

brain care institute

A powerful team dedicated to a single purpose. Welcome to the Brain Care Institute at Children's Hospital of Pittsburgh of UPMC. As a nationally ranked pediatric hospital, we are a recognized leader in the development of innovative treatments and approaches to disorders of – and injuries to – the brain, spinal cord, nerves, and muscles.

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We continue our commitment to providing the highest level of expertise to patients and families with a team of pediatric neurosurgeons, neurologists, neuroradiologists, critical care doctors, neuro-oncologists, rehabilitation specialists, and behavioral health specialists dedicated to the total well-being of children who face even the most difficult situations.

It is rare to find such a combination of expertise, technology, research, innovation, and compassion all in one convenient place. Every aspect of care is covered within the Brain Care Institute. Our approach is designed to ensure that every patient is given a chance to have the best quality of life possible, and that means more than just treating the actual brain injury or disorder. It means surrounding patients and families with experts from all areas of brain care, and providing long-term, ongoing support, when necessary, so they never feel alone on their journey to recovery.

Helping our young patients meet life's toughest challenges is our passion at the Brain Care Institute. Let us show you more reasons why there is no better place to be for children and families.

#### MAGNET RECOGNIZED MERICAN NURSES CREDENTIALING CENTER

Among only 6 percent of hospitals nationwide to earn prestigious Magnet<sup>®</sup> recognition

Top care. Top results.



Named to *U.S. News & World Report's* Honor Roll of America's Best Children's Hospitals year after year



Named to *Parents* magazine's 2013 listing of the 10 Best Children's Hospitals



of the tristate region's families in need of pediatric neurological consultation and care choose Children's as their preferred provider

One the 1st

Pediatric Intensive Care Units with physicians specialized in neurological disorders and trauma available 24-7

home

of the internationally recognized Program for the Study of Neurodevelopment in Rare Disorders

#### Specialty Services and Clinics

Brain Injury Follow-Up Clinic Brain Tumor Chiari Malformation Cleft-Craniofacial Disorders Craniofacial Surgery Craniosynostosis Endonasal Surgery Epilepsy Surgery Fetal Repair of Neurosurgical Problems Glioma Vaccine Head Injuries Headache Clinic Hydrocephalus Ketogenic Diet Clinic Minimally Invasive Brain Surgeries Mitochondrial & Metabolic Disorders Movement Disorders Moyamoya Syndrome Neonatal Neurocritical Care Neonatal Neurology Neurodegenerative Disorders Neurodevelopment Neurotrauma & Neuro-Critical Care Neurofibromatosis Neuroimaging Neuroimmunology Neuromuscular Disorders Seizures Spasticity Spina Bifida Stroke Tethered Spinal Cords Tourette Syndrome Tuberous Sclerosis Vascular Anomalies

# The faces of hope.

They are everywhere at Children's Hospital. At the Brain Care Institute, we see more than 14,000 patients a year, and they come from all parts of the nation and the world. Everything we do, from our innovative research to our unique treatment plans, is driven by a tireless work ethic and a compassionate understanding of the needs of both the child and family.

# Expertise built on a tradition of excellence.

Our physician-scientists are nationally recognized for their work in pediatric neurology, neurosurgery, neuro-oncology, neuroradiology, behavioral health, and critical care, and provide an unparalleled level of expertise to infants, children, and teens suffering from brain and spinal cord injuries and disorders. Our teams work together to evaluate neurological disorders and injuries at their deepest level, and provide both patients and families with more effective and more comprehensive treatments and care plans.

- Board-certified, nationally and internationally recognized doctors
- Pioneering breakthrough studies and clinical trials
- Innovative, leading-edge advancements across all areas of brain care

# A state-of-the-art hospital for leading-edge brain care.

Quality care and patient and family comfort go hand in hand here. We immerse children and families in a bright, colorful environment powered by the world's most advanced medical technology. We were the first pediatric hospital to achieve a Stage 7 Award from HIMSS Analytics (Healthcare Information and Management Systems Society) for our electronic medical record – which made us one of the nation's first paperless pediatric hospitals. Stage 7 is the highest recognition possible from HIMSS, a leading independent data and analytics firm. Our commitment to technology reduces errors, streamlines decision-making, and puts critical information at the fingertips of doctors and caregivers. Our new hospital also features playful interiors, comfortable rooms, a family resource center, outdoor Healing Garden, music therapy room, and more.

- We were recognized by KLAS (an independent health care research organization) as the leader in our use of health care information technology.
- We achieved Magnet designation in 2012 from the American Nurses Credentialing Center. The Magnet Recognition Program<sup>®</sup> recognizes health care organizations for quality patient care, nursing excellence, and innovations in professional nursing practice.



#### Research driven. Results oriented.

Whether developing breakthrough vaccines to treat complex brain tumors or discovering new medications for epilepsy patients, we are continually pushing the boundaries of medical research. As one of the fastest growing National Institutes of Health-funded pediatric research programs in the country, we explore cutting-edge medical treatments and conduct innovative clinical trials. Our research has improved treatments and therapies, expanded the use of minimally invasive surgical techniques, and shed new light on neuromuscular disease, inflammatory brain and spinal cord disease, nerve tissues, childhood cancers, head injuries, and more.

- Ian F. Pollack, MD, chief, Pediatric Neurosurgery, received the prestigious Mahaley Clinical Research Award from the National Brain Tumor Society for a first-of-its-kind study of a peptide vaccine that showed evidence of immunological response in children with gliomas. This reflects a collaborative effort of Neurosurgery, Neuro-Oncology (Dr. Regina Jakacki), and the University of Pittsburgh Cancer Institute (Drs. Hideho Okada and Lisa Butterfield).
- The Pediatric Neurosurgery Division is at the forefront of cutting-edge research in brain tumors, hydrocephalus, and other neurosurgical disorders of childhood.

- Children's PICU and NICU participated in an international clinical trial that studied the effects of hypothermia therapy in the treatment of children with traumatic brain injuries.
- Our Division of Child Neurology receives in excess of \$1 million in federal, corporate, and foundation research funding each year, enabling us to continue our leading studies in a wide array of areas – from identifying seizure medications to use for particular epilepsies to what affects the recovery of a child post-stroke.
- Our Division of Pediatric Critical Care Medicine received in excess of \$10 million in federal research funding this year to support cutting-edge research with the goal of transforming care of the brain-injured child.



# Stories of courage.

We are inspired every day by the resiliency, strength, and fearlessness of our patients and families. Their smiles lift our spirits. Their struggles make us work harder. And their ability to take on whatever life throws at them gives us profound hope in the future.

#### Nicolas Griffith Boonsboro, Maryland

Dopamine-Responsive Dystonia (DRD) -Tyrosine Hydroxylase Deficiency (TH)

Nicolas was just 10 months old when his parents noticed the symptoms of his movement disorder. He wasn't developing as a typical baby should, which led them to consult physicians around the country and eventually led them to the specialists at Children's Brain Care Institute. A neurologist and movement disorder expert provided the Griffiths with Nicolas' complete diagnosis, while adjusting his medications and therapies to fit his needs. He also worked closely with Dr. Elizabeth Tyler-Kabara, a neurosurgeon at Children's who has an extensive background in movement disorders and spasticity. It was their unique collaboration that resulted in the decision to implant a deep brain stimulation device to limit Nicolas' uncontrolled movements. The surgery required approval from the Food and Drug Administration because at the time of his surgery, Nicolas was the youngest patient in the United States to receive this sort of implantation. Nicolas' quality of life has significantly improved, and he is becoming increasingly independent.

"From the first visit we had with our doctor, he gave us hope. He said that Nicolas was at a doorway, but the door is shut and we need to open it and go through."

– Dawn Griffith, Nicolas' Mother



#### Leah Koller Waynesburg, Pennsylvania

#### Pediatric Glioma

Several years ago, Leah took part in an experimental treatment for gliomas spearheaded by the Brain Care Institute at Children's Hospital of Pittsburgh of UPMC. Gliomas, a complicated form of brain tumors, are particularly challenging to treat. Because of the location of Leah's tumor, doctors knew that removing it would cause her to be paralyzed on her right side. It also appeared that Leah's tumor was spreading throughout the brain, which made surgery an even less viable option. And other treatments, like radiation, posed the threat of developmental damage. Leah and her family chose to participate in the Glioma Vaccine Trial, led by Drs. Ian Pollack and Regina Jakacki, which was adapted from an earlier adult study. As a result, the glioma in Leah's brain slowly began to shrink and is now half its original size. Due to its success with Leah and other patients of the Brain Care Institute, the trial is now in the process of being adopted by children's hospitals across the nation.

"Dr. Jakacki is just part of our family, whether she wants to be or not, she's part of us now."

- Raelene Koller, Leah's Mother

#### Nathan Barcaskey Pittsburgh, Pennsylvania

#### Moyamoya Syndrome

Nathan Barcaskey was a healthy, happy, energetic kid. He loved to wrestle, play basketball, and take hikes in the woods. When Nathan started complaining of bad headaches, his mother took him to the family's PCP, who recommended that she see Dr. Bilal Sitwat, a neurologist in the Brain Care Institute at Children's Hospital of Pittsburgh of UPMC. Dr. Sitwat immediately ordered an MRI for Nathan and reviewed the scans with a team of doctors from the Brain Care Institute. They concluded that Nathan was suffering from a rare brain disorder known as Moyamoya syndrome, which restricted blood flow to Nathan's brain. Within a few weeks, Dr. Stephanie Greene, a neurosurgeon at Children's, performed a complex and delicate operation to redirect healthy blood vessels to Nathan's brain. Today, he has regained the energy and youthful spirit that made him a favorite among his six siblings and countless friends.

"They spoke to me in terms I could understand, and they quickly found out what my son was suffering from. I felt confident that they were the best people to treat Nathan and I was right – they saved his life."

- Colleen Barcaskey, Nathan's Mother

# How it all comes together for you.

What is truly innovative about the approach of the Brain Care Institute at Children's Hospital of Pittsburgh of UPMC is the speed with which experts from all areas of brain care can come together and put the full force of their training, technology, and intelligence to bear upon any particular child's case. The system is designed so that doctors and other specialists can quickly get to the heart of a problem – even the most rare – and identify the most effective ways to treat it. Our top priority is to give families the confidence and comfort of knowing there is no better place in the world for them to be.



The Brain Care Institute at Children's Hospital of Pittsburgh of UPMC is an innovative model of efficiency, expertise, and world-class care. It comprises a team of highly experienced physicians and caregivers dedicated to providing top-of-the-line, compassionate care to children suffering from injuries to – or disorders of– the brain, spinal cord, nerves, and muscles.



#### Neurology & Neurosurgery

At the core of this system of care are Neurology, where neurological diseases and disorders are diagnosed and treated to provide the most up-to-date care plans, and Neurosurgery, where our team of pediatric neurosurgeons focuses on finding the least invasive and quickest ways to enable a child's recovery.



#### Epilepsy Center & Epilepsy Surgery

Our expertise in the research, diagnosis, and treatment of epilepsy is a key component of the Brain Care Institute. Our Epilepsy Monitoring Unit (EMU) provides state-of-the-art individualized treatment to patients 24/7. And we are recognized around the world for our groundbreaking research and comprehensive testing procedures, such as epilepsy focus mapping, which is used to diagnose the root causes of seizures.



#### Pediatric & Neonatal Neurocritical Care

This core care is then supplemented by other important specialty services such as Pediatric and Neonatal Intensive Care for both acquired (such as traumatic) and congenital cases.

#### Oncology/Neuro-Oncology

Dur neuro-oncologists apply the latest research findings and protocols to treat the wide range and complexities of pediatric brain tumors. Radiology Neuroimaging

Behavioral Health Neuro-Ophthamology Developmental Medicine

> Autism & Down Syndrome

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# Neurology

Neurodevelopmental Disorders & Rare Disorders

Genetic & Metabolic Medicine

Pediatric & Neonatal Intensive Care

> Neurocritical Care

Epilepsy Center & Epilepsy Surgery

> Neurorehabilitation

Rehabilitation Medicine

Hematology Oncology

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Neuro-Oncology

Endoscopic Endonasal

Approach

Neurosurgery

Radiology Neuroimagi

Behavioral Health Neuro-Ophthalmology

ENT

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#### ENT Our neur approach

#### ENT/Endoscopic Endonasal Approach

Our neurosurgeons work closely with ear, nose, and throat surgeons, using leading-edge approaches and minimally invasive surgical techniques that can speed recovery and shorten hospital stays.

## **Rehabilitation Medicine**

Our focus on healing is further enhanced through Pediatric Rehabilitation Medicine services that offer patients neurorehabilitation focusing on recovering lost function and improving quality of life.

## Developmental Medicine/Autism & Down Syndrome

Our expertise in autism, Down syndrome, and other neurodevelopmental disorders allows us to provide a lifetime of child development support and resources to patients and their families.

## Genetic & Metabolic Medicine/Neurodevelopmental Disorders & Rare Disorders

Enormous advances are being made in the diagnosis and treatment of these complicated disorders. We have a team of experts to guide families through many new testing procedures, medical concepts, and therapies.

## Radiology/Neuroimaging

Intersecting all areas of this total system of care is Radiology/Neuroimaging, where our leading expertise in pediatric neuroimaging and research gives us the ability to see the unseen and identify the unknown. Through advanced technologies and next-generation imaging systems, we raise the level of care for every patient.

## Behavioral Health/Neuro-Ophthalmology

Caring for the emotional and physical impact of a brain injury or disorder begins the moment a family enters our doors. Our pediatric Behavioral Health team features some of the world's most experienced clinicians and specialists, dedicated to giving kids and parents the tools they need to enjoy the highest quality of life possible. Our Neuro-Ophthalmology program combines the fields of ophthalmology and neurology through diagnosis and management of patients with neurological disorders that affect vision and the eye.

To learn about our breakthrough clinical trials and studies, please visit www.chp.edu/bci.

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# Innovation, leadership, compassion.

Our success in uncovering the mysteries of the brain is reflected in our world-renowned status among pediatric hospitals, and the impact that our doctors make on the field of neuroscience. Parents, as well as physicians, seek out our expertise because they know the level of care they receive here is second to none.

#### Neurosurgery

- Elizabeth Tyler-Kabara, MD, PhD, is part of a team of researchers at the University of Pittsburgh who worked on the brain-computer interface (BCI) technology resulting in the first time that a person with longstanding quadriplegia could maneuver a mind-controlled, humanlike robot arm in seven dimensions (7D) to consistently perform many of the natural and complex motions of everyday life.
- In utero myelomeningocele surgery can prevent the extreme symptoms of spina bifida and postnatal surgery. Stephanie Greene, MD, trained in the surgery at a course at the University of California San Francisco.
- Our Spina Bifida clinic here is one of the largest clinics of its kind in this country.

We have four pediatric neurosurgeons on staff.

#### Endoscopic Endonasal Approach (EEA)

Surgeons at UPMC have pioneered two minimally invasive alternatives to open brain surgery. Our multidisciplinary team of neurosurgeons, otolaryngologists, and ophthalmic surgeons is among the most experienced in the world in using these surgical techniques for patients of all ages — including pediatric patients. In addition, the vibrant new Children's Hospital of Pittsburgh of UPMC offers a state-of-the-art neurosurgical suite that was designed especially for these procedures.

#### Program for the Study of Neurodevelopment in Rare Disorders

 Conducts extensive evaluations for parents referred to the program because of genetic neurodegenerative diseases in the area of neurogenetics/neurometabolism, including lysosomal storage diseases such as mucopolysaccharidosis, white matter diseases, and leukodystrophies.

## The NDRD has developed new techniques to identify injury in the brain of young infants even before the babies have symptoms.

• Maria L. Escolar, MD, MS, director of the NDRD, is recognized internationally as an expert in these diseases.



#### Neurogenetics/Mitochondrial Disease

• Patients from around the country come to the Comprehensive Mitochondrial Clinic due to the reputation of Amy Goldstein, MD, as an expert in these complex diseases and her involvement with the United Mitochondrial Disease Foundation.

The North American Mitochondrial Disease Consortium (NAMDC) named Children's Hospital of Pittsburgh of UPMC a participating clinical center. We are one of only 14 hospitals to have this distinction.

- One aspect of our multidisciplinary approach that is appealing to families is that we involve a geneticist early on to examine family history and DNA. Pediatric rehabilitation medicine specialists are involved in our multidisciplinary Neurogenetics Clinic.
- We offer state-of-the-art cardiac MRI and exercise treadmill testing.
- Dr. Goldstein, Division of Child Neurology, received a K-12 grant from the National Institutes of Health (NIH).
- We collaborate with the University of Pittsburgh Center for Environmental Toxins and Health, Hillman Cancer Center, and adult colleagues.
- Pittsburgh boasts a high level of expertise in autosomal-recessive disease and is close geographically to the Amish population.

#### Neurodevelopmental Disabilities

*Children's has one of only eight neurodevelopmental disabilities residency programs in the nation.* 

#### Movement Disorders

 Here, child neurologists, pediatric neurosurgeons, and pediatric physiatrists work together, and we structure the clinic so they can see the same patients on the same day, easing the strain on families.

## We are one of very few multidisciplinary movement disorders clinics in the country.

- We provide a one-stop, holistic approach, bringing together pediatric neurologists, neurosurgeons, rehabilitation specialists, orthopaedists, OT, PT, and social work services.
- We performed deep brain stimulation on one of the youngest patients ever, a procedure that was documented in the Journal of Neurosurgery.

#### Epilepsy

- Children's Hospital's Epilepsy Center is a member of the National Association of Epilepsy Centers and a level 4 comprehensive epilepsy center.
- Seven dedicated pediatric epileptologists contribute to all aspects of the clinical care of infants, children, and adolescents with epilepsy, in the inpatient and outpatient settings. Two pediatric neurosurgeons perform epilepsy surgery.
- Equipped with 3T MRI, MRS, PET, fMRI, and MEG scanning.
- Inpatient EEG monitoring is available 24 hours a day.

#### An eight-bed Epilepsy Monitoring Unit is staffed 24 hours a day by highly trained pediatric epilepsy nurses and EEG technicians, many of whom trained in our EEG Tech training program.

• Specialty clinics are offered in the areas of intractable epilepsy, vagal nerve stimulation, tuberous sclerosis and the ketogenic diet. In addition, we offer a variety of research trials of new anticonvulsant medications.



#### Neurocritical and Neonatal Neurocritical Care

- Our Neurocritical Care program is the first service of its kind for pediatrics in the country. A unique feature is that the neuro-ICU attending physicians are not consulting physicians, rather, they become the child's physician of record, taking care of all the child's needs and treating the whole patient.
- We have 12 critical care physicians, of whom four are neuro-ICU attendings. All four have research grants on brain injuries. Research projects include how infections can alter brain development in the ICU, and what injuries are more common at different times of the day.
- The goal of our program is to develop critical care protocols in order to ensure the entire team is on the same page throughout the continuum of care. This prevents sporadic treatment and helps identify when treatment needs to be changed. Our computerized provider order entry system helps systematize Children's Hospital care and provides quality control.

#### In the NICU, hypothermia is now standard of care for newborns with birth asphyxia, neonatal encephalopathy, and/or hypoxic-ischemic encephalopathy.

- Children's is one of only three hospitals nationwide with a neuro-focused Neonatal Intensive Care Unit. Two child neurologists are dedicated to the NICU, working daily in the NICU, and are available 24/7.
- Neuroradiology rounds meet once a week with Ashok Panigrahy, MD, a leading voice in neonatal neuroimaging.

#### Neuroimaging

#### We have seven pediatric neuroradiologists on staff.

- Ashok Panigrahy, MD, chief, Department of Pediatric Radiology, developed the first neonatal head coil, now approved by the Food and Drug Administration, for use in neonatal magnetic resonance imaging. These coils provide fast, high-resolution imaging for babies. Dr. Panigrahy is collaborating with researchers to optimize the neonatal head coil.
- In a strong research collaboration with colleagues in Radiology at UPMC Presbyterian, Dr. Panigrahy modified the technique of sodium MRI in children and was the first to offer this type of imaging to the pediatric population.
- Children's Hospital of Pittsburgh of UPMC offers cutting-edge imaging modalities like MR spectroscopy, diffusion tensor imaging, and sodium MRI imaging.

#### Neuro-Oncology

- Children's Hospital of Pittsburgh of UPMC is a member of the Pediatric Brain Tumor Consortium (PBTC). Dr. Ian Pollack sits on the consortium's executive committee.
- Children's Hospital is also a founding member of the Children's Oncology Group (COG).

#### The Neuro-Oncology Tumor Board meets regularly to individualize each patient's treatment, so as to minimize late effects but maximize the chance of cure.

- Two dedicated Neuro-Oncology clinics are held per week, and the program works with families to schedule all other visits and MRI scans to occur on the same day if possible.
- Cutting-edge, innovative treatment options, some pioneered at Children's, are available, as is a vaccine study for patients with gliomas.



• The division runs a multidisciplinary program for children with brain injuries.

The division collaborates with UPMC Sports Medicine to provide care for children with complex concussions.

- The division runs outreach clinics in multiple communities and at the School for the Blind in Pittsburgh.
- Brad Dicianno, MD, runs a transition clinic for adolescents with childhood-onset disabilities.
- Dr. Dicianno and Amy Houtrow, MD, PhD, MPH, are internationally recognized researchers in spina bifida and have multiple grants between them. Dr. Dicianno is the site PI for the multicentered CDC registry project. Dr. Houtrow is the program director for the multicentered follow-up study of the Management of Myelomeningocele study.

#### Neuro-Ophthalmology

- We employ a multidisciplinary approach to patient care and collaboration with other services within the hospital.
- Ophthalmic genetic counselors are available in clinic for patient assessment and counseling.

We are using sophisticated non-invasive imaging of the optic nerve and retina with optical coherence tomography (OCT).

• Electrophysiologists are on-site for ERG testing of the retina and VEP testing of visual pathway disorders.

#### Child Advocacy Center

- Our physician-researchers are using serum biomarkers to provide information about the pathophysiology of brain injury in children, specifically to compare the biochemical response of the brain to different types of injury. This may provide information about what types of treatment might work in different types of brain injury.
- We are evaluating whether these blood biomarkers may be able to predict outcome after brain injury.

We are developing a panel of blood biomarkers that could be used to identify which infants who present with nonspecific symptoms (fussiness, apparent life-threatening event, seizure-like activity) should undergo a head CT to evaluate for brain injury.

• By studying the epidemiology of abusive head trauma (AHT), we are able to evaluate, among other things, the relationship between the rate of AHT and the economy.



## World-class care. Close to you.

You don't have to travel far to get the advanced care and treatment of the Brain Care Institute. Our convenient location allows families to stay close to home. We are within easy driving distance of many points throughout Ohio, West Virginia, Maryland, and much of New York – and we offer many ancillary sites in the surrounding communities. We also give you more ways to get in touch with us. Utilize the materials enclosed for information on physicians and locations, or email us at braincareinstitute@chp.edu.

To reach the BCI, email braincareinstitute@chp.edu





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