BARROW Neurological Institute

PHOENIX CHILDREN'S Hospital

COMMITMENT

2015 ANNUAL REPORT

OUR MISSION

Improving the health and quality of life for children with neurological, behavioral and mental health diseases and disorders.

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In 2015, the neurosciences, neurosurgery and neurology continued to gain further national recognition as a Center of Excellence from the *U.S. News & World Report* Best Children's Hospitals ranking, attaining a designation as a top U.S. Children's Neuroscience Program with a ranking of number 14.

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The Translational Neurotrauma Research Program represents one research pillar within Barrow Neurological Institute at Phoenix Children's Hospital and the Department of Child Health at the University of Arizona College of Medicine – Phoenix and also involves collaboration with the Phoenix Veterans Affairs Health Care System.

27 ED

OUR VISION

To be recognized as the premier "Center of Excellence" and destination for management and cure of neurologically, behaviorally and mentally-related pediatric diseases and disorders by providing comprehensive, high-quality and patient and family-centered care; state-of-the-art clinical and translational research; and professional and community education.

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More than 20 patients with Down syndrome modeled the latest fashions during the Second Annual Downright Beautiful Fashion Show in 2015. The event raised more than $25,000 for the Pediatric Down Syndrome Clinic at Barrow at Phoenix Children's.

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41 MEET THE 2015-16 TEAM

Dear Friends of Barrow at Phoenix Children's,

Just a few years ago, we cast a vision for Phoenix Children's Hospital to be among the best children's hospitals in the country, nationally recognized for the most comprehensive pediatric care services in the Southwest region. We have done this by providing a full range of services solely dedicated to children, innovative research supported by leading clinical trials of new treatment and diagnostic methods, advanced education and training for clinical providers and effective advocacy for Arizona's children.

GROWTH AND CHANGE

This was another exciting year of growth and change at Phoenix Children's. We advanced our vision by expanding clinical programs, improving access to care with new locations across the state and continuing our focus on patient quality and safety.

The growth and achievements of Barrow Neurological Institute at Phoenix Children's Hospital play an important role in the fulfillment of our vision. Under the leadership of Dr. P. David Adelson, Barrow at Phoenix Children's has built a world-renowned reputation for exceptional care for children with neurological diseases and disorders.

This high level of care was recognized once again by ***U.S. News & World Report,*** **which named Barrow at Phoenix Children's to its 2015-2016 Best Children's Hospital ranking for neurology and neurosurgery. Most impressive was the leap from number 46 to number 14 in the country!** This designation assures parents that their child will receive the highest-quality care from a center with deep experience and comprehensive programs.

Cutting-edge research and state-of-the-art medical care will continue to play a vital role in the fulfillment of our vision. Research conducted right here at Phoenix Children's is contributing valuable knowledge and innovative treatments that have transformed the lives of children with rare and complex neurological disorders.

I am excited to share with you the 2015 accomplishments of Barrow at Phoenix Children's.

Sincerely,

Robert L. Meyer
President and Chief Executive Officer
Phoenix Children's Hospital

Dear Colleagues, Friends and Supporters,

It has once again been an exciting year at Barrow Neurological Institute at Phoenix Children's Hospital, and we're honored to share with you our 2015 Annual Report. This year's report details all the programs and clinics that have been developed or strengthened, as well as highlights the wonderful work of our unique neuroscience research programs, dedicated to improving pediatric neurological and mental health care.

All of us here at Barrow at Phoenix Children's continue to work to achieve our mission of improving the health and quality of life for children with neurological, behavioral and mental health disorders and diseases, as it reflects the inspiration we garner from the children. Their courage and tenacity continually inspire us to seek out and develop new understanding of the diseases and disorders they face. We seek to apply state-of-the-art care and novel therapeutic strategies to their treatment, and we also strive every day to provide the best possible environment for recovery with patient and family mental health support.

Within this year's annual report, you'll read about Daniel, a small boy with near-constant seizures, who underwent neurosurgery to try to achieve a cure and improve his quality of life. Similarly, Tommy, who survived a severe traumatic brain injury after a motorbike accident, who benefited from the depth and breadth of clinical knowledge of our team and the cutting-edge research that was translated from the lab directly to the patient's bedside. In addition, we give you an ongoing glimpse inside our clinical programs, our innovative research initiatives that have become a part of our day-to-day patient care, and the professional and community educational outreach opportunities we have developed to create a more informed support community for each and every child that we care for here at Barrow at Phoenix Children's.

COURAGE AND TENACITY

It is not about a single physician, a single nurse, a single subspecialty or a single administrator. It takes teams of specialists at all levels, dedicated to working together to treat the complex diseases and disorders that we see at Barrow at Phoenix Children's. Our staff includes some of the most respected physicians and scientists in the areas of neurology, neurosurgery, developmental pediatrics, psychology, psychiatry, neuroradiology, physical medicine, neuro-oncology and research, but also committed and specialized individuals in nursing, rehabilitation, medical assistance, social work and administrative staff who create the healing environment and support for these children.

Our advancements in 2015 represent not just a tribute to all of those individuals who have worked hard to improve the health and quality of life for our patients but also to our ongoing commitment to children now and in the future.

From all of us at Barrow at Phoenix Children's, we thank you for sharing in our mission and for all of your support this year and into the future! If you are interested in learning more about our programs, educational opportunities and research activities, I encourage you to visit our website at barrow.phoenixchildrens.org or contact me at dadelson@phoenixchildrens.com.

Sincerely,

P. David Adelson, MD, FACS, FAAP
Director, Barrow Neurological Institute at Phoenix Children's Hospital
Diane and Bruce Halle Endowed Chair in Pediatric Neurosciences
Chief, Pediatric Neurosurgery

ABOUT THE INSTITUTE

Barrow Neurological Institute at Phoenix Children's Hospital cares for children with neurological and behavioral disorders. In 2015, the neurosciences, neurosurgery and neurology continued to gain further national recognition as a Center of Excellence from the *U.S. News & World Report* Best Children's Hospitals ranking, attaining a designation as a top Children's Neuroscience Program with a ranking of number 14.

Recognizing the importance of not just the ability to diagnose and treat a particular disease or disorder, it was important to bring behavior and mental health for the children and their families within our circle of care to truly ensure and improve their quality of life. Our collaborative and comprehensive approach to medicine across disciplines, education and research has resulted in Barrow at Phoenix Children's being the largest pediatric neuroscience center in the Southwest. We are proud to be one of the few hospitals to offer pediatric neurological, behavioral, psychiatric and neurosurgical care and rehabilitation in one central location.

Barrow at Phoenix Children's is committed to continually improving care through research and education. We are unwavering in this commitment to providing comprehensive care through our team of nationally recognized neuroscience experts to ensure Barrow at Phoenix Children's offers state-of-the-art, individualized patient care.

OUR STAFF

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

Randall Ricardi, DO
Interim Division Chief,
Psychiatry

Sauder Bernes, MD
Interim Division Chief,
Neurology

Michael Lavoie, PhD
Division Chief,
Psychology and
Neuropsychology

Robin Blitz, MD
Director,
Developmental Pediatrics

2015 BY THE NUMBERS

299 PATIENTS TREATED FOR STROKE BY PEDIATRIC NEUROCRITICAL CARE PROGRAM

286 PATIENTS TREATED IN THE JAYDIE LYNN KING NEURO-ONCOLOGY PROGRAM

641 NEONATAL PATIENTS TREATED BY NEUROLOGISTS

793 PATIENTS TREATED FOR SPINE-RELATED CONDITIONS

2,712 PATIENTS TREATED IN THE HEADACHE CLINIC

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44 PATIENTS SURGICALLY TREATED FOR CHIARI I MALFORMATION

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5 NURSE PRACTITIONERS

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Craniofacial
PROGRAM

Craniofacial abnormalities are conditions that affect the shape and look of the face or head and can be present at birth or occur after injury. They often cause speech, vision or auditory difficulties.

The Craniofacial Program at Barrow Neurological Institute at Phoenix Children's Hospital is a comprehensive program focused on providing multidisciplinary care in the evaluation, management and treatment for infants and children with craniofacial abnormalities.

Ruth Bristol, MD, is the co-director of the Craniofacial Program at Barrow at Phoenix Children's Hospital along with Davinder Singh, MD, division of plastic surgery. They use minimally-invasive and endoscopic techniques whenever possible to treat craniofacial abnormalities.

The program also includes a dedicated team of pediatric plastic surgeons; audiologists; psychologists; geneticists; dental specialists; ear, nose and throat specialists; and speech pathologists who collaborate to help patients and their families. Patients and their families are able to see all of these specialists in one day. The team also meets monthly to discuss patient care, new treatment techniques and related research, as well as educational opportunities that apply to the program.

There are a number of conditions that are considered craniofacial abnormalities, including cleft lip and palate, which are among the most common of all birth defects, according to the National Institutes of Health, and craniosynostosis, a condition in which the bones on a baby's head close earlier than usual. Other problems are less common in the general population, but seen frequently by our team, such as hemifacial microsomia, ankylosis of the temporomandibular joint, Pierre-Robin sequence and the side effects of trauma.

In infants with craniosynostosis, changes in the shape of the head and face may be noticeable and are usually the first and only symptom. The appearance of the child's face may not look the same when both sides are compared to one another. Another sign may be

the existence of ridging along the abnormal growth plate. Craniosynostosis can lead to not only a misshapen head, but can also, in some of the more complicated syndromes, involve other organ systems and possibly lead to increased intracranial pressure, impacting development.

The conditions are most often diagnosed after a physical examination. Sometimes diagnostic testing, such as a computed tomography scan (CT or CAT scan) or magnetic resonance imaging scan (MRI) are ordered, but these are not always necessary. During the exam, a measurement of the circumference of the child's head is taken and plotted on a graph to identify normal and abnormal ranges. The cephalic index is also calculated to determine where and the extent by which the shape is abnormal.

Craniofacial conditions include:

- Apert's, Crouzon's and Pfeiffer's syndromes
- Cleft lip and palate
- Single suture and multi-suture craniosynostosis
- Goldenhar syndrome
- Jaw fractures
- Hemifacial microsomia
- Facial injury from trauma and dog bites
- Temporomandibular joint ankylosis
- Macroglossia
- Plagiocephaly or flattened head

CRANIOFACIAL PROGRAM BY THE NUMBERS

628
PATIENTS EVALUATED IN THE CRANIOFACIAL PROGRAM CLINIC

64
PATIENTS UNDERWENT SURGERIES FOR CRANIOSYNOSTOSIS

Everleigh

"WE APPRECIATE EVERYONE AT PHOENIX CHILDREN'S HOSPITAL AND BARROW NEUROLOGICAL INSTITUTE. EVERLEIGH IS EVERYTHING SHE'S SUPPOSED TO BE, AND IT'S BECAUSE OF THEM."

– SANDY FINDLAY, EVERLEIGH'S MOTHER

From the day Everleigh Findlay was born, her mother Sandy knew something wasn't quite right.

"Her head was definitely different," Sandy recalled. "I just thought, 'oh no.'"

Everleigh was the third child born to Sandy and Robby Findlay, who live in Flagstaff. When her brothers Kingston and Krew were born, neither one had any issues with the shapes of their heads. But Everleigh was different.

"Her temples looked very pinched," Sandy said, "like her little brain had nowhere to go."

Just days after she was born, Sandy took the newborn to a routine appointment with a doctor, who told her Everleigh had craniosynostosis, a condition in which the bones of the skull prematurely fuse together and change the shape of the head. The little girl would need surgery.

Sandy and Robby consulted a craniofacial specialist in Flagstaff, who recommended a major surgery that would cause a large incision and a long recovery time.

"She's our baby girl," Sandy said, "so I said no way we wanted to do that."

Instead, Sandy began to search the country for a craniofacial specialist to care for Everleigh. They talked to specialists in Boston, California and Washington and then they found a premier craniofacial specialist in Arizona, Ruth Bristol, MD, neurosurgeon and director of the Craniofacial Program at Barrow at Phoenix Children's Hospital.

The Craniofacial Program at Barrow at Phoenix Children's is comprised of a multidisciplinary team of neurosurgeons; plastic surgeons; audiologists; psychologists; ear; nose and throat (ENT) physicians; speech pathologists; and other specialties to provide the unique, comprehensive care these children require.

Sandy drove the two hours south to Phoenix to meet Dr. Bristol. While the more invasive surgery was a reasonable and old way of doing things, she suggested a less invasive, more state-of-the-art surgery to correct Everleigh's head shape.

The family knew they'd have many long car trips so Everleigh could receive the initial care and follow-up treatment she needed.

"We were literally willing to go anywhere," Sandy said. "And we picked Dr. Bristol. I couldn't be happier that we did. They turned something so sad into something so beautiful."

At just three months old, Everleigh underwent a successful neurosurgery. During the procedure, Dr. Bristol removed the fused bones along the top of Everleigh's skull and created space for her head to grow normally. Dr. Bristol worked alongside Stephen Beals, MD, another craniofacial neurosurgeon and director of the Craniofacial Program at Barrow Neurological Institute at Dignity Health St. Joseph's Hospital and Medical Center.

Within three days, the family returned to their Flagstaff home for recovery.

Everleigh was also fitted with a special helmet, decorated with flowers and polka dots, which helped protect and reshape her head. For several months afterward, she and Sandy traveled weekly to Phoenix to have the helmet refitted.

"I got that alone time with her," Sandy said about their frequent road trips. "It was nice to have that special time with her."

Today, Everleigh only has to see Dr. Bristol annually until the age of 5. She's an energetic and happy 18-month-old who adores her two brothers. The only indication of her former condition is a nearly invisible scar on the top of her head that's well-hidden by her brown, curly locks of hair.

"We appreciate everyone at Phoenix Children's Hospital and Barrow Neurological Institute," Sandy said. "Everleigh is everything she's supposed to be, and it's because of them."

Watch a video of Dr. Bristol explaining the Craniofacial Program at barrow.phoenixchildrens.org/annualreport.

Early Access to Care - AZ
PROGRAM

Arizona has one of the highest rates of autism across the United States. One in 64 children living in the state has autism spectrum disorder, according to the Centers for Disease Control.

In addition, in order for children with autism to receive medically necessary services and interventions, Arizona's Division of Developmental Disabilities of the Department of Economic Security (DDD) requires the diagnosis of autism to be determined only by a developmental pediatrician, licensed clinical psychologist or child psychiatrist.

Meanwhile, there are few developmental pediatricians in Arizona, and most are located within Maricopa County, forcing children who live elsewhere in the state to compete for appointments and delay early diagnosis.

But thanks to grant funding and a vision created by Robin Blitz, MD, director of developmental pediatrics at Barrow Neurological Institute at Phoenix Children's Hospital, Early Access to Care – AZ (EAC-AZ) seeks to remove these roadblocks by training physicians across the state in how to assess children for autism and provide them with a medical home.

Created in 2015, EAC – AZ is a program that trains medical providers around the state to diagnose and treat children with autism. The program provides training and support for regional teams across Arizona. Each team consists of a pediatrician, an Arizona Early Intervention Program provider and a school representative. Team members are trained in using tools and scales to screen for autism in children.

After a provider completes the program, Dr. Blitz works to get the pediatricians' diagnoses approved for DDD services, thus providing much-needed early access to medical intervention, therapies and school services to children living in the Phoenix area and across Arizona. The Board of Visitors, a charitable organization in Phoenix that supports the health care needs of women, children and the elderly, has provided financial support to the program.

"I am so encouraged and excited about the interest and dedication that our EAC – AZ pediatricians have demonstrated in participating in the trainings and with helping to provide high quality care to children with autism," Dr. Blitz said. "Our hope is that EAC – AZ will change the landscape for children with autism and their families in Arizona, by providing earlier diagnosis and access to interventions and medical homes, resulting in better outcomes for our children and support for their families."

The first teams began training in August 2015, and the second cohort of pediatricians began in January 2016. So far, EAC – AZ has trained 12 providers in the regions of Casa Grande, Flagstaff, Lake Havasu, Pinetop-Lakeside, Prescott Valley, Tucson, Yuma and Maricopa. The second cohort consists of 11 pediatricians in Maricopa County and one in Cottonwood.

EAC – AZ is open to board-certified pediatricians across Arizona. The six-month training course for primary care providers consists of learning modules, independent readings, webinars, online case discussions and two in-person trainings at Phoenix Children's.

FOR MORE INFORMATION ON PARTICIPATING IN EAC-AZ, PLEASE CONTACT EARLYACCESSTOCAREAZ@PHOENIXCHILDRENS.COM.

AUTISM PROGRAM BY THE NUMBERS

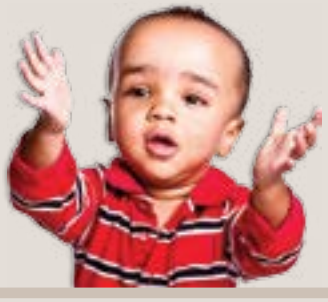
1 in 64
CHILDREN IN ARIZONA HAVE AUTISM

1 in 68
CHILDREN IN THE U.S. HAVE AUTISM

4 years
AVERAGE AGE OF AN AUTISM DIAGNOSIS NATIONALLY

4 years, 10 months
AVERAGE AGE OF AN AUTISM DIAGNOSIS IN ARIZONA

18-24 months
IDEAL AGE OF AN AUTISM DIAGNOSIS



433
PATIENTS EVALUATED IN THE AUTISM PROGRAM CLINIC IN 2015

23
MEDICAL PROVIDERS FROM ACROSS ARIZONA ENROLLED IN EARLY ACCESS TO CARE – AZ TRAINING IN 2015 AND 2016

6 months
HOW LONG IT TAKES FOR PRIMARY CARE PROVIDERS TO COMPLETE THE EARLY ACCESS TO CARE – AZ TRAINING PROGRAM

Pediatric Epilepsy PROGRAM

EPILEPSY BY THE NUMBERS

1,093
PATIENTS EVALUATED FOR EPILEPSY

2,517
PATIENTS UNDERWENT STANDARD EEG EVALUATIONS FOR EPILEPSY

The epilepsy specialists, neurosurgeons and dieticians who make up the comprehensive Pediatric Epilepsy Program at Barrow Neurological Institute at Phoenix Children's Hospital are dedicated to finding the best solutions for children with epilepsy and other seizure disorders.

All five of our pediatric epilepsy specialists are board-certified for the advanced expertise needed for providing epilepsy care and electroencephalography (EEG) services.

Barrow at Phoenix Children's has the only comprehensive epilepsy program for children in Arizona. In 2015, the Program was again certified as a Level 4 Epilepsy Center, the highest level designated by the National Association of Epilepsy Centers (NAEC). It is the only pediatric Level 4 Epilepsy Center in Arizona.

The program, led by John Kerrigan, MD, uses evidence-based anti-epilepsy medications, alternative therapies like the ketogenic diet, epilepsy surgery and state-of-the-art technologies, including vagus nerve stimulation, to control seizures and improve quality of life.

In addition, the Pediatric Epilepsy Monitoring Unit (PEMU) at Barrow at Phoenix Children's is a specialized inpatient unit outfitted with the latest in video and audio equipment to capture seizure activity while the patient's brain waves are recorded simultaneously on the EEG to make the most accurate diagnoses for the patient. The PEMU is the only such pediatric unit in Arizona. Lastly, our Hypothalamic Hamartoma (HH) Program is a destination center for patients from around the world who have this rare disease.

As with all the programs at Barrow at Phoenix Children's, research is a priority with efforts in new drug development, including scientific investigation of compounds derived from medical marijuana, computational analysis of EEG wave forms, brain protection from the cellular injury that can result from seizures and differential EEG monitoring in critically ill children in the intensive care unit. We are also active and collaborative with community organizations including the Epilepsy Foundation of Arizona to increase the knowledge base for better advocacy for these children.

553

PATIENTS ADMITTED TO THE PEDIATRIC EPILEPSY MONITORING UNIT

Epilepsy and the Ketogenic Diet

For children with epilepsy that is not easily controlled by medication and for whom neurosurgery may not be an option, Barrow Neurological Institute at Phoenix Children's Hospitals offers an alternative.

The ketogenic diet is one of the primary options patients are offered as part of the comprehensive Pediatric Epilepsy Program at Barrow at Phoenix Children's, especially in children who do not respond to standard therapy and medicines. It is a safe and effective method of treatment for epilepsy that requires a diet high in fat, moderate in protein and low in carbohydrates.

The diet is a time-tested, safe and effective method for the treatment of epilepsy. It is considered a medical nutrition therapy diet that is intended to be used in conjunction with or in place of seizure medications to help control seizures. It is a precisely calculated diet that is intended to be used in coordination with the child's prescribed medication. Calculations of the diet are based on the child's age, height and weight. It provides enough calories and other nutrients for the child to grow and is designed so the body uses fat for energy instead of sugar.

The goal of the diet is to reduce the number and intensity of seizures. Improvement in seizure control is achieved in more than 50 percent of patients, with nearly one-third of children experiencing complete seizure control. In addition to seizure treatment, children on the diet also often experience increased alertness and attentiveness.

The ketogenic diet is most effective in children with atonic or drop seizures, myoclonic seizures, generalized tonic-clonic seizures, multi-focal as in Lennox-Gestaut and seizures related to structural abnormalities of the brain such as prenatal stroke and migration abnormalities.

The ketogenic diet can also be used in acute and emergent situations such as status epilepticus.

At Barrow at Phoenix Children's, the Ketogenic Diet Program is coordinated by dieticians Lisa Vanatta, MS, RDN, CSP, and Kelly Kolp, RD, CNSC, and epilepsy neurologist Randa Jarrar, MD.

"As ketogenic dietitians, we save lives," Vanatta said. "We may not be able to do neurosurgery, but when there are patients in status epilepticus in the Pediatric Intensive Care Unit who are not eligible for surgical treatment and have failed all the other medical therapy, we can help.

"It is up to the ketogenic dietitian with clinical expertise to implement this very specialized medical nutrition therapy for these patients."

Because of the complexity of this diet, supervision by an expert team including the medical practitioner and dietician is required. As this diet cannot be provided just anywhere, our experts treat patients from across the country.

When first starting on the diet, it may take up to three months for it to be effective. Because of the restrictive nature of the diet, it's not for every patient. Taking on the diet often means change for the entire family. At Barrow at Phoenix Children's, the program dieticians will help develop meal plans and recipe ideas for the patient and family.

In 2015, Barrow at Phoenix Children's treated more than 40 patients who were prescribed the ketogenic diet.

For more information about the ketogenic diet and the Pediatric Epilepsy Program, visit barrow.phoenixchildrens.org.

RELATED PEER-REVIEWED PUBLICATIONS

Wu J(1), Gao M, Shen JX, Qiu SF, Kerrigan JF. Mechanisms of intrinsic epileptogenesis in human gelastic seizures with hypothalamic hamartoma. CNS Neuroscience & Therapeutics, 21 (2):104-111. Feb. 2015.

Semaan S(1), Wu J, Gan Y, Jin Y, Li GH, Kerrigan JF, Chang YC, Huang Y. Hyperactivation of BDNF-TrkB signaling cascades in human hypothalamic hamartoma. CNS Neuroscience & Therapeutics, 21 (2):164-172. Feb. 2015.

Yang A(1), Arndt DH(2), Berg RA(3), Carpenter JL(4), Chapman KE,...Williams K, et, al. Development and validation of a seizure prediction model in critically ill children. Seizure. 2015, Feb; 25: 104-11. Feb., 2015.

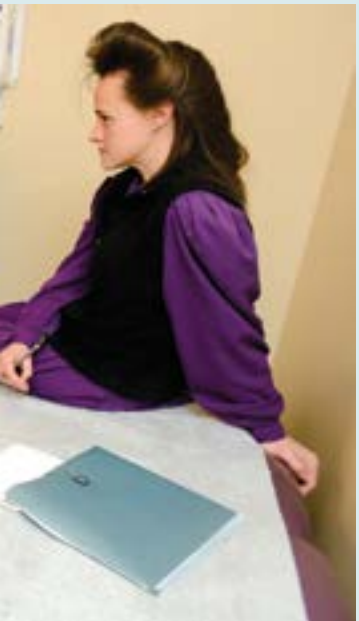
Appavu B, Mangum T, Obeid, M. Glucose transporter 1 deficiency: A treatable cause of opsoclonus and epileptic myoclonus. Pediatr Neurol. 2015 Oct, 53(4):364-6. Oct., 2015.

50%

OF PATIENTS ON THE KETOGENIC DIET HAVE IMPROVED SEIZURE CONTROL

40

PATIENTS TREATED WITH KETOGENIC DIET IN 2015



RELATED CLINICAL TRIALS, REVIEWS AND OBSERVATIONAL STUDIES

Clinical Trials

Spatiotemporal Evolution of Epileptic Seizures Using ECoG and EEG
P. David Adelson, MD

The purpose of this study is to elucidate novel information regarding seizure propagation from a quantitative perspective using signal and image processing techniques on ECoG data collected during ictal periods. Further, the study will analyze EEG data to ascertain if the methods used on ECoG data can determine if the patient is a candidate for resection surgery prior to ECoG grid implantation.

Macro and Micro Electrocorticography in Cortical Interfacing
P. David Adelson, MD

The purpose of this study is to improve our understanding of the significance and limitations of using electrocorticography for epilepsy monitoring. Signals collected will be evaluated to determine whether microelectrode grids are suitable tools for the clinical diagnosis and characterization of seizure disorders, for understanding how the brain encodes complex movement and for function restoration efforts.

Examining the Mechanisms of Epileptogenesis in Tissue Resected from Pediatric Patients
Jorge Arango, MD

The purpose of this study is to learn about the different characteristics of epileptic brains. Information learned from this study will help clinicians improve treatment for children with epilepsy that does not respond to medication.

Restrospective Reviews

Ketogenic Diet for Status Epilepticus
Randa Jarrar, MD

The purpose of this study was to describe the experience at Phoenix Children's Hospital of patients with super-refractory status epilepticus who underwent ketogenic diet therapy.

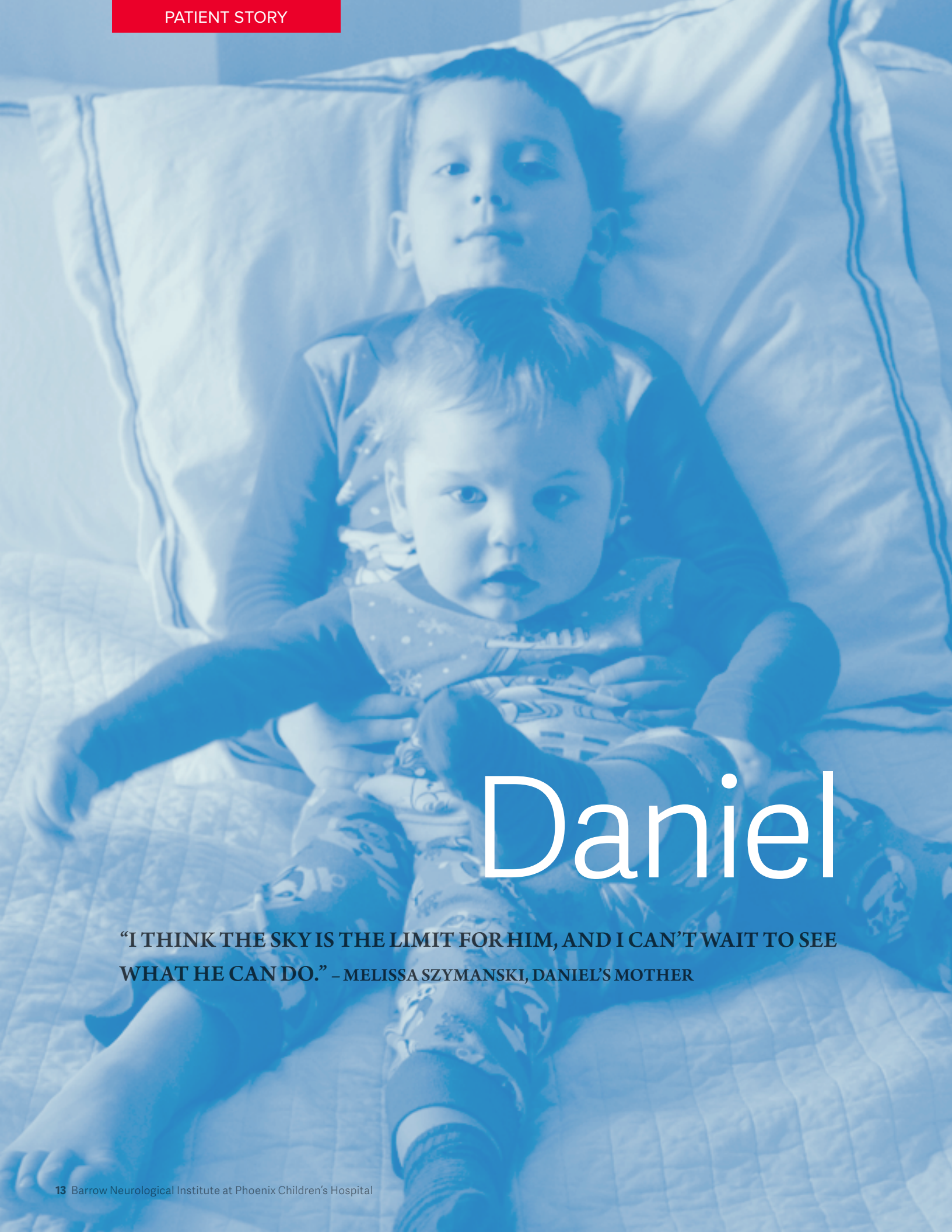
Treatment of Infantile Spasms with Prednisone versus Prednisone and Topamax
Randa Jarrar, MD

The purpose of this study was to determine if there was a difference in outcomes between two treatment regimens for Infantile Spasms. The results of this study may help to direct new treatment practices for children with this disorder.

Observational Studies

pSERG's Outcome in Status Epilepticus
Korwyn Williams, MD

The purpose of this study is to gather information on signs and symptoms of status epilepticus, the hospital course during treatment and how patients respond to different treatments.



Daniel

"I THINK THE SKY IS THE LIMIT FOR HIM, AND I CAN'T WAIT TO SEE WHAT HE CAN DO." – MELISSA SZYMANSKI, DANIEL'S MOTHER

When Daniel Szymanski was born, there was no hint that his brain was different than any other infant. His family had no idea the medical tests or neurosurgery he would undergo at a young age.

The first indication that something was wrong was when, at just four weeks old, he had his first seizure. Daniel's parents, Melissa and Michael, took him to a pediatrician who encouraged them to take him immediately to Barrow Neurological Institute at Phoenix Children's Hospital.

Once there, they met with Randa Jarrar, MD, a neurologist and epileptologist with Barrow at Phoenix Children's. She immediately began running extensive tests on Daniel. The testing lasted late into the night, and the results finally gave Michael and Melissa the answers they were seeking about what was wrong with their young son. The left side of his brain was abnormal.

The next morning, he was officially diagnosed with polymicrogyria, a malformation of the brain that can cause developmental delays and intractable seizures. The right side of Daniel's brain seemed to be functioning normally, while the left side was smaller, malformed and was likely causing the seizures.

"We were devastated, crying, scared," Melissa recalls about hearing the diagnosis.

Dr. Jarrar initially prescribed medication for Daniel to control the seizures and scheduled him to return to Barrow at Phoenix Children's for further testing in the Pediatric Epilepsy Monitoring Unit (PEMU), a specialized inpatient unit that uses cutting-edge technology to study seizures in order to provide a more accurate diagnosis of the types of epilepsy in children.

By the time Daniel returned and was studied in the PEMU a few months later, he no longer had any seizures. Dr. Jarrar took him off medication and sent him home. He went seven months without a seizure.

"He was doing really well," Melissa said.

Then in the summer of 2015, Daniel had a growth spurt, and with that development came the return of the seizures.

"He went haywire," Melissa said. "He was having more seizures, they were lasting longer and they turned into infantile spasms."

Daniel was having near-continuous seizures each day, and steroids and different medicines didn't seem to help. Dr. Jarrar asked them to return to the PEMU where they documented and characterized Daniel's seizures.

"Dr. Jarrar said we need to do something quick," Melissa said. "We were told he was an excellent candidate for a cerebral hemispherotomy."

P. David Adelson, MD, chief of pediatric neurosurgery and director of Barrow at Phoenix Children's, told the family that through this surgery, he aimed to stop the left side of Daniel's brain from causing seizures.

"A child as young as three or four months of age can undergo that procedure and benefit from it," Dr. Adelson said.

Before the surgery, Melissa and Michael researched the procedure and Barrow at Phoenix Children's, to make sure it was the right place for Daniel to be treated.

"We talked about going elsewhere if we had to," Michael said.

But they didn't have to.

"We knew this was the right place," Melissa said. "I researched and made sure we were at the right hospital, that it was the best at this surgery. I knew we were."

At Barrow at Phoenix Children's, patients like Daniel are treated by an entire team of specialists.

"When someone has medically intractable seizures, they need a whole team of people which includes pediatric neurology, neuroradiology and neurointensive care – basically the whole gamut," Dr. Adelson said. "That's why we have Barrow at Phoenix Children's, so we can bring together all those subspecialists."

Dr. Adelson successfully performed the hemispherotomy on Daniel in November of 2015.

"We knew surgery was the right call," Michael said. "It was more about what was going to happen when he woke up."

Shortly after the surgery, Daniel began moving both sides of his body.

"He's still talking and wiggling and laughing," Melissa said. "He's eating normally."

Going forward, Daniel will continue to be treated by Dr. Jarrar and will undergo physical therapy. His future is still unknown, but after surgery, he has every chance to live a full life.

"We have great therapists who we work with and great doctors," Melissa said. "They all say he has the best possible chance to walk and talk and run around outside in the backyard. I think the sky is the limit for him, and I can't wait to see what he can do."

Listen to Daniel's story in his parents' own words at barrow.phoenixchildrens.org/annualreport.

Movement Disorders

AND RESEARCH OVERVIEW

In 2015, Michael Kruer, MD, joined Barrow Neurological Institute at Phoenix Children's Hospital to grow its programs in the area of movement disorders. He is a board-certified pediatrician, child neurologist and neurodevelopmentalist specializing in movement disorders in children, as well as neurogenetics.

Dr. Kruer is the director of the Cerebral Palsy and Pediatric Movement Disorders Program (PMD) at Barrow at Phoenix Children's, which provides comprehensive diagnosis and management for young patients with neurodevelopmental and neurodegenerative disorders that affect movement. Conditions treated by the program include cerebral palsy, tic disorders, tremor, ataxia, dystonia, chorea, gait disorders, myoclonus and juvenile parkinsonism.

Comprehensive 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 our experts to use video, kinematics and surface electromyography (EMG) to characterize movement disorders accurately in order to create customized treatments for patients.

Once a diagnosis had been made, we offer comprehensive medical and surgical options, including medications, rehabilitation, botulinum toxin injections, dorsal rhizotomy and an intrathecal baclofen pump program. Barrow at Phoenix Children's also has one of the few pediatric deep brain stimulation programs in the country. The program is a collaboration with the Muhammad Ali Parkinson Center at Barrow Neurological Institute at Dignity Health St. Joseph's Hospital and Medical Center and Barrow Neurosurgical Associates.

Research is a core part of the mission of the Cerebral Palsy and Pediatric Movement Disorders Program. The next generation of diagnostics and treatments will only be made possible through research. Accordingly, every family visiting the PMD Program is given the opportunity to participate in our ongoing clinical or translational research projects. Dr. Kruer's research laboratory team studies the neurogenetic basis of pediatric movement disorders. New research led by Sergio Padilla-Lopez, PhD, director of the Barrow at Phoenix Children's Molecular and Cellular Neurogenetics Research Laboratory, has uncovered core cellular mechanisms that led to a new class of pediatric brain diseases: The epileptic-dyskinetic encephalopathies.

Another key accomplishment in 2015 was the discovery of a new lysosomal storage disorder caused by mutations in the trafficking gene AP5Z1, achieved through collaboration with colleagues at the University of Cambridge and the National Institutes of Health. Research in the program is supported by the Phoenix Children's Hospital Foundation, the Doris Duke Foundation and the National Institute of Neurological Diseases and Stroke.

The PMD Program 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 consensus 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

MOVEMENT DISORDERS BY THE NUMBERS

1,670
PATIENTS EVALUATED IN THE MOVEMENT DISORDERS CLINIC

592
PATIENTS EVALUATED AND TREATED FOR CEREBRAL PALSY AND SPASTICITY

is the Complex Tourette Syndrome Clinic, in which patients struggling with tics and/or comorbidities receive detailed recommendations from specialists in psychology, neurology and psychiatry in a single visit.

This program is in a stage of rapid growth and exciting new clinical and research programs are in development. These include a proposed juvenile Huntington Disease program and new research initiatives using precision medicine to develop novel therapies for cerebral palsy.

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 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.

RELATED PEER-REVIEWED PUBLICATIONS

Snijders Blok L(1), Madsen E(2), Juusola J(3), Gilissen C(1), Baralle D(4)...Kruer MC et al. Mutations in DDX3X Are a Common Cause of Unexplained Intellectual Disability with Gender-Specific Effects on Wnt Signaling Am J Hum Genet. 2015 Aug 6;97(2):343-52. Aug., 2015.

Hirst J(1), Edgar JR(2), Esteves T(3), Darios F(4), Madeo M(5)...Kruer MC, et al. Loss of AP-5 results in accumulation of aberrant endolysosomes: defining a new type of lysosomal storage disease Hum Mol Genet. 2015 Sep 1;24(17):4984-96. Sep., 2015.

Zarate YA, Jones JR, Jones MA, Millan F, Juusola J, Vertino-Bell A, Schaefer GB, Kruer MC. Lessons from a pair of siblings with BPAN. Eur J Hum Genet. Nov., 2015.

RELATED OBSERVATIONAL STUDIES

Identifying Novel Causes of Idiopathic Neurological Syndromes
Michael Kruer, MD

The purpose of this research study is to further our understanding of and identify the etiology of idiopathic neurological syndromes.

Gene Discovery in Inherited Neurological Diseases
Michael Kruer, MD

The purpose of this research study is to identify novel genetic causes of pediatric neurological disorders and characterize their pathophysiology. In so doing, we will not only substantially inform clinical diagnosis, but will enable future studies that focus on developing targeted therapies.

Traumatic Brain Injury and Neurotrauma

RESEARCH

The Translational Neurotrauma Research Program (TNRP) is a partnership between Barrow Neurological Institute at Phoenix Children's Hospital and the Department of Child Health at the University of Arizona College of Medicine – Phoenix.

We aim to be a destination for translational neurotrauma research, training and clinical care, to improve the quality of life of those with acquired neurological injury who are treated at Barrow at Phoenix Children's.

Translational research investigates clinically relevant questions, typically in a basic science laboratory, to provide new knowledge, protocols and devices that empower clinical providers to improve the quality of life of patients. The communication between scientists, investigators and clinicians advances patient care and improves lives.

To conduct translational neurotrauma research, scientists must first identify gaps in our knowledge of the pathophysiology that occurs after traumatic brain injury (TBI) and how these processes can be manipulated to improve clinical outcomes. Our scientists use clinically relevant models of disease, particularly TBI, to expand our understanding, with the goal of translating findings to clinical care. These models possess the necessary relationships between neurons, blood vessels and support cells that are found in humans, providing means to model the effects of TBI, with the application of controlled mechanical force. The ensuing cellular pathophysiology, as well as the accompanying neurological changes after experimental TBI, permit investigations aimed at advancing academic medicine.

Our TNRP scientists work within the framework that TBI disrupts the neuronal network within the brain that mediates cognitive, emotional and sensory processing. Damaged cells can survive, but go through a number of reparative and regenerative processes in an effort to restore the functions prior to TBI.

More often than not, the brain repairs itself successfully by reconnecting neurons into the correct network (adaptive plasticity). Other times, repair connects neurons into the wrong network, effectively rewiring the brain, and leading to problems in how we think, react and feel (maladaptive plasticity).

Research led by TNRP faculty member, Theresa Currier Thomas, PhD, seeks to understand how disrupted networks repair themselves by mapping the time course of network reconnection, and determining the mechanisms that control when and how these reparative processes promote network reconnection.

As the team learns when and how reparative processes occur after TBI, they can manipulate processes by preventing the wrong connections with drug interventions. The goal is to minimize maladaptive plasticity. However, adaptive plasticity needs to be promoted to optimize neurological outcome.

Studies on treatments to minimize maladaptive plasticity are being combined with rehabilitation strategies to promote adaptive plasticity. Additionally, these studies are searching for biomarkers that will guide the timing of drug delivery or start of rehabilitation in order to maximize clinical therapies geared towards patient outcome. At the same time, these biomarkers provide additional methods to measure the efficacy of therapeutic interventions.

Treatment strategies that prove effective in experimental models can aid physicians in managing clinical care for TBI patients. The goal of our translational research is to inform clinical decision-making to modify diagnosis, prognosis and treatment to improve outcomes from acquired neurological injury, including TBI.

975

PATIENTS EVALUATED AND TREATED FOR TRAUMA AND POST-CONCUSSION

9

PEER-REVIEWED PUBLICATIONS ABOUT TRAUMA AND CONCUSSIONS

3

STUDIES RELATED TO TRAUMATIC BRAIN INJURY

RELATED PEER-REVIEWED PUBLICATIONS

Spritzer SDA(1), Kinney CL, Condie J, Wellik KE, Hoffman-Snyder CR, Wingerchuk DM, Demaerschalk BM. Amantadine for patients with severe traumatic brain injury: A critically appraised topic. Neurologist. Jan., 2015.

Buttram SD(1), Garcia-Filion P(2), Miller J(3), Youssfi M(3), Brown SD(4), Dalton HJ(5), Adelson PD(6). Computed tomography vs magnetic resonance imaging for identifying acute lesions in pediatric traumatic brain injury. Hosp Pediatr. Feb., 2015.

Nichols J(1), Perez R, Wu C, Adelson PD, Anderson T. Traumatic brain injury induces rapid enhancement of cortical excitability in juvenile rats. CNS Neurosci Ther. Feb., 2015.

Ziebell JM(1), Adelson PD, Lifshitz J. Microglia: dismantling and rebuilding circuits after acute neurological injury. Metab Brain Dis. April, 2015.

Khodadad A(1), Adelson PD(2), Lifshitz J(3), Thomas TC(4). The time course of activity-regulated cytoskeletal (ARC) gene and protein expression in the whisker-barrel circuit using two paradigms of whisker stimulation. Behav Brain Res. May, 2015.

Chin KH(1), Bell MJ, Wisniewski SR, Goundappa BG, Kochanek PM, Beers SR, Brown SD, Adelson PD. Effect of administration of neuromuscular blocking agents in children with severe traumatic brain injury on acute complication rates and outcomes. Behav Brain Res. May, 2015.

Adelson PD. Editorial: Severe traumatic brain injury and decompressive craniotomy. J Neurosurg Pediatr. July, 2015.

Harrison JL(1), Rowe RK(2), Ellis TW(3), Yee NS(4), O'Hara BF(5), Adelson PD(1), Lifshitz J(6). Resolvins AT-D1 and E1 differentially impact functional outcome, post-traumatic sleep, and microglial activation following diffuse brain injury in the mouse. Brain Behav Immun. July, 2015.

Ziebell JM, Rowe RK, Harrison JL, Eakin KC, Colburn T, Willyerd FA, Lifshitz J. Experimental diffuse brain injury results in regional alteration of gross vascular morphology independent of neuropathology. Brain Inj. Dec., 2015.

RELATED REVIEWS AND OBSERVATIONAL STUDIES

Retrospective Reviews

Comparative Assessment of Severe Pediatric TBI Management Between Developed and Developing Country Institutions
P. David Adelson, MD

The purpose of this study was to describe the differences in TBI management between two institutions – one in the United States and one in Colombia. This study also compared short and long term outcomes of children managed at each institution.

Do Traumatic Brain Injuries Correlate with Subsequent Development of Endocrine Disorders in Children?
Jonathan Lifshitz, PhD

The purpose of this study was to describe the prevalence and demographic make-up of children who develop endocrine dysfunction after suffering a traumatic brain injury.

Observational Studies

Approaches and Decisions for Acute Pediatric TBI (ADAPT) Trial
Sandra Buttram, MD

The purpose of this study is to learn the best way to take care of a child with a severe traumatic head injury.

Tommy

"WE CHOOSE TO SPECULATE ON THE POSITIVE END. HE HASN'T GIVEN UP ON HIS DREAMS; HIS PLATE IS FULL." – MARIANNA ROBERTSON, TOMMY'S MOTHER

The moment life changed for Tommy Robertson was the day in July 2015 when he went for a ride on his motorized dirt bike, like he always did.

He was with one of his two brothers, who filmed Tommy as he performed jumps. During one of those leaps, Tommy and his bike went over a hill and he disappeared from sight. He didn't get back up.

It isn't clear how Tommy was injured, but it was obvious that he suffered a traumatic brain injury after his bike crashed.

His brother and father called for help and the teenager was rushed to Phoenix Children's Hospital. The prognosis wasn't good.

"The doctors weren't sure he would survive," said Marianna Robertson, Tommy's mother.

Because of the expertise of the Phoenix Children's Level 1 Pediatric Trauma Center team, Tommy quickly received aggressive, state-of-the-art resuscitation and management of his injuries. He was transferred to the Pediatric Intensive Care Unit where protocols and clinical algorithms, specifically for children with severe traumatic brain injury, were immediately instituted to try to mitigate the damage from further bleeding, poor oxygenation, poor blood flow and brain swelling.

Fortunately for Tommy, these type of clinical algorithms, as part of a multidisciplinary approach to care for children and adolescents after severe traumatic brain injury, were available at Phoenix Children's Hospital. P. David Adelson, MD, Tommy's neurosurgeon, was primarily involved in their development and implementation at Phoenix Children's, among other locations.

While initially Tommy responded to medical therapy, the swelling in his brain became unresponsive to the medicines, and six days after the crash, Dr. Adelson performed a craniotomy on Tommy that gave his brain room to swell.

While this saved his life, Tommy remained in a medically induced coma for more than two weeks to let the brain swelling subside as Marianna, his father Mike, three siblings and other family and friends huddled near his bedside. Then he opened his eyes and gave Mike a thumbs-up sign.

"I feared that he might die," Marianna said. "But I thought if he makes it, then he's going to make it well. He's either going to die or he's going to recover and I didn't really dwell on the dying."

Tommy did recover. He was released from the Pediatric Intensive Care Unit at Phoenix Children's more than a month after his accident brought him there.

But the road ahead would be long. Before he even left Phoenix Children's, Tommy began rehabilitation with the therapists at the Frances H. McClelland Rehabilitation Program at Phoenix Children's.

For the next several months he underwent intense physical therapy at two other facilities that specialize in the rehabilitation of traumatic brain injury.

Since the crash, Tommy has had to relearn most of his daily functions, including how to walk, talk, eat and use his arms. He's relearned how to speak English, as well as his mother's native language, Hungarian, which he speaks fluently.

But the now-16 year old has difficulty with his memory and retaining new information. He speaks slower, and still has very limited use of his dominant right hand. His friends regularly visit him to keep his spirits up, bringing up old memories or laughing at Tommy's jokes.

The neurocritical care physicians who first cared for him say his brain likely has another 18 to 24 months of healing to do. Marianna says that Tommy and his family have refused to give him a prognosis, fearing it will only limit him.

"We choose to speculate on the positive end," Marianna said. "He hasn't given up on his dreams; his plate is full."

Tommy still spends many hours a day in physical therapy, but he's also taking online classes. He still wants to be a veterinarian. He has kept his old passions for fishing, being outdoors and eating good food, like Thai soups and sushi.

Most days are not easy. One particular difficult day, Tommy walked into a room where Marianna was crying. He asked her what was wrong.

"Because of your TBI," Marianna recalled telling him. "That's when he told me, 'but I made it. I'm OK.' He was telling me what I usually tell him. It was so good to hear it from him."

Translational Research

The Translational Neurotrauma Research Program represents one research pillar within Barrow Neurological Institute at Phoenix Children's Hospital and the Department of Child Health at the University of Arizona College of Medicine – Phoenix and also involves collaboration with the Phoenix Veterans Affairs Health Care System.

The program operates with the mission to improve the quality of life of those with acquired neurological injury with a vision to be the destination for translational neurotrauma research, training and clinical care of these children. Acquired neurological injury obviously includes direct trauma, but also includes stroke, infection, hypoxia-ischemia and status epilepticus, to name but a few.

The program achieves its mission through hypothesis-driven, peer-reviewed research, while providing Socratic educational opportunities in a collaborative, partnership-driven environment involving all levels of researchers from senior to junior, students of science, in an open welcoming collaboration with any and all community partners. Our efforts are measured by their impact on improving health care delivery.

RESEARCH EXCELLENCE

- Focus on reorganization, regeneration and restoration of neural circuits damaged in the wake of acquired neurological injury to improve clinically-relevant outcomes.
- Generate novel and forward-thinking hypotheses to address key questions based on clinical and laboratory observations.
- Execute specific aims to test these hypotheses using quantifiable protocols, advanced technology and strategic collaborations.
- Communicate results to the scientific and lay communities with clarity through publications and presentations.
- Introduce this new knowledge back to the clinical setting to test and improve outcomes.

COMPREHENSIVE EDUCATION

- Train scientists, clinicians and clinician-scientists at every level in the art of scientific discovery towards meaningful interventions for acquired neurological injury.
- Lead local and national communities in education and outreach related to understanding, diagnosis, prognosis, treatment and quality of life for acquired neurological injury.
- Be lifelong learners in the subject matter, technical skills and marketing of our work.

CLINICAL AND COMMUNITY PARTNERSHIPS

- Integrate with clinical partners and health care providers to more quickly translate knowledge, interventions and devices that empower clinical algorithms to improve health care.
- Lead the development and advance the progress of programs to improve the health care delivery and quality of life for those with acquired neurological injury.
- Engage in complementary research programs that quickly advance basic understanding and clinical treatment of acquired neurological injury. We look to facilitate and expedite the translation of knowledge to implementation in the clinical setting.

Within the Translational Neurotrauma Research Program, research efforts focus on restorative and regenerative treatments for acquired neurological conditions, using traumatic brain injury as a specific model. In particular, scientific aims target circuit disruption that occurs following injury that contributes to lasting neurological symptoms.

In response to neural injury in the brain, circuits dismantle over a short period of time, due to the mechanical forces and ensuing enzymatic activity. After this happens, the brain repairs, rebuilds and reorganizes itself, but not necessarily reconstituting the original template. Instead, circuits can become rewired, and thus, processing information differs from before injury. In this way, new neurological behaviors emerge after acute neurological insults, including new symptoms and morbidities that may or may not be "bad" but are different from pre-injury.

Pharmacological and rehabilitative therapies can mitigate circuit dismantling and promote adaptive circuit reorganization, to preserve function and quality of life. Ongoing investigations target inflammatory and synaptic mechanisms to improve clinically-relevant outcomes.

The Translational Neurotrauma Research Program was established in 2012 under the directorship of Jonathan Lifshitz, PhD. Scientists at all levels, including faculty, residents, postdoctoral fellows, medical students and students of all levels, train and conduct research towards understanding and treating neurotrauma conditions. Experiments and studies are conducted in open-space collaborative laboratories, with access to state-of-the-art molecular, electrochemical, behavioral and anatomical technology unique to the Southwest.

Ongoing projects involve active collaborations with the Phoenix VA Health Care System, Arizona State University, Banner Sun Health, Translational Genomics Research Institute (TGen) and others across the country and around the world. This comprehensive research program helps to unite biomedical science across Arizona and beyond with a focus on translating scientific findings into the clinic to benefit our patients.

Quality Initiative and Assurance/Shunt Procedures

At Barrow Neurological Institute at Phoenix Children's Hospital, shunt placement is one of the most common neurological procedures performed. Medical staff takes great care to deliver safe and effective outcomes to this common procedure.

In 2015, our neurosurgical team performed 104 cerebrospinal fluid (CSF) diversion placements and ventriculostomies, among others. In these cases, the infection rate was less than 2 percent.

QUALITY INITIATIVE AND ASSURANCE

In an effort to optimize our surgical outcomes, processes were put in place to evaluate our performance on a series of postsurgical outcome metrics including mortality, surgical site infection, reoperation within 30 to 90 days and new neurological defects.

The information acquired through this mechanism is discussed monthly in a multidisciplinary conference, which has served to help staff identify areas for potential improvement.

Prophylactic antibiotic administration, asepsis and prepping techniques and presurgical care were targeted for intervention due to their variability. Prospective standardization of surgical double gloving, clorhexidine gluconate prepping and antibiotic administration and timing are delineated for all neurosurgical procedures and processes for the tracking of prepping and antibiotic compliance.

Additionally, an aggressive educational campaign to promote presurgical bathing with clorhexidine gluconate was also developed. This educational campaign included:

- For ambulatory surgery admissions, provision of clorhexidine wipes and instructions on how to use them.
- For Emergency Department admissions, development of an order set for the department to apply on patients admitted urgently.
- For inpatient surgeries, development of an order set for nursing for clorhexidine gluconate bathing on a daily basis in presurgical and then postsurgical patients. The implementation of these pre-operative interventional and educational processes resulted in a 100 percent compliance rate in antibiotic administration and documentation compliance in the last three quarters of 2015, along with concurrent 56 percent decrease in our surgical infection rate.

Clincal Research
ACCOMPLISHMENTS

BIOLOGIC MATERIALS AVAILABILITY PROGRAM (BMAP)

The Biologic Materials Availability Program (BMAP) at Phoenix Children's Hospital is an initiative aimed at ensuring the availability of biological materials to better understand the impact of disease and treatment through our institute's research and/or other investigators and the means to access them. The program, with parental consent, collects a variety of tissues and bio-fluids that would have otherwise been discarded. These include surplus tissues from anatomic and diagnostic pathology and the clinical laboratory and/or discarding materials accessed through surgery or bedside procedures and devices.

The neuroscientific division of BMAP is the most active group of sample collection and processing at Phoenix Children's. The creation of a cerebrospinal fluid (CSF) bank has made this division a leading entity for research support due to the variety of the CSF collected. The relatively wide spectrum of neurological conditions for which CSF is available has promoted associations with investigators and institutions working with advance molecular techniques locally and nationally.

- The Biological Material Availability Program has enrolled a total of 610 patients, of which 144 were enrolled in 2015.
- More than 400 samples including tumors, epileptic tissue, cerebrospinal fluid, blood, plasma, urine, synostotic skull bone and cystic fluid were collected. Biological materials were provided to Barrow Neurological Institute at Phoenix Children's Hospital investigators for numerous neuroscientific research projects.
- Project-specific collaborations locally and nationally were also developed with University of California - San Diego, The Scripps Research Institute, Lpath Incorporated, Vitro Biopharma, Mayo Clinic and the Translational Genomics Research Institute (TGen) for research about condition-dependent molecular expression.

RESEARCH BY THE NUMBERS

15
NEW GRANTS SUBMTTED

18
NEW RESEARCH STUDIES APPROVED BY THE INSTITUTIONAL REVIEW BOARD (IRB)

7
GRANTS SUCCESSFULLY RENEWED

From 2009 to 2015, there were **99 IRB-approved studies**

Of **49 clinical trials** being conducted...

8
FUNDED BY THE NATIONAL INSTITUTES OF HEALTH

5
INDUSTRY-SPONSORED TRIALS

27
OBSERVATIONAL STUDIES

9
PROSPECTIVE CLINICAL DATABASES ON PATIENT CARE

Highlights of Clinical Trials, Observational Studies, Registries and Reviews

CLINICAL TRIALS

Spatiotemporal Evolution of Epileptic Seizures Using ECoG and EEG
P. David Adelson, MD

The purpose of this study is to elucidate novel information regarding seizure propagation from a quantitative perspective using signal and image processing techniques on ECoG data collected during ictal periods. Further, the study will analyze EEG data to ascertain if the methods used on ECoG data can determine if the patient is a candidate for resection surgery prior to ECoG grid implantation.

Macro and Micro Electrocorticography in Cortical Interfacing
P. David Adelson, MD

The purpose of this study is to improve our understanding of the significance and limitations of using electrocorticography for epilepsy monitoring. Signals collected will be evaluated to determine whether microelectrode grids are suitable tools for the clinical diagnosis and characterization of seizure disorders, for understanding how the brain encodes complex movement and for function restoration efforts.

Examining the Mechanisms of Epileptogenesis in Tissue Resected from Pediatric Patients
Jorge Arango, MD

The purpose of this study is to learn about the different characteristics of epileptic brains. Information learned from this study will help clinicians improve treatment for children with epilepsy that does not respond to medication.

Intense Physiotherapies Improve Function in Children with Cerebral Palsy
Jorge Arango, MD

This study is being done to determine if a more intense program of physical and occupational therapies is more effective than the current standard of care in helping young children improve their motor function.

RETROSPECTIVE REVIEWS

Ketogenic Diet for Status Epilepticus
Randa Jarrar, MD

The purpose of this study was to describe the experience at Phoenix Children's Hospital of patients with super-refractory status epilepticus who underwent ketogenic diet therapy.

Treatment of Infantile Spasms with Prednisone Versus Prednisone and Topamax
Randa Jarrar, MD

The purpose of this study was to determine if there was a difference in outcomes between two treatment regimens for infantile spasms. The results of this study may help to direct new treatment practices for children with this disorder.

Comparative Assessment of Severe Pediatric TBI Management Between Developed and Developing Country Institutions
P. David Adelson, MD

The purpose of this study was to describe the differences in TBI management between two institutions – one in the United States and one in Colombia. This study will also compare short and long term outcomes of children managed at each institution.

Do Traumatic Brain Injuries Correlate with Subsequent Development of Endocrine Disorders in Children?
Jonathan Lifshitz, PhD

The purpose of this study was to describe the prevalence and demographic make-up of children who develop endocrine dysfunction after suffering a traumatic brain injury.

Effectiveness of Prophylactic Onabotulinum Toxin A in Adolescents with Chronic Migraines
Marcy Yonker, MD

The purpose of this study was to describe any difference in the frequency of headache days for children treated with Onabotulinum toxin A and those who do not receive this management.

Sphenopalatine Ganglionic Block in Pediatric Headache
Marcy Yonker, MD

The purpose of this study was to characterize the tolerability and efficacy of sphenopalatine ganglionic block in the treatment of pediatric headaches. This study will also describe the reduction of pain and the duration of the effect, as well as the tolerability of the procedure.

OBSERVATIONAL STUDIES

Towards the Establishment of Standards of Practice and the Initiation of Multi-Center, Multi-National Clinical Trials for Neonates and Children with Stroke
John Condie, MD

The study is an effort to learn more about childhood stroke and to create a network of collaboration for research advancement in the area.

A Multicenter Retrospective Study of Avance® Nerve Graft Utilization, Evaluations and Outcomes in Peripheral Nerve Injury Repair
P. David Adelson, MD

To evaluate the utilization, functional recovery and health outcomes data from patients who have had nerve repair using the Avance® Nerve Graft.

pSERG's Outcome in Status Epilepticus
Korwyn Williams, MD

The purpose of this study is to gather information on signs and symptoms of status epilepticus, the hospital course during treatment and how patients respond to different treatments.

Phoenix Children's Hospital Biological Material Availability Program (BMAP)
David F. Carpentieri, MD

The Biological Material Availability Program is a program which collects, stores, processes and distributes biological materials and/or health information including genetic test results for use in future research studies.

Approaches and Decisions for Acute Pediatric TBI (ADAPT) Trial
Sandra Buttram, MD

The purpose of this study is to learn the best way to take care of a child with a severe traumatic head injury.

Syringomyelia Research Consortium
P. David Adelson, MD

The purpose of this research study is to further our understanding of Syringomyelia and Chiari malformations. A Chiari malformation is a condition in which part of the brain sits below and pushes through the hole where the spinal cord leaves the skull. Syringomyelia is the formation of cysts along the spinal cord. It is believed to occur as a result of the Chiari malformation.

Identifying Novel Causes of Idiopathic Neurological Syndromes
Michael Kruer, MD

The purpose of this research study is to further our understanding of and identify the etiology of idiopathic neurological syndromes.

Gene Discovery in Inherited Neurological Diseases
Michael Kruer, MD

The purpose of this research study is to identify novel genetic causes of pediatric neurological disorders and characterize their pathophysiology. In so doing, we will not only substantially inform clinical diagnosis, but will enable future studies that focus on developing targeted therapies.

Pediatric Delirium: A Multi-Institutional Point Prevalence Study
Sandra Buttram, MD

The purpose of this research study is to determine the prevalence of delirium in critically ill children and to describe risk factors that may be associated with delirium.

PRE-CLINICAL 2015

Micro Ribonucleic Acid Markers of Hydrocephalus Development in Infants with Intraventricular Hemorrhage
Jorge Arango, MD

The purpose of this study is to identify markers of brain injury and the development of hydrocephalus in children with perinatal ischemic insults and those born with neural tube defects and use to estimate and prevent secondary injuries.

The Role of Lysophosphatidic Acid (LPA) in Human Hydrocephalus
Jorge Arango, MD

The purpose of this study is to evaluate the association of cerebrospinal fluid levels of lysophosphatidic acid and the development neonatal hydrocephalus.

Optimization and Normalization Studies for CSF as a Biomarker
Jorge Arango, MD

The purpose of this study is to identify ideal mechanisms for the isolation and analysis of extracellular vesicles and their contents in cerebrospinal fluid.

Cerebrospinal Fluid Transfer for Testing of a Microvalve
Ruth Bristol, MD

The purpose of this study is to test the functionality of a microvalve for the treatment of hydrocephalus.

Education Innovation

- Neurology, psychology, neuroradiology and neurosurgery departments filled their internships and fellowships respectively with their top choice candidates, representing growing awareness that Barrow at Phoenix Children's is a quality destination for education.
- Our Pediatric Neurology Program is collaborative with the Adult Neurology Residency Program at Barrow Neurological Institute at Dignity Health St. Joseph's Hospital and Medical Center. The Pediatric Neurology Program became part of Phoenix Children's Hospital in 2011 and has grown in the past four years, increasing from three residents to six.
- The Pediatric Neurosurgery Program, as part of Barrow Neurological Institute at Dignity Health St. Joseph's Hospital and Medical Center, trains adult residents as part of their required rotations.
- Our second pediatric neurosurgery fellow, **Kelly Mahaney, MD**, accepted a position as an assistant professor of neurosurgery at the University of Virginia in Charlottesville, Virginia.
- Barrow at Phoenix Children's successfully matched our third pediatric neurosurgery fellow, **Jamal McClendon, Jr., MD**.
- The divisions of neuropsychology and psychology accepted another fellow, **Laura Freeman, PhD**, into the two-year Neuropsychology Postdoctoral Fellowship Program. The psychology department continues to offer an accredited, one-year Postdoctoral Internship Program, which offers experiences in both pediatric clinical and neuropsychological training.
- The International Neurotrauma Fellowship is a combined academic effort certified by Barrow at Phoenix Children's in the United States and the Foundation for Medical Education and Research in Emergency and Disasters in Colombia. This one-year clinical and research fellowship is based at Trauma Reference University Hospital in Colombia, South America and has an international research component based at our specialized Barrow at Phoenix Children's Neuroscience Research Center here in the United States. The 2015 International Neurotrauma Fellow, Raul Echeverri, MD, joined Barrow at Phoenix Children's in 2015.

Kelly Mahaney, MD

Jamal McClendon, Jr., MD

Laura Freeman, PhD

Collaborative Arrangements and Strategic Partnerships

Arizona Alzheimer's Consortium

Arizona Biomedical Research Commission

Arizona Governor's Council on Spinal and Head Injuries

Arizona State University Schools of Biodesign Institute, Biological Systems and Health Engineering, Bioinformatics, Education, Law, Nursing

Banner University Medical Center

Barrow Neurological Institute at Dignity Health St. Joseph's Hospital and Medical Center

The CACTIS Foundation

Industry partners: AstraZeneca™, Baxter™, Cyberonics®, Integra™, Lundbeck™, Pfizer, Quintiles®, Schering-Plough™

DSM Pharmaceuticals

EPIC – TBI

Insys Therapeutics

Mayo Clinic Arizona

National Institutes of Health

Phoenix VA Healthcare System

Science Foundation Arizona

Sojourner Center

Southwest Autism Research and Resource Center (SARRC)

Translational Genomics Research Institute (TGen)

University of Arizona College of Medicine - Phoenix, Department Of Child Health

University of Arizona College of Medicine - Tucson, AzNETT

University of Arizona Mel and Enid Zuckerman College of Public Health

University of Arizona College of Nursing

IN 2015, BARROW NEUROLOGICAL INSTITUTE AT PHOENIX CHILDREN'S HOSPITAL WAS RANKED NUMBER 14 IN THE COUNTRY BY *U.S. NEWS & WORLD REPORT* BEST CHILDREN'S HOSPITALS FOR NEUROLOGY AND NEUROSURGERY.

Marketing and Communications

Barrow Neurological Institute at Phoenix Children's Hospital aims by 2020 to be ranked among the top 10 children's hospitals for neurology and neurosurgery as designated by *U.S. News & World Report* Best Children's Hospitals.

- Communication efforts at Barrow at Phoenix Children's include advertising, marketing, media relations, physician relations, website content, social media and communication materials including brochures, flyers and newsletters.
- The Institute's 2014 Annual Report, "Vision," was distributed in the winter of 2015 to more than 15,000 people within regional, national and international audiences.

Barrow.phoenixchildrens.org

- Digital content on the website was updated in 2015 with videos about programs at Barrow at Phoenix Children's including the Pediatric Epilepsy Program.
- Communication staff updated and added content to the website's more than 1,000 webpages throughout 2015.

BarrowAtPhoenixChildrens

- Barrow at Phoenix Children's Facebook page continues to grow with a total of 1,865 "likes" in 2015, which was an increase of 26 percent over 2014.

@BarrowPCH

- Barrow at Phoenix Children's Twitter page has continued to grow with a total 8,310 people reached in 2015.
- The account ended 2015 with 257 followers, an increase of 64 percent over 2014. This is a 58 percent increase from 2014.

MARKETING, MEDIA RELATIONS AND ADVERTISING ACCOMPLISHMENTS

- Sponsorship of the December 2015 Phoenix premiere of the movie "Concussion," including a full-page program advertisement and physician participation in a post-event expert panel.
- Regional advertising campaign featuring the story of Kade, an epilepsy patient.
- Throughout 2015, Barrow at Phoenix Children's was mentioned 159 times in media stories, reaching audiences of more than 3.7 million people.
- Two newsletters, featuring patient stories and news, were sent to regional, national and international recipients.
- Four Barrow at Phoenix Children's patients participated in the Arizona Diamondbacks' Kids Run the Bases Program, which highlights success stories of patients with videos and recognition at a regular season home game.
- National advertising campaign featured Barrow at Phoenix Children's, reaching physicians, trending organizations and researchers over a three-month campaign.

PHYSICIAN RELATIONS ACCOMPLISHMENTS

- Six Lunch and Learn Programs
- A strong presence at numerous conferences:
  - Pediatric Update: 300 attendees
  - Pediatric Academic Society (International): 8,000 attendees
  - Arizona Osteopathic Medical Association: 600 attendees
  - Arizona Academy of Pediatrics Red Rocks: 250 attendees
- The 19th Annual Children's Neuroscience Symposium welcomed 136 attendees.

2015 Sponsored Events

- **The 19th Annual Children's Neuroscience Symposium**
- **Down Syndrome Fashion Show**
- **Pediatric Epilepsy Conference**
- **Down Syndrome Medical Conference**
- **Arizona Fragile X Education Workshop**

THE 19TH ANNUAL CHILDREN'S NEUROSCIENCE SYMPOSIUM

Barrow at Phoenix Children's continues to offer the annual Children's Neuroscience Symposium, which features nationally prominent faculty and guest speakers presenting on topics and case studies. The Symposium aims to give pediatric providers the latest information and tools to assess complex neurological conditions and manage patient care. In 2015, the four-day symposium addressed neurological emergencies, epilepsy, neurosurgical treatments and spinal cord issues.

COMMUNITY EDUCATION

In 2015, Barrow at Phoenix Children's continued its community education outreach with events on the following topics: Epilepsy, Down syndrome and Fragile X. The events offered information from and interactive sessions with experts.

THINKFIRST PROGRAM

Barrow at Phoenix Children's impacts the health of our community by offering and participating in a number of outreach activities. Prevention activities include educating children and families using the ThinkFirst program curriculum to address prevention of head and spinal cord injuries. This curriculum stresses the importance of helmet use, swimming and diving precautions and child passenger safety.

In addition, the Pediatric Concussion Program at Barrow at Phoenix Children's offers educational programs and baseline neurocognitive evaluations for children participating in youth soccer and football programs. Our team is available to comprehensively assess and treat children who have sustained a concussion. Educational seminars related to neurological and neurosurgical conditions are offered for families and the community.

THINK FIRST BY THE NUMBERS

650
HELMETS WERE DISTRIBUTED

1,650
CHILDREN WERE REACHED BY PROGRAM STAFF THROUGH 14 BICYCLE RODEOS

1,140
CHILDREN WERE EDUCATED THROUGH CLASSROOM AND ASSEMBLY PRESENTATIONS

Honors and Awards

P. David Adelson, MD
- Arizona Top Doctors, Castle Connolly Medical
- Visiting Professor, Legacy Hospital, Portland, Oregon
- Visiting Professor, Rush University Hospital, Chicago
- Elected to American Academy of Neurological Surgeons

Saunder Bernes, MD
- Top Doctor, *Phoenix Magazine*

Robin Blitz, MD
- Top Doctor, *Phoenix Magazine*
- Arizona Top Doctors, Castle Connolly Medical

Ruth Bristol, MD
- Recipient, Phoenix Children's Hospital Research Advancement Committee Award

Allen Kaplan, MD
- Top Doctor, *Phoenix Magazine*
- Honored for Lifetime Achievements, *Phoenix Business Journal's* Health Care Heroes

John F. Kerrigan, MD
- Invited Member, Consulting Editors Board of Epilepsy Research

Kara Lewis, MD
- Top Doctor, *Phoenix Magazine*

Makram Obeid, MD
- Recipient, Phoenix Children's Hospital Research Advancement Committee Award

Sarah Ogle, DO
- First Place Oral Presentation, Arizona Chapter, American College of Surgeons Committees on Trauma
- First Place Oral Presentation, Regional, American College of Surgeons Committees on Trauma
- First Place Poster Presentation, Arizona Trauma & Acute Care Consortium
- Top Poster Presentation, National Neurotrauma Society
- Travel Grant Award, National Neurotrauma Society

Randall Ricardi, DO
- Top Doctor, *Phoenix Magazine*
- Director of the Mental Health Consultation and Liaison Service for Psychiatry Department, Barrow Neurological Institute at Phoenix Children's Hospital

Rachel Rowe, PhD
- Young Investigator Award, International Brain Injury Association
- International Travel Award, Society for Neuroscience Global Membership Committee
- Travel Award, International Neurotrauma Society

Jeanette Smith, PhD
- Recipient, Cystic Fibrosis Foundation Mental Health Grant

Richard Towbin, MD
- Top Doctor, *Phoenix Magazine*

Matthew Troester, DO
- Arizona Top Doctors, Castle Connolly Medical
- Top Doctor, *Phoenix Magazine*

Jacob Venter, MD
- Top Doctor, *Phoenix Magazine*


P. David Adelson, MD


Saunder Bernes, MD


Robin Blitz, MD


Ruth Bristol, MD


Allen Kaplan, MD


John F. Kerrigan, MD

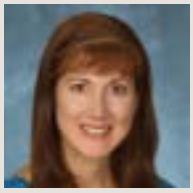

Kara Lewis, MD


Makram Obeid, MD


Sarah Ogle, DO


Randall Ricardi, DO


Rachel Rowe, PhD


Jeanette Smith, PhD


Richard Towbin, MD


Matthew Troester, DO


Jacob Venter, MD

Leadership and Academic Appointments

P. David Adelson, MD
- Director, Barrow Neurological Institute at Phoenix Children's Hospital
- Chief, Pediatric Neurosurgery/Neurosciences, Barrow Neurological Institute
- Clinical Professor of Surgery/Neurosurgery, Department of Child Health, University of Arizona College of Medicine – Phoenix
- Professor, Adjunct Faculty, School of Biological and Health Systems Engineering, Arizona State University
- Professor, Mayo Clinic Arizona
- Neurological Surgery Faculty, Barrow Neurological Institute
- Ad Hoc Member, National Institutes of Health Brain Injury and Neurovascular Pathologies Study Section (BINP)
- Affiliate Research Faculty, Arizona Emergency Medicine Research Center, University of Arizona – Tucson
- American Epilepsy Society
- American Medical Association
- American Society of Pediatric Neurosurgeons
- European Association of Neurosurgical Societies
- Hydrocephalus Association
- International Neurotrauma Society
- International Society for Pediatric Neurosurgery
- Journal of Neurosurgery: Pediatrics Editorial Board
- National Neurotrauma Society
- Past Chairman, Nominations Committee American Association of Neurological Surgeons Committee Scientific Program
- Pediatric Neurocritical Care Research Group
- Quality Impact Workgroup and Strategic Planning Committee Member, Congress of Neurological Surgeons, Washington Committee
- Senior Advisor, International Division, Congress of Neurological Surgeons
- Senior Delegate, World Federation of Neurosurgical Societies
- Society of University Neurosurgeons
- Vice Chair, Committee for International Initiatives, World Federation of Neurosurgical Societies

John Barton, PhD
- Training Director, Psychology Department, Barrow Neurological Institute at Phoenix Children's Hospital
- Clinical Associate Professor, Department of Child Health, University of Arizona College of Medicine – Phoenix
- Clinical Professor, Department of Psychology, Arizona State University
- Senior Lecturer, Department of Psychology, Clinical Psychology Center
- American Psychological Association
- Arizona Psychological Association
- Board Certified, American Board of Professional Psychology
- Fellow, American Academy of Clinical Child and Adolescent Psychology
- Director, Department of Psychology, Clinical Psychology Center
- Society for Pediatric Psychology

Saunder Bernes, MD
- Interim Division Chief, Child Neurology, Barrow Neurological Institute at Phoenix Children's Hospital
- Child Neurology Society
- Fellow, The American Academy of Pediatrics
- Medical Director, Muscular Dystrophy Association Clinic
- Greater Phoenix Pediatric Society

Robin Blitz, MD
- Director, Developmental Pediatrics, Barrow Neurological Institute at Phoenix Children's Hospital
- Clinical Associate Professor of Pediatrics, Department of Child Health, University of Arizona College of Medicine – Phoenix
- Clinical Associate Professor of Pediatrics, Creighton University School of Medicine
- Arizona Chapter of American Academy of Pediatrics: Autism Consensus Document Committee
- Director, Pediatric Developmental and Behavioral Clinic, Phoenix Indian Medical Center
- Down Syndrome Medical Interest Group
- Governor's Advisory Committee for Autism Spectrum Disorder
- Member, American Academy of Pediatrics Sections: Developmental and Behavioral Pediatrics, Children with Disabilities, and Council on Adoption, Foster Care and Kinship
- National Fragile X Clinical and Research Consortium for Fragile X and Autism Consensus
- Society for Developmental and Behavioral Pediatrics
- Zero to Three, National Center for Infants, Toddlers and Families

Camille Bloom, MS, MMS, RD, PA-C
- American Academy of Physician Assistants
- Assistant Faculty, Physician Assistant Program, Northern Arizona University
- Congress of Neurological Surgeons

Clairmar Borerro-Mejias, MD
- Child Neurology Society
- American Academy of Neurology
- American Academy of Pediatrics

continued...

Ruth Bristol, MD
- Co-Director, Hypothalamic Hamartoma Program, Barrow Neurological Institute at Phoenix Children's Hospital
- Co-Director, Craniofacial Neurosurgery Program, Barrow Neurological Institute at Phoenix Children's Hospital
- Clinical Assistant Professor, Department of Neurosurgery, Department of Child Health, University of Arizona College of Medicine – Phoenix
- Professor, Barrow Neurological Institute
- American Association of Neurological Surgeons
- American Society of Pediatric Neurosurgery
- Congress of Neurological Surgeons
- Greater Phoenix Pediatric Society
- Maricopa County Medical Society

Nancy Buckner, MD
- Assistant Professor, Psychiatry and Child Health, University of Arizona College of Medicine – Phoenix
- Assistant Professor in Psychiatry, Creighton University School of Medicine
- American Academy of Child and Adolescent Psychiatry
- American Board of Psychiatry and Neurology
- Board-Certified, Child Psychiatry

Raymond Bunch, MD
- Clinical Assistant Professor, Department of Child Health, University of Arizona College of Medicine – Phoenix
- American Academy of Child and Adolescent Psychiatry
- American Neuropsychiatric Association
- American Psychiatric Association
- Substance Abuse Training and Screening Program, Medical Education and Research Foundation for the Treatment of Alcoholism and Other Drug Dependencies

Ginger Carlson, PhD
- Adjunct Professor, Arizona State University
- American Board of Professional Psychology
- American Psychological Association
- Arizona Psychological Association

John Condie, MD
- Child Neurology Society
- Neurocritical Care Society
- Pediatric Neurocritical Care Group

Michael Etzl, MD
- American Society of Pediatric Hematology Oncology
- American Academy of Pediatrics
- Children's Oncology Group
- Head Start Consortium
- Pediatric Oncology Experimental Therapeutics Investigator Consortium

Shelley Flecky, PA-C
- American Academy of Physician Assistants
- American Association of Neurological Surgeons

John Fulton, PhD, ABPP-CN
- Adjunct Professor, Arizona State University
- Assistant Professor, Department of Psychiatry, University of Arizona College of Medicine – Phoenix
- Member -at-Large, Arizona Neuropsychological Society
- Medical Advisory Board Member, Hope for Hypothalamic Hamartomas

Andrew Haber, MD
- Assistant Professor, Department of Psychiatry, University of Arizona College of Medicine – Phoenix
- Assistant Professor, Department of Psychiatry, Creighton University School of Medicine

Aida Hadziahmetovic, MD
- American Academy of Child and Adolescent Psychiatry
- American Psychiatric Association

Carolyn Hickman, PhD, RN, CPNP
- Clinical Faculty, Division of Child Health, University of Arizona College of Medicine – Phoenix
- American Headache Society
- Arizona Pediatric Nurse Practitioners
- Association of Child Neurology Nurses
- Council for the Advancement of Nursing Science
- National Association of Pediatric Nurse Practitioners
- Phoenix Children's Hospital Scientific Review Committee
- Sigma Theta Tau International Nursing Honor Society

Randa Jarrar, MD
- Assistant Professor, Neurology, Mayo Clinic Arizona
- Clinical Assistant Professor, Department of Child Health, University of Arizona College of Medicine – Phoenix
- American Academy of Neurology
- American Epilepsy Society

Mary Johnson, MD
- American Academy of Neurology
- American Neurological Association
- Central Society for Neurological Research
- Child Neurology Society
- International Child Neurology Association
- Society for Neuroscience
- Society for Pediatric Research
- Research Society on Alcoholism
- Western Society for Pediatric Research

Allen Kaplan, MD
- Professor, Department of Child Health, University of Arizona College of Medicine – Phoenix
- American Epilepsy Society
- Child Neurology Society
- Children's Oncology Group

John F. Kerrigan, MD
- Director, Pediatric Epilepsy Program, Barrow Neurological Institute at Phoenix Children's Hospital
- Chairman and Member, Academic Promotions and Tenure Committee, Department of Child Health, University of Arizona College of Medicine – Phoenix
- Editorial Board, Epilepsy Research
- International League Against Epilepsy (ILAE), Pediatric Epilepsy Surgery Workgroup
- Member and Founding President, Medical Advisory Board, Hope for Hypothalamic Hamartoma Foundation

Kathleen Klas, NP
- Advanced Practice Committee, Arizona Board of Nursing

Michael Kruer, MD
- Director, Pediatric Movement Disorders Program, Barrow Neurological Institute at Phoenix Children's Hospital
- Co-Director, Neurogenetics Program, Barrow Neurological Institute at Phoenix Children's Hospital
- Associate Professor, Department of Child Health, University of Arizona College of Medicine – Phoenix
- Associate Professor, Neuroscience Program, Arizona State University
- American Academy for Cerebral Palsy and Developmental Medicine
- American Academy of Neurology
- American Academy of Pediatrics
- American Neurological Association
- American Physician Scientists' Association
- American Society for Cell Biology
- American Society for Human Genetics
- Barrow Neurological Institute Children's Neuroscience Steering Committee
- Child Neurology Society
- Editorial Board, Journal of Child Neurology
- International Child Neurology Association
- Mitochondrial Medicine Society
- Movement Disorder Society
- Phoenix Children's Hospital Internal Review Board #2
- Phoenix Children's Hospital Laboratory Utilization Committee
- Valley Research Partnership Steering Committee

Michael Lavoie, PhD
- Division Chief, Neuropsychology Department, Barrow Neurological Institute at Phoenix Children's Hospital
- Clinical Associate Professor, Department of Child Health, University of Arizona College of Medicine – Phoenix
- American Psychological Association
- Arizona Neuropsychological Society
- Arizona Psychological Association
- Brain Injury Alliance of Arizona
- Cancer Center Committee, Phoenix Children's Hospital
- Division 40 Clinical Neuropsychology
- Division 12 Clinical Psychology
- Governor's Council on Spinal and Head Injuries
- International Neuropsychological Society
- National Academy of Neuropsychology
- Neuroscience Advisory, Phoenix Children's Hospital
- Psychiatry Section Committee, Phoenix Children's Hospital
- Psychology Training Committee, Phoenix Children's Hospital
- Youth Sports Concussion Coalition of Arizona

Kara Stuart Lewis, MD
- Associate Professor of Clinical Pediatrics, University of Arizona College of Medicine – Phoenix
- Contributor, Accreditation Council for Graduate Medical Education (ACGME) National Milestones for Child Neurology Residency
- Councillor for the West, National Committee for Child Neurology Society
- Fellow, American Headache Society
- Program Director, Child Neurology Residency, Barrow Neurological Institute at Phoenix Children's Hospital
- Social Media Editor, Journal of Child Neurology

Jonathan Lifshitz, PhD
- Director, Translational Neurotrauma Research Program at Barrow Neurological Institute at Phoenix Children's Hospital
- Associate Professor, Department of Child Health, University of Arizona College of Medicine – Phoenix
- Associate Professor, Barrow Neurological Institute
- Associate Professor, Psychology, Arizona State University
- Councilor, Governor's Council on Spinal and Head Injuries
- Health Scientist (WOC), Phoenix VA Health Care System
- Member, Research Senate, Department of Child Health, University of Arizona College of Medicine – Phoenix
- Member, Scientific Advisory Board, The CACTIS Foundation
- Member, Society for Pediatric Research
- Vice President, National Neurotrauma Society

Robert Little, MD
- Assistant Professor, Department of Pediatrics, Creighton University School of Medicine
- Assistant Professor, Division of Neurology, Barrow Neurological Institute
- Clinical Assistant Professor, Department of Pediatrics, University of Arizona College of Medicine – Phoenix

Marika Maris, PhD
- American Psychological Association
- International Neuropsychological Society
- National Academy of Neuropsychology

Jeffery Miller, MD
- Assistant Professor of Radiology, Mayo Clinic Arizona
- Assistant Professor/Clinical Scientist, Barrow Neurological Institute
- Adjunct Assistant Professor, Biological and Health Systems Engineering, Ira A. Fulton School of Engineering, Arizona State University
- Clinical Assistant Professor of Radiology, University of Arizona College of Medicine – Phoenix

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Makram Obeid, MD
- Assistant Professor, Clinical Scholar, Department of Child Health, University of Arizona College of Medicine – Phoenix
- American Academy of Neurology
- American Epilepsy Society
- Society for Neuroscience

Mark Popenhagen, PsyD
- Society of Pediatric Psychology Division 54 of the American Psychological Association

Reena Rastogi, MD
- Clinical Assistant Professor, Department of Child Health, University of Arizona College of Medicine – Phoenix
- American Headache Society
- American Academy of Pediatrics, Arizona Chapter
- Child Neurology Society
- International Headache Academy, National Institutes of Health

Randall Ricardi, DO
- Consult and Liaison Section Chief, Psychiatry Department, Barrow Neurological Institute at Phoenix Children's Hospital
- Adjunct Professor, School of Nursing, Arizona State University
- Assistant Clinical Professor of Psychiatry, University of Arizona College of Medicine – Phoenix
- Assistant Clinical Professor, Midwestern University School of Medicine
- Assistant Clinical Professor, Creighton University School of Medicine

Amy Rosenfeld, MD
- Clinical Assistant Professor, Department of Child Health, University of Arizona College of Medicine – Phoenix
- Institutional Review Board

David Shafron, MD
- Clinical Assistant Professor, Pediatrics and Child Health, University of Arizona College of Medicine – Phoenix
- Fellow, American Association of Neurological Surgeons
- Fellow, Congress of Neurological Surgeons

Jeanette Smith, PhD
- American Psychological Association
- Arizona Psychological Association
- Association for Contextual Behavioral Science (ACBS)
- AZPA Ethics Committee
- Society of Behavioral Medicine
- Society of Pediatric Psychology
- Head of Parent and Teen Groups for Patients with Complex Pain

Theresa Currier Thomas, PhD
- Research Scientist, Translational Neurotrauma Research Program, Barrow Neurological Institute at Phoenix Children's Hospital
- Assistant Professor, Department of Child Health, University of Arizona College of Medicine – Phoenix
- Faculty Reviewer for Scholarly Projects, University of Arizona College of Medicine – Phoenix
- Instructor, University of Arizona College of Medicine – Phoenix
- Instructor, Arizona State University
- Member, Alumni, Community Project Mentor, Alumni Committee, Scottsdale Leadership
- Member, Emerging Leaders, Phoenix Children's Hospital
- National Neurotrauma Society and Society for Neuroscience
- Research Investigator (WOC), Phoenix VA Health Care System

Richard Towbin, MD
- Radiologist-in-Chief, Department of Radiology, Phoenix Children's Hospital
- Academic Division Chief of Radiology, Department of Child Health, University of Arizona College of Medicine – Phoenix
- Adjunct Professor, Biological and Health Systems Engineering, Arizona State University
- Clinical Professor of Radiology, College of Medicine, Mayo Clinic Arizona
- Clinical Professor of Radiology, University of Arizona College of Medicine – Phoenix

Matthew M. Troester, DO
- Assistant Clinical Professor, Department of Pediatrics, Creighton University School of Medicine
- Clinical Assistant Professor of Neurology, University of Arizona College of Medicine – Phoenix
- American Academy of Sleep Medicine: Pediatric Obstructive Sleep Apnea Outcome Measure Task Force
- American Academy of Sleep Medicine: Consensus Conference – Pediatric Sleep Duration
- American Academy of Sleep Medicine Sleep Trends: Pediatric Track Course Chair
- American Epilepsy Society

Jacob Venter, MD, MBA, CPE, FAPA
- Division Chief, Psychiatry Department, Barrow Neurological Institute at Phoenix Children's Hospital
- Associate Professor in Psychiatry and Child Health, Department of Child Health, University of Arizona College of Medicine – Phoenix
- Associate Professor in Psychiatry, Creighton University School of Medicine

Korwyn Williams, MD, PhD

- Assistant Professor of Neurology, Mayo Clinic Arizona
- Clinical Assistant Professor, Department Child Health, University of Arizona College of Medicine – Phoenix
- American Academy of Neurology
- Board of Directors, Epilepsy Foundation of Arizona
- Coding Subcommittee Member, Medical Economics and Management Committee of the American Academy of Neurology
- Member of the American Epilepsy Society
- Professional Advisory Board, Epilepsy Foundation of America
- Reviewer, Journal of Pediatric Neurology

Amber C. Wright, MSN, RN, CPNP

- President-Elect, Arizona Chapter of National Association of Pediatric Nurse Practitioners
- DSMIG-USA 2016 Annual Conference Planning Committee
- Triple P Level 4 Group Facilitator

Marcy Yonker, MD

- American Epilepsy Society
- American Headache Society
- Board Member, Pediatric and Adolescent Section, American Headache Society
- Liaison, Child Neurology Society
- Member, American Academy of Neurology

John Zaharopoulas, DO

- Assistant Professor, Psychiatry and Child Health, Department of Child Health, University of Arizona College of Medicine – Phoenix
- Assistant Professor, Psychiatry, Creighton University School of Medicine
- Arizona Osteopathic Association
- American Psychiatric Association
- Arizona Psychiatric Society

Peer Reviewed Publications

P. David Adelson, MD

Buttram SD(1), Garcia-Filion P(2), Miller J(3), Youssfi M(3), Brown SD(4), Dalton HJ(5), Adelson PD(6). Computed tomography vs. magnetic resonance imaging for identifying acute lesions in pediatric traumatic brain injury. Hosp Pediatr. Feb., 2015.

Nichols J(1), Perez R, Wu C, Adelson PD, Anderson T. Traumatic brain injury induces rapid enhancement of cortical excitability in juvenile rats. CNS Neurosci Ther. Feb., 2015.

Ziebell JM(1), Adelson PD, Lifshitz J. Microglia: Dismantling and rebuilding circuits after acute neurological injury. Metab Brain Dis. April, 2015.

Zammar SG(1), Hamade YJ(2), Aoun RJ(2), El Tecle NE(1), El Ahmadieh TY(3), Adelson PD, et, al. The cognitive and technical skills impact of the congress of neurological surgeons simulation curriculum. World Neurosurg. April, 2015.

Khodadad A(1), Adelson PD(2), Lifshitz J(3), Thomas TC(4). The time course of activity-regulated cytoskeletal (ARC) gene and protein expression in the whisker-barrel circuit using two paradigms of whisker stimulation. Behav Brain Res. May, 2015.

Chin KH(1), Bell MJ, Wisniewski SR, Goundappa BG, Kochanek PM, Beers SR, Brown SD, Adelson PD. Effect of administration of neuromuscular blocking agents in children with severe traumatic brain injury on acute complication rates and outcomes. Behav Brain Res. May, 2015.

Adelson PD. Editorial: Severe traumatic brain injury and decompressive craniotomy. J Neurosurg Pediatr. July, 2015.

Harrison JL(1), Rowe RK(2), Ellis TW(3), Yee NS(4), O'Hara BF(5), Adelson PD(1), Lifshitz J(6). Resolvins AT-D1 and E1 differentially impact functional outcome, post-traumatic sleep, and microglial activation following diffuse brain injury in the mouse. Brain Behav Immun. July, 2015.

Quinn JF(1), Patel T(2), Wong D(3), Das S(4), Freedman JE(5), Adelson PD, et, al. Extracellular RNAs: Development as biomarkers of human disease. J Extracell Vesicles. Aug., 2015.

Laurent LC(1)(2), Abdel-Mageed AB(3), Adelson PD(4), Arango J(4), et, al. Meeting report: Discussions and preliminary findings on extracellular RNA. J Extracell Vesicles. Aug., 2015.

Zammar SG(1), El Tecle NE(1), El Ahmadieh TY(1), Adelson PD(2), Veznedaroglu E(3), et, al. Impact of a vascular neurosurgery simulation based course on cognitive knowledge and technical skills in European neurosurgical trainees. World Neurosurg. Aug., 2015.

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Wahnoun R(1), Benson M(2), Helms-Tillery S(3), Adelson PD(1). Delineation of somatosensory finger areas using vibrotactile stimulation, an ECoG study. Brain Behav. Sept., 2015.

Charry JD(1), Rubiano AM(1),(2), Puyana JC(3), Carney N(4), Adelson PD. Damage control of civilian penetrating brain injuries in environments of low neuro-monitoring resources. Br J Neurosurg. Oct., 2015.

Jorge Arango, MD

Quinn JF, Patel T, Wong D, Das S, Freedman JE, Laurent LC, Carter BS, Hochberg F, Van Keuren-Jensen K, Huentelman M, Spetzler R, Kalani MY, Arango J, Adelson PD, Weiner HL, Gandhi R, Goilav B, Putterman C, Saugstad JA. Extracellular RNAs: development as biomarkers of human disease. J Extracell Vesicles. Aug., 2015.

Laurent LC, Abdel-Mageed AB, Adelson PD, Arango J, Balaj L, Breakefield X, Carlson E, Carter BS, Majem B, Chen CC, Cocucci E, Danielson K, Courtright A, Das S, Abd Elmageed ZY, Enderle D, Ezrin A, Ferrer M, Freedman J, Galas D, Gandhi R, Huentelman MJ, Van Keuren-Jensen K, Kalani Y, Kim Y, Krichevsky AM, Lai C, Lal-Nag M, Laurent CD, Leonardo T, Li F, Malenica I, Mondal D, Nejad P, Patel T, Raffai RL, Rubio R, Skog J, Spetzler R, Sun J, Tanriverdi K, Vickers K, Wang L, Wang Y, Wei Z, Weiner HL, Wong D, Yan IK, Yeri A, Gould S. Meeting report: discussions and preliminary findings on extracellular RNA measurement methods from laboratories in the NIH extracellular RNA communication consortium. J Extracell Vesicles. Aug., 2015.

Saunder Bernes, MD

Schrauwen I(1), Szelinger S(2), Siniard AL(2), Corneveaux JJ, Bernes S, et, al. A de novo mutation in TEAD1 causes Non-X-Linked Aicardi Syndrome. Invest Ophthalmol Vis Sci. June, 2015.

Hunter JM, Ahearn ME, Balak CD, DeMello DE, Hall JG, Bernes SM, et, al. Novel pathogenic variants and genes for myopathies identified by whole exome sequencing. Mol Genet Genomic Med. July, 2015.

Chen DH, Méneret A, Friedman JR, Korvatska, Bernes S. ADCY5-related dyskinesia: Broader spectrum and genotype-phenotype correlations. Neurology. Dec., 2015.

Kiley (Bernhard) Vander Wyst, MPH

Baumgardner DJ, Bernhard KA, Egan, G. Pulmonary blastomycosis in Vilas County, Wisconsin: Weather, exposures and symptoms. J Patient-Centered Res Rev. 2015.

Endres L, DeFranco E, Conyac T, Adams M, Zhou Y, Magner K, O'Rourke L, Bernhard KA, Siddiqui D, McCormick A, Abramowicz J, Merkel R, Jawish R, Habli M, Floman A, Magann E, Chauhan SP, CAOG FAR Research Network. Association of fetal abdominal—head circumference size difference with shoulder dystocia: A multicenter study. Am J Perinatol Rep. 2015;5:e99—e104. 2015.

Ruth Bristol, MD

Schwerdt HN, Amjad U, Appel J, Elhadi AM, Lei T, Preul MC, Bristol RE, Chae J. In vitro hydrodynamic, transient, and overtime performance of a miniaturized valve for hydrocephalus. Ann Biomed Eng. 2015 Mar 4. Epub ahead of print. March, 2015.

S. Danielle Brown, RN, MSN

Buttram SD(1), Garcia-Filion P(2), Miller J(3), Youssfi M(3), Brown SD(4), Dalton HJ(5), David Adelson P(6). Computed tomography vs magnetic resonance imaging for identifying acute lesions in pediatric traumatic brain injury. Hosp Pediatr. Feb., 2015.

Chin KH(1), Bell MJ, Wisniewski SR, Goundappa BG, Kochanek PM, Beers SR, Brown SD, Adelson PD. Effect of administration of neuromuscular blocking agents in children with severe traumatic brain injury on acute complication rates and outcomes. Pediatr Crit Care Med. 2015.

John Condie, MD

A Spritzer SD(1), Kinney CL, Condie J, Wellik KE, Hoffman-Snyder CR, Wingerchuk DM, Demaerschalk BM. Amantadine for patients with severe traumatic brain injury: a critically appraised topic. Neurologist. Jan., 2015.

Appavu B, Ashby D, Condie J. Manifestation of West Nile Encephalitis in Infancy. Pediatric Infect Dis Soc. Dec., 2015.

Theresa Currier Thomas, PhD

Khodadad A(1), Adelson PD(2), Lifshitz J(3), Thomas TC(4). The time course of activity-regulated cytoskeletal (ARC) gene and protein expression in the whisker-barrel circuit using two paradigms of whisker stimulation. Behav Brain Res. May, 2015.

Carolyn Hickman, PhD, RN, CPNP

Hickman C, Jacobson D, Melvnk BM. Randomized controlled trial of the acceptability, feasibility, and preliminary effects of a cognitive behavioral skills building intervention in adolescents with chronic daily headaches: A pilot study. J Pediatr Health Care. 2015 Jan-Feb; 29(1): 5-16. Feb., 2015.

Hickman C(1), Lewis KS(1) (2), Little R(1)(2)(3), Rastogi RG(1), Yonker M(1). Prevention for pediatric and adolescent migraine headache. Oct., 2015.

John F. Kerrigan, MD

Wu J(1), Gao M, Shen JX, Qiu SF, Kerrigan JF. Mechanisms of intrinsic epileptogenesis in human gelastic seizures with hypothalamic hamartoma. CNS Neuroscience & Therapeutics, 21(2):104-111. Feb., 2015.

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Michael Kruer, MD

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Philanthropy, Innovation and Growth

In 2015, the Phoenix Children's Hospital Foundation raised $595,107 in cash, pledges and gifts-in-kind for Barrow Neurological Institute at Phoenix Children's. Since 2008, the Foundation has raised a total of $14,601,107 in gifts in-kind, events, pledges and donations.

SUPPORTING BARROW NEUROLOGICAL INSTITUTE AT PHOENIX CHILDREN'S HOSPITAL

Your investment in Barrow at Phoenix Children's helps us develop new paradigms for clinical care and cures for the children we treat. We are grateful for the funding provided by our donors. You can express your support of Barrow at Phoenix Children's 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

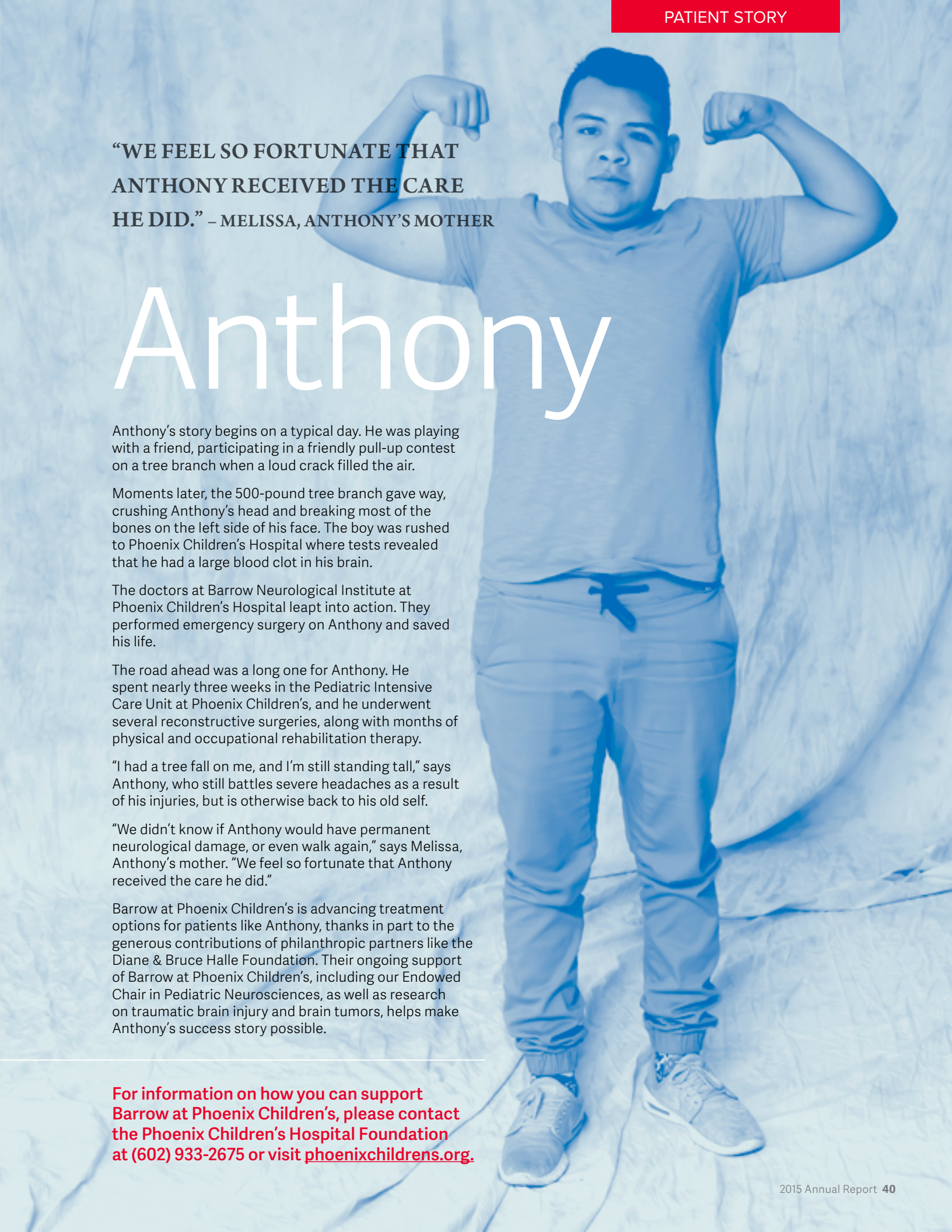
- Development and the enhancement of existing and/or new clinical programs
- Cutting edge programs in clinical, translational, laboratory and experimental research
- Community and professional educational initiatives
- Infrastructure supporting the biorepository, bioinformatics and data centers

WAYS TO GIVE

You've helped us grow! The following are fully or extensively funded through philanthropy:

- Fragile X Clinic
- International Neurotrauma Fellowship
- The Director's Fund has supported:
  - Post-Traumatic Brain Injury Lab
  - Postdoctoral Programs
  - Joint Arizona State University, Phoenix Children's Hospital and Barrow research collaborations

More than 20 patients with Down syndrome modeled the latest fashions during the ***Second Annual Downright Beautiful Fashion Show*** *in 2015. The event raised more than $25,000 for the Pediatric Down Syndrome Clinic at Barrow at Phoenix Children's.*



"WE FEEL SO FORTUNATE THAT ANTHONY RECEIVED THE CARE HE DID." – MELISSA, ANTHONY'S MOTHER

Anthony

Anthony's story begins on a typical day. He was playing with a friend, participating in a friendly pull-up contest on a tree branch when a loud crack filled the air.

Moments later, the 500-pound tree branch gave way, crushing Anthony's head and breaking most of the bones on the left side of his face. The boy was rushed to Phoenix Children's Hospital where tests revealed that he had a large blood clot in his brain.

The doctors at Barrow Neurological Institute at Phoenix Children's Hospital leapt into action. They performed emergency surgery on Anthony and saved his life.

The road ahead was a long one for Anthony. He spent nearly three weeks in the Pediatric Intensive Care Unit at Phoenix Children's, and he underwent several reconstructive surgeries, along with months of physical and occupational rehabilitation therapy.

"I had a tree fall on me, and I'm still standing tall," says Anthony, who still battles severe headaches as a result of his injuries, but is otherwise back to his old self.

"We didn't know if Anthony would have permanent neurological damage, or even walk again," says Melissa, Anthony's mother. "We feel so fortunate that Anthony received the care he did."

Barrow at Phoenix Children's is advancing treatment options for patients like Anthony, thanks in part to the generous contributions of philanthropic partners like the Diane & Bruce Halle Foundation. Their ongoing support of Barrow at Phoenix Children's, including our Endowed Chair in Pediatric Neurosciences, as well as research on traumatic brain injury and brain tumors, helps make Anthony's success story possible.

For information on how you can support Barrow at Phoenix Children's, please contact the Phoenix Children's Hospital Foundation at (602) 933-2675 or visit phoenixchildrens.org.

Meet the 2015-16 Team

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  P. David Adelson, MD
- **Brain Computer Interface at Phoenix Children's Hospital and Arizona State University**
  P. David Adelson, MD; Stephen Helms-Tillery, PhD; and Remy Wahnoun, PhD
- **Neurophysiology of Epilepsy at Phoenix Children's Hospital and University of Arizona College of Medicine – Phoenix**
  P. David Adelson, MD, and Trent Anderson, PhD
- **Neurotrauma-Traumatic Brain Injury in the Developing Brain at Barrow Neurological Institute and University of Arizona College of Medicine – Phoenix**
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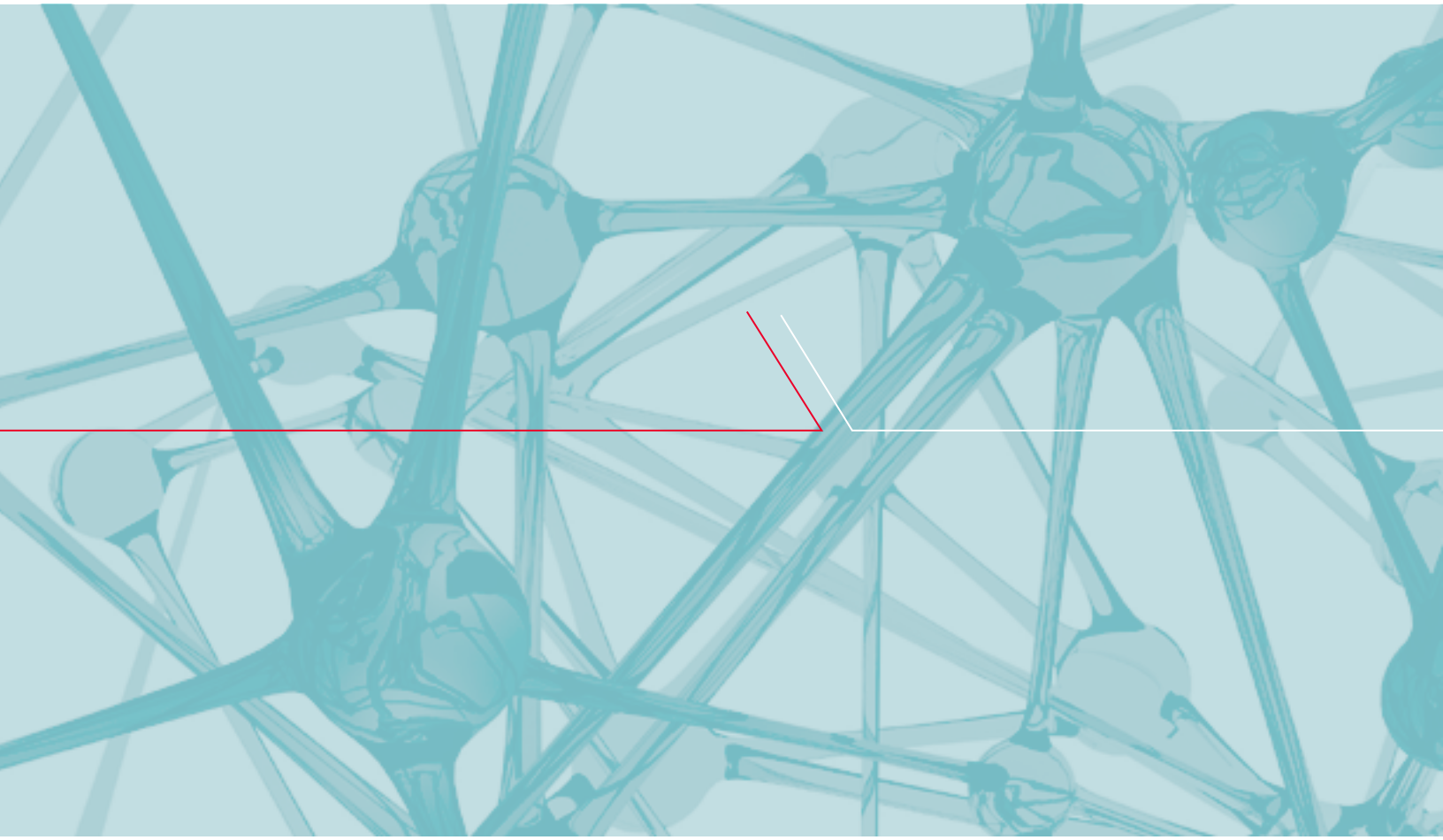

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