

BARROW Neurological Institute

at **PHOENIX CHILDREN'S Hospital**

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Cerebral Palsy: What You Should Know

Receiving a diagnosis of cerebral palsy (CP) can be frightening for a parent, because of the perceived negative connotations associated with the disorder, and because the definition may have different meanings to different people. CP is a neurological disorder characterized by abnormal motor function due to some type of insult to the developing brain. There are many different causes of CP, including prenatal insults, birth-related problems, and prematurity. Any early injury to the developing brain within the first several years of life, including trauma, metabolic disorders, infections, and other problems, can lead to CP.

The spectrum of CP is vast, and can range from mild tightness in a limb, causing little to no gait disturbance, to severe global involvement, with significant cognitive delay, language and intellectual impairments, and severe tightness and disuse of arms and legs. Thus, a child with CP may function with only a very mild problem requiring nothing more than observation, or may be wheelchair bound, requiring maximal assistance with all activities. Almost half of all children with CP have seizure disorders.

The motor manifestations of CP are commonly divided into three broad categories:

- Spasticity
- Dyskinesia
- Ataxia

Spastic CP is the most common type, and is associated with increased muscle tone or stiffness, in the legs more so than arms, often resulting in gait impairment or difficulties with fine motor tasks. Dyskinesia is characterized by uncontrollable movements or abnormal, involuntary postures, and can lead to problems with limb function, as well as embarrassment in social situations. Children with ataxia have difficulties with coordination and balance. Often, the clinical picture is mixed, with a variety of motor disturbances.

100% for Tenley

When Theron and Beth Martineau took their twenty-one-month old daughter, Tenley, to their pediatrician last January they had no idea of the journey they would soon be taking. In early January they noticed Tenley walking off balance and regressing in her milestones. They weren't real worried and thought that since she recently had an ear infection, it could be related. However, their pediatrician recognized Tenley did not fit the usual profile of a child with an ear infection and recommended an MRI. "We wanted to have the very best care available," said Beth. So, the Martineau family brought Tenley to the best hospital for children, Phoenix Children's Hospital. At the hospital, an MRI was ordered and the Martineau's anxiously awaited the results.

The news was not good. Tenley had a large tumor growing in

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

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P. David Adelson, MD
Director, Barrow Neurological
Institute at
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From the Director

In this issue, we focus on children with cerebral palsy or CP, which unfortunately affects three out of every 1,000 children. Most often due to an anoxic and or ischemic injury in utero or at birth, the resulting complex condition affects many aspects of a child's life. In particular it is the most common motor disability seen in children with spasticity affecting gait and activities of daily living. As well many children with CP are left with cognitive and other neurological problems. Often the children living with this condition require a full continuum of care throughout their childhood and into adulthood. The diagnosis of a complex neurological condition impacts the entire family and as part of our vision to provide the optimal patient centric care, we also need to provide families with the support and education necessary to help them make the best decisions and be the best advocate for their children.

The CP Center, as part of the collaboration between Barrow Neurological Institute at Phoenix Children's Hospital and the Department of Orthopedics, is a multidisciplinary program dedicated to providing the best possible care for these children. Our mission is to improve the health and quality of life of children with neurological disorders, the CP Clinic combines the wide array of expertise of our many subspecialists in neurology, neurosurgery, orthopedics, physiatry, physical medicine and rehabilitation, amongst others. This collaborative initiative, under the leadership of M. Wade Shrader, MD, PhD, who has vast experience in the needs, care, and advances in CP management, provides the necessary patient-and-family centered, high quality care children with cerebral palsy need, improving their clinical experience.

Aside from providing state-of-the-art care for these children, our team participates in and helps drive clinical and translational laboratory research that will ultimately lead to new and more effective treatments and improve in the care given to these children to improve their quality of life. Besides

the cutting edge technologies for the care and management of these children, new and innovative approaches are being developed to assist in a better understanding of the unique aspects of care that each individual child needs. With the newly developed Bubba Watson Motion Analysis Laboratory, through the recruitment of new pediatric motion analysis expertise and the growing collaboration with the School of Biological and Health Systems Engineering at Arizona State University, we expect to be able to report about all of the new initiatives on the horizon happening here at Phoenix Children's Hospital that make this an exciting time for generating new advances in the care and rehabilitation of these children right now.

Again, we hope you enjoy each of our newsletters. As you may have noticed, topics change from issue to issue because we listen and are responsive to your suggestions for improving the content and format and providing information that interests you. Please continue to send us suggestions and comments about improving this publication and, more importantly, ways we can enhance the care and service we provide. Thank you!

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

Cerebral Palsy: What You Should Know

continued from cover...

Many studies have shown that early intervention can help improve the quality of life of children with CP. This is why multidisciplinary care may lead to the best possible outcome for a child. Our multidisciplinary team includes some of the most respected pediatric cerebral palsy and neurological specialists in the country. A comprehensive approach to treating cerebral palsy begins with early awareness of an episode or event that puts a child at risk for cerebral palsy. The neonatal intensive care unit and the Phoenix Children's Fetal Care Network are especially equipped to recognize these high-risk situations, to ensure close surveillance of at-risk children.

TREATMENT OPTIONS

The mainstay of treating the motor dysfunction in kids with CP is rehabilitative therapy, including physical, occupational, and speech therapy. These vital interventions should be started as early as possible, and can be done in the home, in the community, or as part of a school-based program. Our division of Physical Medicine and Rehabilitation (physiatry), under the leadership of Dr. Ewa Brandys, is at the forefront of providing this level of care for these children and their families.

If more intervention is necessary, the use of oral antispasmodics may be helpful, and is usually the next tier of treatment initiated. For most children with cerebral palsy, rehabilitative therapy and oral medications are the primary treatments during the first few years of life.

Children with CP who have severe spasticity or dystonia may not gain relief from medication or physical therapy alone. As a result, there are times neurosurgical and other types of operative intervention can significantly help improve a child's ability to overcome his or her functional limitations. David H. Shafron, MD, Neurosurgical Director of CP and pediatric neurosurgeon has a strong interest in and over 15 years of vast experience helping and treating children with cerebral palsy and other complex movement disorders. By utilizing both medical and surgical management for the care of children with such problems, the goal is to minimize the degree of spasticity and dystonia, resulting in enhanced comfort, improved gait, and ultimately, quality-of-life. There are a number of interventions available to treat spasticity and dystonia. These include: botulin (Botox®), intrathecal baclofen, selective dorsal rhizotomy, deep brain stimulation (DBS), and other modalities.

If further relaxation of muscle stiffness is needed, Botox injections provide a targeted, minimally invasive means to help reduce muscle



Cerebral Palsy Team



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tone. This year, the center is on track to perform nearly 150 such treatments, with numbers growing each year.

For children in whom oral medications are unable to provide enough relaxation of tone, another commonly used means of treatment is the placement of an intrathecal baclofen (ITB) pump. Baclofen is the most commonly used oral agent to treat both spasticity and dystonia, but in order to exert its beneficial effect, the drug must travel through the circulation and then cross a barrier to gain access to the brain and spinal cord, resulting in systemic side effects, such as sedation. Intrathecal therapy allows much lower doses of the medicine to be delivered directly into the fluid compartment that bathes the central nervous system, providing potent relaxation and reducing systemic side effects. ITB therapy has been shown to be effective for both spasticity and dystonia, and in addition to reducing tone and abnormal movements, it enhances comfort, makes it easier for patients and parents to perform activities of daily living (ADLs), and may reduce the need for future orthopedic procedures.

Another procedure performed by a neurosurgeon for tone reduction is a selective dorsal rhizotomy (SDR), an operation in which a percentage of the sensory nerves emanating from the spinal cord, enervating the legs, is cut. During the operation, the spinal sensory nerves serving the legs are exposed and electronically tested, and the ones involved in the most problematic tone patterns are divided. This interrupts a pathologic reflex arc that leads to lower extremity

spasticity, resulting in significant and rapid tone reduction.

The best candidates for a SDR procedure are children with spastic diplegia, a subtype of cerebral palsy that primarily affects the legs, and in which there is little or no dystonia. The main benefit of a rhizotomy is that spasticity in the legs is dramatically reduced, and improved gait is seen in the majority of patients. The need for future orthopedic surgery is also reduced. After the surgery, a child requires intensive, often inpatient, therapy in order to strengthen the leg muscles and relearn effective gait patterns.

Children with CP often have orthopedic challenges, because of the effects of abnormal nervous input to the muscles, with subsequent deformity of bones, joints, and spine. Many children with CP require orthopedic procedures in order to enhance function, lessen discomfort, and improve self-image and quality of life.

Pediatric orthopedic surgeon and Center for Pediatric Orthopedics Co-Division Chief M. Wade Shrader, MD, who leads the CP Center, is a leading expert in the orthopedic care of children with CP and was the first in Arizona to perform the Ganz Osteotomy, a

surgical procedure that deepens the hip socket to prevent the pain of hip dislocation, something often experienced by children with cerebral palsy.

CP results in a complex neurological disorder that requires a multidisciplinary team like the one at Phoenix Children's Hospital's Center for CP and Barrow at Phoenix Children's. Early intervention has been shown to improve the health and quality of life of children with CP, and therefore it is important they obtain a comprehensive evaluation and treatment plan to optimize their long-term outcome. There are a number of medical and surgical interventions that we feel are best performed at specialized centers that have the requisite expertise and ability to follow patients throughout childhood and young adulthood.

For more information on CP, please visit <http://barrow.phoenixchildrens.org/cerebral-palsy>

New and Improved Frances H. McClelland Pediatric Rehabilitation Center

We are dedicated to helping children achieve their highest level of independence through the use of specialized pediatric clinical interventions and state-of-the-art pediatric equipment and age appropriate, developmentally selected activities.

The Frances H. McClelland Pediatric Rehabilitation Center is the only inpatient pediatric rehabilitation facility in the state of Arizona and was made possible through the generosity of the family of Francis H. McClelland the Shamrock Foundation. The Center, led by Ewa Brandys, MD, has always been committed to offering comprehensive, multidisciplinary care that helps children achieve their optimal level of independence. With the recent opening of our new and improved 15,451-square-foot inpatient and outpatient centers, the rehabilitation team is now even better equipped to assist in providing the best possible care for children with complex conditions. The new center is located in the East Building on the main campus of Phoenix Children's Hospital. It features the only inpatient rehabilitation program in Arizona just for kids. This allows even very ill children who need intensive rehabilitation to get the therapies they need but close to the acute care hospital and pediatric medical specialists.

Our comprehensive rehabilitation program has a dedicated unit with two teams of pediatric therapists including physical, occupational, and speech therapy. The team also includes the care of physician specialists, pediatric nursing, Child Life specialists, hospital based school teachers, music therapy, animal assisted therapy, nutrition, social work, and case management.



The new rehabilitation center offers:

- 12 private inpatient rooms
- A large, open patient gym with rubberized flooring
- Private treatment rooms
- Wii system
- RT600 and RT300 integrated therapy systems
- Sensory integration swing
- Rock climbing wall
- Kitchen space for intensive feeding program
- Dedicated sensory therapy room
- Certified hand specialist
- Dedicated Child Life and social work team members
- Community re-entry program

Recognition

John Condie, MD; **Sandra Buttram, MD**; and **Paul Liu, MD** were recently Board Certified in the sub-specialty of Neurocritical Care.

Barrow at Phoenix Children's Epilepsy Center Recognized

Barrow Neurological Institute at Phoenix Children's Hospital is proud to announce it was again recognized by the National Association of Epilepsy Centers (NAEC) as a Level 4 epilepsy center. Level 4 epilepsy centers have the professional expertise and facilities to provide the highest-level of medical and surgical evaluation and treatment for patients with complex epilepsy.

Congratulations to Developmental Pediatrics Director **Robin Blitz, MD** who was selected as one of Phoenix magazines Top Doctors for 2014.

Science Foundation Arizona recently announced that **Rachel Rowe, PhD**, a research scientist trainee with the Translational Neurotrauma Research Program at Barrow at Phoenix Children's and University of Arizona, was awarded a Bisgrove Fellowship. The award is given to outstanding post-doctoral or early tenure track scholars in support of their research in Arizona. Congratulations, Dr. Rowe!

Congratulations to Pediatric Neurosurgeon **Ratan Bhardwaj, MD** who was recently recognized by Phoenix Business Journal as a Health Care Hero.

Down Syndrome Clinic

On March 21, we celebrated World Down Syndrome Day and the one year anniversary of Barrow at Phoenix Children's opening Arizona's first Down syndrome Clinic. This one of a kind Clinic has evaluated more than 100 children since opening and offers a coordinated continuum of care under one roof.

More than 200 people attended the Inaugural Down Syndrome Fashion Show on May 5th. All proceeds from this event, \$14,034 were donated to the Down Syndrome Clinic.

Gainey Ranch Golf Charity Event Supports Barrow at Phoenix Children's

Thank you to everyone who joined us at the Gainey Ranch Club Corp Charity Classic. In support of Gary Rossman, a benefactor of Barrow Neurological Institute at Phoenix Children's Hospital, the event raised almost \$15,000 for the Neuro-Regenerative Neuroscience Program. To learn more about this event please visit our website: <http://barrow.phoenixchildrens.org/ClubCorp-Gainey-Ranch>



Barrow at Phoenix Children's Professional and Community Education Presentations

Barrow Neurological Institute at Phoenix Children's Hospital director and Division Chief of Neurosurgery **P. David Adelson, MD**, presented the keynote address at the Pediatric Brain Injury Management at the European International Paediatric and Neonatal Intensive Care Symposium in Ljubljana, Slovenia.



P. David Adelson, MD, lectured on Neurocutaneous Disorders at the European Association of Neurosurgical Societies Resident Training Course in Nicosia, Cyprus

Jonathan Lifshitz, PhD, and Theresa Thomas, PhD, presented the poster, "Extracellular Matrix Biomarkers for Acute Neurological Injury," at the International Neurotrauma Society Meeting in Budapest, Hungary.

6th Annual Down Syndrome Medical Conference, Community and Parent Educational Conference, held in May.

Recent Advances in Pediatric Epilepsy presented by Barrow at Phoenix Children's and the Epilepsy Foundation of Arizona, Community and Parent Educational Conferences, held in April.

The **2014 Annual Children's Neuroscience Symposium** was a great success. With more than 200 attendees in the span of four days, doctors, nurses and other medical professionals came from all over the world to hear presentations on topics such as pediatric spasticity, concussions, developmental pediatrics and epilepsy.

100% for Tenley

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the center of her brain. It was obstructing the cerebrospinal fluid flow within the brain. “We were devastated, shocked, upset, and terribly frightened. It was the worst day of our life,” said Beth. Pediatric neurosurgeons from Barrow Neurological Institute at Phoenix Children’s Hospital were called and came immediately to consult on the case. “Dr. Krystal Tomei (pediatric neurosurgery fellow) was amazing—she talked to us with such empathy, in such a consoling and caring way. We will never forget this amazing woman. It was obvious she cared and would do everything in her power to help Tenley,” said Beth. Throughout the Martineau’s hospital stay, Dr. Tomei remained close to them forming a special bond that would not be forgotten. The family, more and more, were convinced if anyone could help Tenley, it would be the dedicated physicians and staff at Phoenix Children’s Hospital and Barrow Neurological Institute.

After discussions between the doctors and the family, it was decided Tenley needed a two stage approach to treatment. The first surgery had to be done as soon as possible due to the obstruction of her cerebrospinal fluid pathway. The surgery was performed the next morning with two goals: first to find out the pathologic diagnosis and secondly to create an alternative pathway for her obstructed cerebrospinal fluid. As a result, Tenley underwent a third ventriculostomy. The doctors created a small hole in the floor of the third ventricle in the brain, to relieve the build-up of fluid pressure in Tenley’s brain and obtain a piece of the tumor for diagnosis. This was done endoscopically using a small camera through a small incision on the top of Tenley’s head. The first surgery successfully relieved the fluid pressure and the tissue provided the necessary information to make a decision of what to do next.

The family’s worst nightmare though came with the results of the biopsy. The tumor was a very rare and a potentially fatal brain tumor—a mixed germ cell tumor called a teratoma. Due to the complexity and location of the tumor the next step was major surgery, to remove as much of the tumor as safely possible. This surgery was scheduled two days later. Because of his expertise, chief pediatric neurosurgeon and Director of Barrow at Phoenix Children’s, Dr. P. David Adelson was brought in to care for Tenley and her family.

“It was a serious diagnosis and a difficult location; this tumor was growing deep in the middle of Tenley’s brain. In many instances, it is difficult to visualize the borders of this type of tumor because the abnormal tissue often blends into the surrounding normal tissues,” said Dr. Adelson. “Fortunately at Phoenix Children’s we have all the tools necessary to take care of these children and families.” Barrow at Phoenix Children’s is equipped to provide all the necessary complex and comprehensive care for children with brain tumors. They have the expertise in neurosurgery, image guidance, microsurgical techniques, neuro-imaging and neuro-oncology, expertise that is vital for the total care of a child with difficult tumors from diagnosis through cure. In the five hour surgery, Dr. Adelson gained access to the tumor through a small corridor between the hemispheres of the brain to microscopically dissect the tumor away from the normal brain and major blood vessels, isolating the tumor and preserving the surrounding normal brain tissue. While a difficult surgery, especially for a small child like Tenley, the tumor was successfully and completely removed.

The Martineau’s were happy Tenley’s walking skills significantly improved within a few weeks.

The final pathology though showed yet another concern. Because a small part of the tumor was found to be malignant, there was a possibility of the cancer spreading to the rest of Tenley’s central nervous system. Dr. Michael Ettl, the medical director of the Center for Cancer and Blood Disorders, and a neuro-oncologist at Barrow at Phoenix Children’s was consulted early on. Phoenix Children’s Hospital is the only pediatric cancer center in Arizona able to care for children with complex brain tumors like Tenley. With access to all of the latest technologies, drugs and clinical expertise they are the only pediatric cancer center with the ability to do clinical trials with cutting-edge knowledge and interventions that would otherwise not be available in other parts of the community. For children like Tenley, this means they have the best chance to have their tumors eradicated and cured.

Tenley underwent a comprehensive evaluation to determine whether further therapy was necessary. “It only took two days for us to get an answer, but it was the longest two days ever,” said Beth. Since the tumor had been completely removed and there were no indications it had spread to other areas no further treatment would be necessary other than surveillance at this time. “We were ecstatic! We took Tenley out for ice cream, a favorite of hers! We also will be going to San Diego for a vacation in a few weeks. We are looking forward to being normal again,” said Beth.

Today, Tenley is doing remarkably well. She has been through more in a few months than most people will experience in a life time—and all before her second birthday. Tenley goes to physical therapy three times a week to catch up on milestones she lagged behind on while the tumor was impairing her development. She is growing, walking, running, talking and playing happily with her two older siblings. She loves music, dancing and tea parties. “We are all very grateful for the care and compassion she received while at Barrow Neurological Institute at Phoenix Children’s,” said Beth, “Our friends—at Phoenix Children’s Hospital will never be forgotten—they are etched forever in our hearts.”



“Our friends at Phoenix Children’s Hospital will never be forgotten – they are etched forever in our hearts.”

Upcoming Events

2015 Children's Neuroscience Symposium Update

We look forward to seeing everyone at our next conference March 1-4, 2015 in Phoenix. We welcome keynote speaker Mark S. Wainwright, MD, PhD, Medical Director of the Pediatric Neurocritical Care Program and attending pediatric neurologist at the Ann & Robert H. Lurie Children's Hospital of Chicago.

Keynote Address

Brain-Directed Critical Care for Children:
Opportunities and Lessons from the Laboratory
Please visit: www.phoenixchildrens.org/CNS2015
for more information.

4th Annual Current Topics in Sports Medicine

Join us at the Concussions: 2015 Conference, held in conjunction with the Cactis Foundation on February 28, 2015.

Please visit: www.cactisfoundation.org for more information.

Recently Published Research

Kidd SA, Lachiewicz A, Barbouth D, Blitz RK, Delahunty C, McBrien D, Visootsak J, Berry-Kravis E. Fragile X Syndrome: A review of associated medical problems. *Pediatrics*. October, 2014.

Casella EM, Thomas TC, Vanino DL, Fellows-Mayle W, Lifshitz J, Card JP, Adelson PD. Traumatic brain injury alters long-term hippocampal neuron morphology in juvenile, but not immature, rats. *Child's Nervous System*, August 2014.

Arango JI, Allred K, Adelson PD, Soni P, Stradleigh R, Wahnoun R, Carballo C. Hypothermia in Hypoxic Ischemic Encephalopathy: A 5-Year Experience at Phoenix Children's Hospital Neuro NICU. *Advances in Pediatrics*, August 2014.

Welcome to New Faculty and Staff

Barrow at Phoenix Children's continues to grow!! It is our pleasure to welcome new faculty and staff since the last newsletter:



**Rebecca Berghorst, MD,
Psychiatry**



**Kiley A. Bernhard, MPH,
Research Coordinator**



**Nancy Buckner, MD,
Psychiatry**



**Brian Burrows,
Research Assistant**



**Shelley Flecky, PA-C,
Neurosurgery**



**Aida Hadziahmetovic, MD,
Psychiatry**



**Mary Johnson, MD,
Neurology**



**Joanna Kowalik, MD,
Psychiatry**



**Kelly Mahaney, MD,
Neurosurgery Fellow**



**Makram Obeid, MD,
Neurology/Epilepsy**



**John Zaharopoulos, DO,
Psychiatry**



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

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or scan this code with your smartphone.



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

Barrow Neurological Institute at Phoenix Children's Hospital continues to grow and is only possible through your and the community's support. Any funding support can be directed to the clinical support of children with neurological disease or disorder, to research or education, or to improve the quality of life for these children while here at the hospital. While you prepare for your own future, you have the opportunity to impact the future of our patients with a legacy gift or bequest to Barrow Neurological Institute at Phoenix Children's Hospital. Legacy gifts and bequests have an enduring impact on the children treated at Barrow Neurological Institute at Phoenix Children's Hospital - patients who need our specialized care. Planned giving enables you to focus your philanthropic goals, while realizing significant income and tax benefits. Your visionary gift can help us provide a brighter future for our patients as you plan for your own.

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

WHAT PHILANTHROPY SUPPORTS:

- Development/enhancement of existing and new clinical programs
- Funding cutting-edge programs in clinical, translational, laboratory and experimental research
- Community and professional educational initiatives
- The Institute's infrastructure supporting the Biorepository and Bioinformatics and Data Centers

WAYS TO GIVE:

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

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