pediatrics. For more information and to RSVP, visit barrow.phoenixchildrens.org/events.

Third Annual Downright Beautiful Fashion Show Fundraiser, March 20

Join us for a fun-filled afternoon fundraiser to support the Pediatric Down Syndrome Clinic at Barrow at Phoenix Children’s! Our clinic patients will model the latest styles on the runway from 11 a.m. to 2 p.m. on Sunday, March 20 at Warehouse 215 at Bentley Projects, 215 E. Grant St., in Phoenix. Visit DSFashionShow.org for information and tickets.

Recent Research and Publications


For the triplets, Izabelle and Edith both had symptoms, which led Isabel to take the girls to their pediatrician in January 2014. An MRI confirmed the Chiari diagnosis for Izabelle.

“I had no idea what that meant. I didn’t even know how to spell it,” Isabel recalled. “It was very scary.”

Within months, Adlette and Edith received the same diagnosis. In 2014, Izabelle and Edith underwent their first neurosurgeries. More surgeries were on the horizon, and the triplets’ parents researched nine neurosurgeons.

“We would pray a lot that we would be guided and would find the right neurosurgeon for them,” Isabel said. “We looked out of state and we looked within the state.”

Then, Isabel heard P. David Adelson, MD, chief of pediatric neurosurgery at Barrow Neurological Institute at Phoenix Children’s Hospital, speak at a Chiari education event for the community.

Since then, Dr. Adelson has performed several surgeries on the girls.

“What’s important is that you have a multidisciplinary team, so it’s not just neurosurgery – it’s about the team including neurology, physical therapy and social work, who support these children and their families,” said Dr. Adelson. “We consider ourselves a Chiari center because we have all those different components that are necessary to care for these children.”

They’re also seen by other pediatric specialists in urology, gastroenterology, pulmonology, sleep medicine, cardiology, physical medicine and genetics to treat the various symptoms and conditions that are often seen alongside Chiari. On average, they have about five clinical appointments per week.

Their cerebral spinal fluid has also been collected for use in research efforts underway at Barrow at Phoenix Children’s Hospital. Isabel says this is important for the girls.

“The more we do right now, the better their lives are when they’re older for good quality of life,” she said. “The only way we’re going to be able to find solutions for this is with research.”

To watch a video of the triplets, visit youtube.com/phoenixchildrens
Members of our neurosurgery team attended the 44th Annual Meeting of the American Association of Neurological Surgeons/Congress of Neurological Surgeons Section on Pediatric Neurosurgery in Seattle in December. From left, P. David Adelson, MD, Shelley Flecky, PA, David Shafron, MD, and former neurosurgery fellow Kelly Maheny, MD, now at the University of Virginia.

Members of our Pediatric Epilepsy Program and research team at Barrow at Phoenix Children’s traveled to the 2015 Annual Meeting of the American Epilepsy Society to share their work.

Awards

Barrow at Phoenix Children’s Translational Research Program Study Published in Brain Injury

Congratulations to Jonathan Lifshitz, PhD, Jenna M. Ziebell, PhD, Rachel K. Rowe, PhD, Jordan L. Harrison and F. Anthony Willyerd, MD, for their recent publication, “Experimental diffuse brain injury results in regional alteration of gross vascular morphology independent of neuropathology” in Brain Injury. The study looked at traumatic brain injury and its effects on the body.

Rachel Rowe, PhD, Received Prestigious Research Award

Congratulations to Rachel Rowe, PhD, post-doctoral fellow on the Barrow at Phoenix Children’s Translational Research Team for being awarded the prestigious Young Investigator Award from the International Brain Injury Association. The award recognizes Dr. Rowe’s work in brain injury research. Thank you for serving as a wonderful ambassador for our research team and for all of your efforts!

Professional and Community Education Presentations

Barrow at Phoenix Children’s and its Developmental Pediatrics Program, Early Access to Care – AZ, which aims to train medical professionals in the treatment of autism and comorbidities, hosted an autism comorbidities conference for medical professionals. Robin Blitz, MD, director of developmental pediatrics, and other faculty lectured on treating medical comorbidities in children with autism and providing medical home care to children with autism spectrum disorder. About 50 people attended the medical education event held on Jan. 9 and 10 at Phoenix Children’s Hospital. Congratulations to Dr. Blitz and her team for a great event!

In collaboration with the Fragile X Families of Phoenix and of Northern Arizona, Barrow at Phoenix Children’s hosted the Fragile X Workshop for parents, health professionals and community members in December. Dr. Blitz spoke at the conference with other experts.
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:
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• Make a memorial or honor gift
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For more information call Kelly Hurter at (602) 933-2675 or visitphoenixchildrens.com/DonateBarrow