



Children's Hospital
of Wisconsin®

A member of Children's Hospital and Health System.



**NEUROSCIENCES
PROGRAM AND OUTCOMES REPORT**

About Children's Hospital of Wisconsin

Neuroscience Center physicians listed in the Best Doctors in America® database

Catherine Amlie-Lefond, MD

Richard Jacobson, MD, PhD

Bruce Kaufman, MD
Medical director
Neurosurgery

Sean Lew, MD
Program director
Neurosurgery Epilepsy

Elizabeth Moberg-Wolff, MD
Program director
Tone Management and
Mobility

Mary L. Zupanc, MD
Program director
Pediatric Epilepsy



Best Doctors®

Since 1992, a new list has been compiled each year by Best Doctors, Inc. of Boston. The 40,000 U.S. physicians who make the list represent the top 3 to 5 percent of the nation's practicing board-certified physicians.

Children's Hospital of Wisconsin, founded in 1894, is recognized as one of the leading pediatric health care centers in the United States. Named by *U.S. News and World Report* and *Parents* as one of the country's best children's hospitals, it is home to regional centers for cancer and blood disorders, cardiology, neurology, gastroenterology and a host of other medical and surgical services.



Two hundred seventeen Children's Hospital physicians are listed in the 2008 Best Doctors in America® database. Of these, 185 also are on the faculty of The Medical College of Wisconsin. Children's Hospital is a major teaching hospital affiliated with The Medical College.

Our nurses, too, are recognized among the best, having earned Magnet recognition from the American Nurses Credentialing Center. Magnet designation is given to health care organizations that demonstrate excellence in nursing. This honor is bestowed on only 1 percent of the hospitals in the world. Whether a child is referred for outpatient or inpatient care, the patient's family can count on nursing care that sets Children's Hospital apart. Families tell us they come to us on the advice of their own trusted doctors, but they would choose Children's Hospital again because of the attentive, family-focused care they receive.



Children's Hospital is located in Milwaukee. Families traveling to Children's Hospital by car find easy freeway access and parking. For those coming from farther away, daily flights are available on most major carriers to Milwaukee's Mitchell International Airport – just 20 minutes away – and Chicago's O'Hare International Airport – only 90 minutes away.

The cover



Leah

Leah was 3 years old when she started having trouble with her legs. By age 6, Leah was unable to walk. The family traveled to numerous hospitals across the nation looking for answers. Leah's care currently is managed by the Movement Disorder Clinic and multiple specialists at Children's Hospital. "We travel from Iowa almost every month to meet with our physician in Wisconsin," said Janet, Leah's mom. "We know that if they don't have the answer, they'll work with specialists all over to help us. We feel safe here."

For information on our efforts to advance quality service and outcomes, visit our Web site at www.chw.org/neuroscience.

For more information, call (414) 266-2460 or toll-free (800) 266-0366.

Neuroscience Center



Suja Anne Joseph, MD, interim medical director, Neurology



Bruce Kaufman, MD, medical director, Neurosurgery



Sean Lew, MD, program director, Neurosurgery Epilepsy



Mary L. Zupanc, MD, program director, Epilepsy

The Neuroscience Center, ranked number 28 by *U.S. News and World Report*, has grown in expertise and scope. Team members specialize in providing advanced diagnosis and treatment for children with a wide range of conditions affecting the neurological system.

The staff in the Neuroscience Center combines specialized care with current research and community outreach to provide the best care possible. ***The philosophy is to treat not only the illness or injury, but the whole child.***

The center combines comprehensive, multidisciplinary programs with a large number of pediatric specialists and support staff. Pediatric neurologists and neurosurgeons work together with child development, neuropsychology, genetics, rehabilitation, speech and other areas to address the unique needs of each child. Neuroscience Center physicians also work with a dedicated team of five physician assistants and four pediatric nurse practitioners who facilitate efficient patient care by triaging referrals and communicating with referring physicians, providing direct inpatient and outpatient care and educating families.

Features of the Neuroscience Center

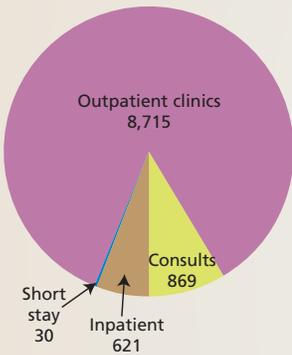
- Home to the *largest and most advanced* pediatric epilepsy monitoring unit in the region.
- Houses a *state-of-the-art epilepsy monitoring unit* to monitor patients 24 hours a day.
- *Nationally known* for the ketogenic diet program, a complex diet requiring specialized plans to control epilepsy.

Exceptional outcomes of the Neuroscience Center

- Seventy-four percent of epilepsy surgery patients are *seizure-free* following surgery.
- Treats a *significantly higher percentage of severe patients* with ventricular shunt procedures compared to peer pediatric hospitals.
- Ventriculoperitoneal shunt infection rate is below 4 percent, consistently *below the national average* of 10 percent. Infection rates for cerebrospinal fluid shunt surgery have been consistently below the national average for more than eight years.
- *Charges significantly less* per day for craniotomy, spinal fusions and ventricular shunt procedures than the national average of peer pediatric hospitals.

Neuroscience Center – programs

2007 Neurology visit volume



Pediatric Neurology

The Pediatric Neurology Program provides general neurological care and includes multiple subspecialty programs, clinics and specialists. These include:

- Neuromuscular disorder specialists.
- Movement Disorder Clinic specialists.
- Headache Clinic specialists.
- Epilepsy specialists.

The Pediatric Neurology team is led by **Suja Anne Joseph, MD**, interim medical director of Neurology. Dr. Joseph is an associate professor of Neurology at The Medical College, where she also directs the Pediatric Neurology Residency Program.

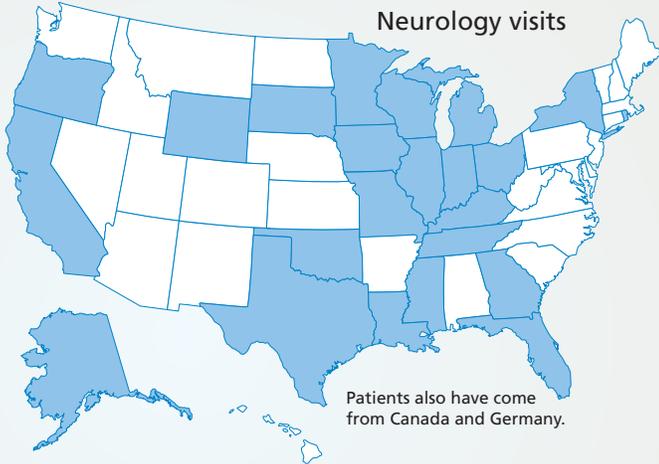
Neurology outpatient - top diagnostic categories

	Visit volume
Other convulsions and abnormal involuntary movements	1,471
Migraine/headache	1,250
Other extrapyramidal disease/movement disorders	564
Neurotic, personality and other nonpsychotic mental disorders (including developmental delay)	437
Disorders of central nervous system	259
Birth trauma	128
Disorders of peripheral nervous system	98
Symptoms concerning nutrition, metabolism, development	67
Cerebral vascular disease	64
Conditions originating in the perinatal period	56
Hemiplegia and hemiparesis	49
Unspecified general symptoms	49
Encephalitis, myelitis and encephalomyelitis	36
Pervasive developmental disorders	35

Neurology inpatient – top diagnostic categories

	Visit volume
Convulsions and abnormal involuntary movements	157
Alteration of consciousness	50
Neurotic, personality and other nonpsychotic mental disorders	28
Extrapyramidal disease/movement disorders	24

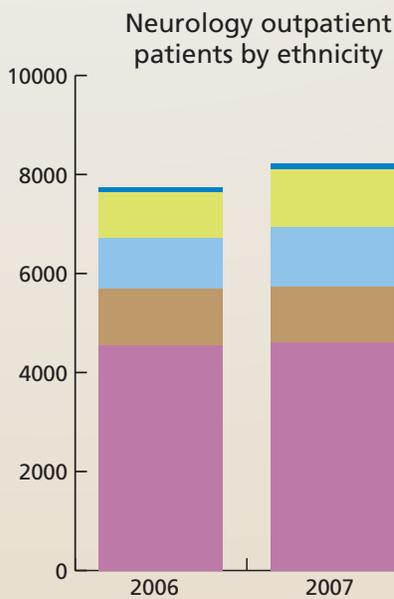
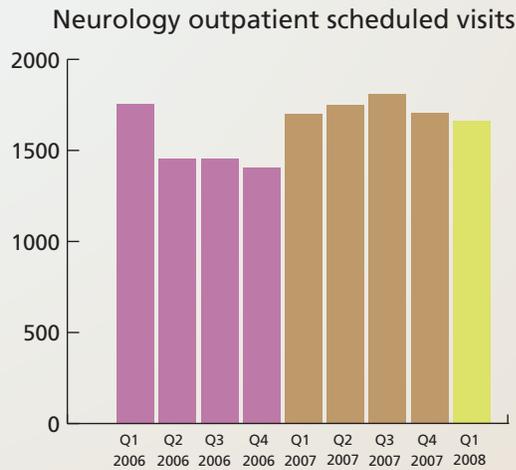
Neuroscience Center – programs



More than 60 percent of Neurology outpatient visits come to Children's Hospital from outside of Milwaukee, and more than 50 percent of inpatients come from outside of Milwaukee.

Scheduled clinic visits from 2006 to the first quarter of 2008.

Neurology urgent clinic visits occur within a week of request.



Combined non-Caucasian groups represent nearly half of the Neurology Clinic patients.

Neuroscience Center – programs

Pediatric Neurosurgery

The Pediatric Neurosurgery team specializes in the surgical management and treatment of neurological conditions that affect children – from newborns to adolescents.

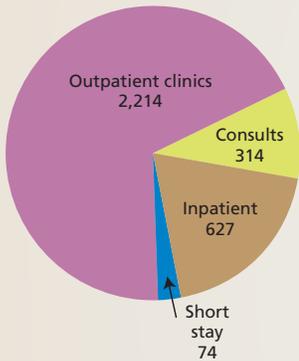
At Children’s Hospital, a Pediatric Brain Tumor Consultation Group comprised of pediatric specialists in neurosurgery, radiology, oncology, neurology, neuropsychology and physical and occupational therapy reviews all tumor cases as a team. The team collaborates with the Children’s Oncology Group and other leading pediatric brain tumor centers to ensure access to the best care available nationwide.

The Pediatric Neurosurgery team is led by **Bruce Kaufman, MD**, medical director of Neurosurgery. Dr. Kaufman also is professor and chief of Pediatric Neurosurgery at The Medical College.

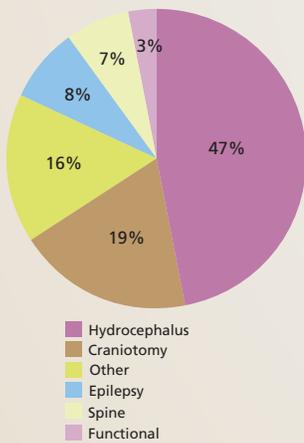
Outcomes

- Staff closely monitor readmission rates for spine procedures, a known complication. Since 2006, readmission rates within 14 days has consistently been below 25 percent.
- Seven percent of craniotomy patients experience a readmission.
- The ventriculoperitoneal shunt infection rate is below 4 percent, consistently lower than the national average of 10 percent.
- The program treats a significantly higher percentage of severe patients with ventricular shunt procedures in comparison to PHIS data. Cerebrospinal fluid shunt surgery infection rate has been consistently below the national average of 10 percent for more than eight years.

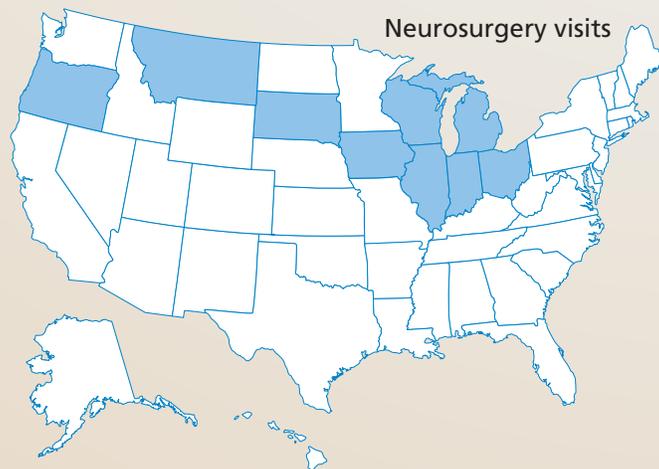
2007 Neurosurgery visit volume



Neurosurgery procedure volumes



Neurosurgery patients top diagnostic categories	
	Volume
Trauma-brain	319
CNS neoplasm	106
Congenital malformation-cranial	102
Hydrocephalus	85
Congenital malformation-spine	60
Cerebrovascular	55
CNS infection	43
Trauma-spine	35
Other	36



More than 50 percent of Neurosurgery outpatient and inpatient visits come to Children’s Hospital from outside of Milwaukee.

Neurosurgery emergency visits occur on the same day or within two days of the request.

Neuroscience Center – programs

SPECIALISTS

Pediatric Epilepsy Program

Neurology

Mary L. Zupanc, MD
Program director
Pediatric Epilepsy

Kurt Hecox, MD, PhD
Charles Marcuccilli, MD, PhD
Sunila O'Connor, MD
Michael J. Schwabe, MD
Uzma Sharif, MD
Maria Chico, CPNP
Kathy Eggener, CPNP
Marge Schweitzer, CPNP
Rhonda Roell Werner, RN, CNS

Neurosurgery

Sean Lew, MD
Program director
Neurosurgery Epilepsy

Marike Zwienenberg-Lee, MD
Nancy Etter, PA
Anne Matthews, PA
Chris Peske, PA
David Tuinstra, PA

Pediatric Epilepsy Program

The Pediatric Epilepsy Program provides comprehensive services for children with epilepsy including the newest drug therapies, vagal nerve stimulation, ketogenic diet and epilepsy surgery. Children's Hospital is home to the largest and most advanced pediatric epilepsy monitoring unit in the region.

Staff has extensive experience with patients who have *unusual or difficult to control epilepsy*. Medical treatment is offered for all types of epilepsy, and epilepsy surgery is provided for certain types of seizures. The pediatric epileptologists are experienced with conventional antiepileptic medication, as well as medications developed in recent years. Surgical results are excellent, a tribute to experienced pediatric neurologists, pediatric epileptologists and pediatric neurosurgeons.

The Pediatric Epilepsy team is led by **Mary L. Zupanc, MD**, program director of Epilepsy. Dr. Zupanc is the Heidi Marie Bauman Chair of Epilepsy at Children's Hospital and professor of Neurology at The Medical College. She is assisted by **Sean Lew, MD**, program director of Neurosurgery Epilepsy at Children's Hospital and assistant professor of Neurosurgery at The Medical College.

Epilepsy patients – top diagnostic categories

	Inpatient	Clinic
Epilepsy-unspecified	354	492
Focal-partial epilepsy/epileptic syndromes with simple partial seizures	245	67
Focal-partial epilepsy/epileptic syndromes with complex partial seizures	72	1,763
Grand mal status	68	4
Generalized convulsive epilepsy	62	521
Infantile spasms	55	38
Generalized nonconvulsive epilepsy	33	299
Epilepsia partialis continua	5	
Other forms of epilepsy/recurrent seizures	3	1

Neuroscience Center – programs

Pediatric Epilepsy Program continued

Epilepsy Program highlights include:

- Seventy-four percent of epilepsy surgery patients are seizure-free following surgery.
- A state-of-the-art Epilepsy Monitoring Unit was created to diagnose and treat children with intractable epilepsy. The eight-bed unit is extended through the use of several mobile units for monitoring patients in the pediatric and neonatal intensive care units and other areas of the hospital. The EMU, the largest of its kind in the region, has a central nurses' station with a 360-degree view of the private patient rooms. Neurophysiology technologists monitor video and EEG equipment in the unit 24 hours a day. Each room in the EMU provides a bed for the parent staying with the child, as well as other amenities to make the family's stay more comfortable.
- Patients can receive long-term video EEG monitoring within the EMU, the Pediatric Intensive Care Unit and the Neonatal Intensive Care Unit.
- Children's Hospital is nationally known for its ketogenic diet program. This complex diet requires specialized plans for each patient. Certified clinical dietitians directly manage all patients admitted for initiation of the diet.



Jesse

Migraines run in Jesse's family, so when he started to get them in first grade, his mom Tracy wasn't surprised. However, his medications were offering him no relief, and he began experiencing seizure-like episodes. Jesse was monitored overnight in the Epilepsy Monitoring Unit at Children's Hospital, where physicians determined that medication, combined with therapeutic techniques Jesse learned in the Headache Clinic would be the best way to manage his headaches and seizures. Jesse has been episode-free for more than a year and has volunteered to take part in the clinic's study to assess childhood headaches. Without nauseating headaches and seizures, Jesse is able to enjoy active hobbies including biking, basketball, baseball and football.

Neuroscience Center – programs

SPECIALISTS

Brachial Plexus Clinic

Richard Jacobson, MD, PhD

Brain Tumor Clinic

Neurosurgery

Bruce Kaufman, MD

Medical director

Neurosurgery

Sean Lew, MD

Marika Zwienenberg-Lee, MD

Nancy Etter, PA

Anne Matthews, PA

Chris Peske, PA

David Tuinstra, PA

Neurology

Catherine Amlie-Lefond, MD

Neuropsychology

Amy Heffelfinger-Miles, PhD

Oncology

Sachin Jugal, MD

Meghan Westenberger, CPNP

Laura Vanswol, RN

Radiation Therapy

Selim Firat, MD

Headache Clinic

Tamara Langhoff, CPNP

Movement Disorders Clinic

Suja Anne Joseph, MD,

Interim medical director

Neurology

Muscular Dystrophy Clinic

Richard Jacobson, MD, PhD

Erika Pyzik, PA

Brachial Plexus Clinic

Children's Hospital offers treatment and surgery for brachial plexus injury. The goal of the Brachial Plexus Clinic is to *restore maximum function to the injured limb and speed the recovery process*. This is accomplished by making an accurate diagnosis, creating a treatment plan and educating family members.

The multidisciplinary clinic team includes a pediatric neurologist, a plastic and reconstructive hand surgeon and occupational therapists. The team performs a thorough evaluation to determine the extent of injury and monitors recovery during follow-up visits, establishes a treatment of therapy for motion, strength and function, and assesses surgical options. The team's neurosurgeons and plastic/reconstructive surgeons perform this specialized surgery.

Brain Tumor Clinic

Children with tumors of the brain, spinal cord and nerves have many different treatment options, including surgery, chemotherapy, radiation therapy or a combination of these. *A team approach is utilized to define the best treatment for each child*. The Brain Tumor Clinic at Children's Hospital provides a multidisciplinary approach at the time of diagnosis, during treatment and in long-term follow-up.

Diagnostic evaluation and treatment for all types of brain, spinal cord and nerve tumors is available. This includes Gamma Knife radiosurgery and high dose chemotherapy with bone marrow transplant. Each patient's treatment plan is individualized, with continuing evaluation and changes as needed.

Headache Clinic

The goals of the team in the Headache Clinic are to identify the type of headache, prescribe appropriate medications and suggest lifestyle changes to *help families manage their child's headaches*. A pediatric psychologist serves as a consultant to teach relaxation and biofeedback exercises.

The team diagnoses and treats the following:

- Migraines.
- Tension-type headaches.
- Other primary and secondary headache disorders.

Movement Disorders Clinic

The Movement Disorders Clinic offers a *comprehensive evaluation* of spasticity, dystonia and paroxysmal movements that are not epileptic in nature. The clinic offers the latest treatments and therapies. Deep brain stimulation, if necessary, is performed in collaboration with Froedtert & The Medical College of Wisconsin.

Muscular Dystrophy Clinic

The Muscular Dystrophy Clinic offers a *comprehensive approach to the diagnosis and management of all types of muscle disorders*. The latest treatments and therapies are available to muscular dystrophy patients and those with neuromuscular diseases. Some of the services provided through the Neurophysiology Laboratory include:

- Repetitive stimulation and single fiber electromyography.
- Central EMG and somatosensory evoked potentials.

Neuroscience Center – programs

SPINA BIFIDA SPECIALISTS

Neurosurgery

Bruce Kaufman, MD
Medical director
Neurosurgery

Sean Lew, MD
Marika Zwienerberg-Lee, MD
Nancy Etter, PA
Anne Matthews, PA
Chris Peske, PA
David Tuinstra, PA

Urology

Anthony Balcom, MD
Charles Durkee, MD
Hrair-George Mesrobian, MD

Orthopedic Surgery

John Thometz, MD
Medical director
Orthopedic Surgery

Physical Medicine and Rehabilitation

Fred Klingbeil, MD
Medical director
Pediatric Rehabilitation and Fitness

Mark Klingbeil, MD

Spina Bifida Clinic

The Spina Bifida Clinic was created to care for patients with all types of spinal dysraphism and related conditions. The program's goal is to *help children with spina bifida stay healthy, gain independence and become confident in their abilities*. The team includes experienced, dedicated professionals who work together to provide and recommend care to benefit each child. The staff is committed to providing quality care and education to maximize each child's quality of life.

Specialized treatments include intermittent catheterization, bowel programs, therapeutic electrical stimulation and biofeedback.

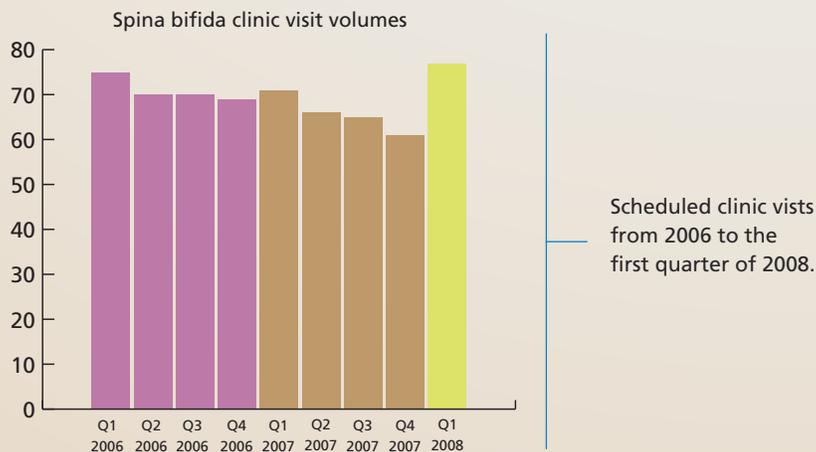
Members of the Spina Bifida Clinic team play an important role in educating the community about the condition and providing outreach through schools and community agencies. Prenatal counseling for families who know their baby will be born with spinal dysraphism is provided by physicians and clinical nurse specialists.

To help families feel connected and up to date, a large communication board is displayed in the clinic, featuring recent articles, activities and announcements about spina bifida. A spina bifida resource room is available on clinic days. Spina bifida family forums are offered periodically on a variety of topics including parent panels.

Pediatric spine care: A collaboration of Neurosurgery and Orthopedic expertise

Through the combined expertise of pediatric neurosurgeons and orthopedic surgeons, Children's Hospital has become a leader in treating children with scoliosis, complex congenital anomalies and severe spinal trauma. The collaborative approach allows us to provide the best care possible for children from infancy to adolescence.

- Children's Hospital treats a large volume of spinal fusion patients compared to the national average of peer pediatric hospitals.
- Children's Hospital charges significantly less for spinal fusions than the national average of peer pediatric hospitals.



Neuroscience Center – programs

TONE MANAGEMENT AND MOBILITY SPECIALISTS

Physical Medicine and Rehabilitation

Elizabeth Moberg-Wolff, MD
Program director
Tone Management and Mobility

Fred Klingbeil, MD
Medical director
Pediatric Rehabilitation and Fitness

Maria A. Ocasio-Silva, MD
Romy Gaynor, PT
Linda Kliebhan, PT
Stefanie Reid, PT

Orthopedic Surgery

John Thometz, MD
Medical director
Orthopedic Surgery

Jeffrey Schwab, MD
Channing Tassone, MD

Neurosurgery

Bruce Kaufman, MD
Medical director
Neurosurgery

Sean Lew, MD
Marika Zwienenberg-Lee, MD
Nancy Etter, PA
Anne Matthews, PA
Chris Peske, PA
David Tuinstra, PA

Tone Management and Mobility

Children's Hospital provides one of the most complete Tone Management and Mobility programs to meet the complex needs of children with spasticity and other movement disorders. Services include:

- A pediatric physiatrist who specializes in physical medicine and rehabilitation to treat pediatric spasticity and related conditions.
- Access to other pediatric specialists, such as pediatric neurosurgeons who offer selective dorsal rhizotomy and baclofen pump placement, pediatric orthopedic surgeons who offer bone and muscle surgery, and physical therapists who provide therapy or consultation.
- The full range of current medical, surgical and rehabilitative treatments such as Botox[®], phenol injections, intrathecal baclofen pump, orthopedic bracing or surgery, selective dorsal rhizotomy, therapeutic interventions and equipment recommendations.

We aim to improve comfort, caregiving, mobility and functional independence for all patients.



Ania

Yvonne and Richard adopted Ania when she was born at 24 weeks. Ania came to Children's Hospital after being diagnosed with cerebral palsy at age 1. In addition to visiting many of the clinics at Children's Hospital, Ania also had a baclofen pump implant to treat her spasticity. Ania, now 6, comes to Children's Hospital every three months for check-ups.

The Neuroscience team is dedicated to engaging in translational research, where clinical problems are taken from patients' bedsides to study in the laboratory. Laboratory discoveries are then converted into new treatments, preventions and therapies for patients.

Neurosurgical research is conducted in collaboration with the Neuroscience Research Laboratory, a division of Neurosurgery at The Medical College. The lab occupies more than 25,000 square feet of space and employs eight doctorate-level researchers and 20 support staff for federally and privately funded research.

Neurology and Neurosurgery research teams not only collaborate with local organizations such as Children's Research Institute and The Medical College, but also with children's hospitals across the country to enhance the care for children and adolescents with neurological disorders.

Neurology research

- **Harry Whelan, MD**, Bleser Family Chair in Neurology, has been inducted into the NASA Space Technology Hall of Fame for his research into the use of near-infrared LEDs for wound healing and the treatment of brain tumors. In a multiyear investigation approved by the Food and Drug Administration, Dr. Whelan found that diabetic skin ulcers and other wounds in mice healed much faster when exposed to the special LEDs in the lab. In a separate protocol, Dr. Whelan is studying the use of LEDs to promote healing of acute mouth ulcers resulting from chemotherapy and radiation used to treat cancer in children.
- **Dr. Whelan** is the principal investigator on a grant from the National Institutes of Health studying near-infrared light therapy for neurodegenerative diseases, such as Parkinson's and diseases of the visual system. He also is conducting a pilot study supported in part by the Clinical Translational Science Institute of near-infrared light therapy for diabetic macular edema, a form of diabetic eye disease. Dr. Whelan presented this translational bench-to-bedside research to the United States Congress at the NASA Spin-off Day on Capitol Hill as an example of how space research is helping patients.



Sam

Michelle took her son Sam to the pediatrician when he couldn't shake a fever. His pediatrician sent him to Children's Hospital for evaluation. Imaging studies revealed infected fluid building up on the outside of his brain. The Neuroscience team sent 5-month-old Sam to surgery for a craniotomy that very day. His dad Chris, a pediatric resident at The Medical College, is grateful for the quality of care they received in a timely manner that led to a good outcome for their baby boy. Today, Sam requires no follow-ups and is a healthy boy who enjoys playing with balls, sliding down slides and dancing.



Rebecca

Rebecca was 8 years old when she started having seizures. Her mom, Lisa, took her to numerous hospitals looking for answers. Lisa then brought Rebecca to Children's Hospital where she was monitored in the Epilepsy Monitoring Unit. Rebecca had intractable, localization-related epilepsy. She underwent extensive presurgical evaluation which led to epilepsy surgery. After a partial resection of her left frontal lobe and proper medications, Rebecca has since been seizure-free – a big relief considering she was having 10 seizures per hour. "The team at Children's Hospital gave Rebecca her life back," said Lisa.

- **Catherine Amlie-Lefond, MD**, is participating in local, national and international studies in childhood stroke. Under Dr. Lefond's leadership, Children's Hospital is a contributor to the International Pediatric Stroke Study organized through the Hospital for Sick Children in Toronto. The IPSS has collected information on more than 1,800 children with stroke in 12 countries to understand childhood stroke, potential triggers and prevention.

Epilepsy research

- **Kurt Hecox, MD, PhD, and Michael Schwabe, MD**, continue to investigate the use of advanced signal processing methods to extract information from the electroencephalography signal. This would allow the early detection of seizures, increase the effectiveness of computerized seizure detection systems and improve the accuracy of locating the site of onset of seizures in children with medication-resistant epilepsy. There are plans to apply these same techniques to the EEG data pool from the Food and Drug Administration's sponsored study trial examining childhood absence epilepsy in more than 300 children.
- **Charles Marcuccilli, MD, PhD**, director of Epilepsy at The Medical College, **Sean Lew, MD, Andrew Tryba, PhD**, and the epilepsy research team are collaborating with other researchers to study epilepsy using human brain tissue – one of only a few programs in the country capable of this technique. The epilepsy research team was the first to identify intrinsic burster cells in humans. These brain cells are thought to initiate seizures. These investigators further classified the mechanism underlying the bursting activity. Through this process, investigators not only can identify the source of the seizure, but also the entire network of abnormal tissue found throughout the brain. The goal of this research is to allow better localization of the seizure focus, improve efficacy of antiepileptic medication and prevent seizures.
- Investigators are looking at the specific gene expression changes and testing drugs on certain brain tissues. This research will help identify the correct treatment options for patients on the first round, as well as identify drugs that could be harmful. This translational research will allow investigators to make recommendations to physicians on which medications to use within as little as 24 hours.

Research

- **Mary L. Zupanc, MD**, and the epilepsy team are evaluating surgical outcomes in a select group of medically refractory epilepsy patients who have undergone epilepsy surgery. The team is evaluating seizure outcomes, as well as quality of life after epilepsy surgery. Investigators also are determining the criteria for choosing patients for surgery, as well as the factors that determine excellent outcomes.
- **Dr. Zupanc** and the epilepsy team recently were invited to participate in the International League Against Epilepsy's Pediatric Epilepsy Surgery Consortium, consisting of 35 international epilepsy centers. This group will determine the criteria for pediatric epilepsy surgery and evaluate surgical outcomes.
- Neuroscience team members are involved in multiple investigational drug studies for epilepsy. Many of these clinical trials are looking at drugs that are approved for adult patients but have yet to be proven in pediatric medicine.

Neurosurgery research

- **John Jensen, MD, and Dr. Lew** are conducting a clinical study that monitors intracranial pressure and cerebral perfusion pressure during sagittal synostosis surgery in infants. Dynamic cranioplasty, or directly applied force on the exposed skull, is a surgical technique commonly used to remodel cranial vaults in infants with craniosynostosis. The study is evaluating whether this technique causes intracranial hypertension that has the potential to damage the brain. A secondary goal of the study is to evaluate a modified technique that accomplishes the same cosmetic effect without exposing the patient to a period of intracranial hypertension.
- **Bruce Kaufman, MD, Dr. Lew and Marike Zwienenberg-Lee, MD**, have joined a multi-institutional ShuntCheck study to investigate a newly developed noninvasive device for assessing ventriculoperitoneal shunt function. The study would aim to compare the diagnostic accuracy of the device to current diagnostic modalities used to evaluate shunt patency in symptomatic patients. The study also combines the device results with other diagnostic methods, including the neurosurgeon's clinical judgment, to improve the overall accuracy of diagnosing cases of suspected shunt failure.
- **Drs. Kaufman, Lew and Zwienenberg-Lee** are examining surgical outcomes using nonpenetrating titanium clips for dural closure in pediatric intraspinal surgery. This novel technique can result in a less invasive surgical approach with potentially shorter operative time while continuing to achieve a low rate of postoperative complication from a cerebrospinal fluid leak.
- **Dr. Lew** and colleagues published a review of their experience utilizing a modified osteoplastic orbitozygomatic craniotomy for pediatric neurosurgical cases that required improved visualization of the anterior and anterolateral skull base. This surgical technique proved advantageous in ease of use, achieved superior operative exposure that minimized risk to the patient by decreasing brain retraction, and lessened the risk of perioperative infection by maintaining a vascularized bone flap. It also resulted in improved cosmesis and function of the temporalis muscle anatomy.
- **Dr. Zwienenberg-Lee and Sachin Jugal, MD**, are lead investigators in a multidisciplinary preclinical study investigating the use of selenoproteins for the prevention of radiation-induced injury in pediatric brain tumors. Brain irradiation is a standard adjuvant treatment for many pediatric brain tumors after surgical resection and has resulted in long-term tumor control. However, many brain tumor survivors develop serious side effects, including decreased cognitive ability, visual perceptual skills, information processing and social skills, poorer memory and concentration skills, hormone deficiencies, hearing and growth impairment. Administration of selenoproteins immediately following radiation therapy may prevent the occurrence of some of these side effects. Mechanisms of cellular injury and cognitive decline after brain irradiation also are being explored in relation to this study.

Community outreach



Wisconsin Seizure Control Network

The network is a statewide referral system designed to help children and youth with epilepsy achieve seizure control more quickly and effectively, and *reduce or prevent the developmental, physical, social and emotional effects associated with poor seizure control*. Health care providers strive to obtain early evaluation and intervention and provide early education to children and families. **Mary L. Zupanc, MD**, is the director of the network through a Federal Health Resources and Services Administration grant.

There is a substantial need for both basic and comprehensive care throughout Wisconsin for the estimated 15,000 children and youth with epilepsy and their families. Access to the specialized care needed to achieve seizure control is difficult for many families.



Darkis

Darkis began experiencing seizures when he was just 10 months old. Darkis underwent surgery for his seizures and with the help of ongoing management, only has experienced one seizure since. Monica, Darkis' mom, is grateful for the compassion and education the physicians and staff at Children's Hospital provided. "They explained everything. They let me know that I could call at any time if I had questions," she said. Darkis, now 11, enjoys living the life of a healthy sixth-grader.

In partnership with primary care physicians and families, the network strives for complete seizure control and improved quality of life for each child. It provides access to state-of-the-art health care expertise and social services. In addition, a public education and awareness campaign is directed toward affected families, targeted racial and ethnic populations, primary care providers, schools and other stakeholders to improve awareness of treatment options and encourage use of available services.

Partners in the network:

- Children's Hospital of Wisconsin.
- Epilepsy Foundation.
- Great Lakes Inter-Tribal Council.
- The Medical College of Wisconsin.
- Parent to Parent of Wisconsin.
- Wisconsin Children and Youth with Special Health Care Needs Program.

Hmong community outreach

In traditional Hmong culture, the shaman's role is revered. Epilepsy, along with other illnesses, is viewed as having a spiritual cause. Working in collaboration with Western Bilingual Services, a Hmong-owned business, WSCN coordinates outreach and educational efforts to increase awareness about epilepsy and seizure control for the Hmong community through several community-based programs. Through HmongABC radio, **Mary L. Zupanc, MD**, has shared the basics of epilepsy and answered questions about neurological disorders. Other outreach components included informational brochures, health fair participation and public service announcements directed at the Hmong community. Recently, a 20-minute educational epilepsy video was completed and will be distributed nationally.

Community outreach continued

Central city outreach

Studies conducted in the U.S. have found that the risk of a seizure during a lifetime is 25 percent for African Americans, compared to 10 percent in the Caucasian community. Historically, seizures have been viewed as a nervous condition, emotional stress or insanity, and instead of seeking medical treatment, patients have sought help from spiritual leaders.

Pastors from Milwaukee central city Baptist churches took an educational tour of Children's Hospital's Neurology Clinic, Epilepsy Monitoring Unit and The Daniel M. Soref Family Resource Center. The tour resulted from the collaboration of the Wisconsin Seizure Control Network and the Milwaukee Chapter of the National Black Nurses Association.

Participating pastors discussed how African American churches can help improve access to health care for children with epilepsy and seizures. The group hopes to increase the general awareness and understanding of epilepsy in their communities.



Dr. Zupanc gives a tour to local community leaders.

The Milwaukee Chapter of the National Black Nurses Association works with the network to enhance education surrounding seizures, epilepsy and other neurological disorders. The groups work together to host central city neighborhood block parties and create church-sponsored focus groups. They brainstorm to develop ways to maintain child health records and enhance communication with medical professionals. Community outreach also includes an annual scholarship fund dinner to encourage young African Americans to pursue nursing careers.

Epilepsy Monitoring Unit Task Force

An interdisciplinary group meets bimonthly in the Epilepsy Monitoring Unit to make improvements in patient care. The group, made up of physicians, nurse practitioners, a patient care manager, advanced practice nurses, pharmacy staff and others, addresses issues that relate to the comfort, education and communication with patients and staff. The group also invites special guests, including parents, as resources to the unit to evaluate processes for care in the EMU.

Their goal is to provide the most comprehensive, safe and efficient care for patients in the EMU. Through the task force team approach, positive changes have been implemented for the unit by creating new protocols for procedures and patient care, staff competencies and continuing education.



From left: Maria Chico, RN, MS, CCRN, CPNP; Kathy Eggner, RN, MS, CPNP; Jody Koenig, RN, BSN, MBA, Dr. Mary Zupanc; and Melissa Raines, MSN, RN, CPN.

The task force is focused on addressing issues, large or small, to improve every aspect of patient care.

Patient services and care

Daniel M. Soref Family Resource Center

The center works as an information hub for patient families. It includes computers, printers, a fax and copy machine, video viewing area and lending library.

Southeast Regional Center for Children and Youth With Special Health Care Needs

The center offers friendly staff who are themselves parents of children with special needs. These staff members provide support and links to other parent-to-parent opportunities, information about funding options, parent resources and referrals to agencies serving children with special health care needs.

Language Services

This service provides face-to-face and telephone oral translation for patients and families with limited English proficiency and those who are hearing or speech impaired.

Kohl's Child Life Program

Child Life specialists help families adjust to the hospital and prepare children for procedures by letting them see and touch instruments that will be used and explaining what the child will see, feel and hear. Child Life specialists also are available to support parents and help explain the hospital and illness to siblings. Preadmission tours are available for children and siblings coming to the hospital for surgery.

Family Accommodations Program

(800) 556-8090 toll-free

To help out-of-town families make arrangements for care at the hospital, this program helps coordinate travel arrangements and lodging. The program provides:

- Dedicated hospital staff to help families secure airline, car rental and lodging arrangements.
- Discounted car rental rates.
- Special rates at area hotels.

While families can make travel arrangements, a number of negotiated discounts only are available through the Children's Hospital Family Accommodations Program. For more information, call the toll-free number.

Families may have the option of staying at the hospital or at a number of facilities near the hospital during a child's visit. Overnight accommodations at the Ronald McDonald House, located across the street from Children's Hospital, also are available for families of children receiving inpatient or outpatient treatment, as space allows.

Children's **Transport and Physician Consultation/Referral Center**

(414) 266-2460 Milwaukee area

(800) 266-0366 toll-free

Physicians who have an emergency or nonurgent patient issue have easy access to services at Children's Hospital. With a single call to the Children's Transport and Physician Consultation/Referral Center, physicians can connect to the resources they need, whether facilitating a patient transport, consulting with a specialist physician or scheduling an appointment with a pediatric specialist.



Megan and Tyler

Megan, Tyler and Kylie were born prematurely at 25 weeks in Nevada. Megan and Tyler were born with cerebral palsy and spinal muscular atrophy. When the family moved back to Wisconsin, their mom, Karen, brought them to Children's Hospital. Today, Megan and Tyler are monitored and treated in multiple clinics, including Tone Management and Mobility. The pair, now 13 years old, enjoy playing computer games with Kylie, swimming and hanging out with friends.

Children's Hospital of Wisconsin

Peggy Troy, MSN, RN, president and CEO

Cynthia Christensen, executive vice president and COO

The analysis for this report was performed by the Quality and Outcomes Department of the National Outcomes Center. The center is headed by Executive Vice President and Chief Operating Officer **Ramesh Sachdeva, MD, PhD, MBA, JD**. Dr. Sachdeva also is an associate professor for Pediatrics (Critical Care) at The Medical College of Wisconsin.

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Children's Hospital is located on the campus of the Milwaukee Regional Medical Center.

From Green Bay:

- Take I-43 South to I-94 West (Madison – Exit 72B).
- Follow I-94 West (Madison) to U.S. Hwy. 45 (Fond du Lac – Exit 305B).
- Go north on U.S. Hwy. 45 (Fond du Lac) to Watertown Plank Road (Exit 40).
- Travel east (right) on Watertown Plank Road to the first stoplight (92nd St.).
- Follow the signs to the entrance of Children's Hospital of Wisconsin.

From Kenosha/Racine/Illinois:

- Take I-94 West toward Milwaukee to the I-894 bypass (Madison/Fond du Lac – Exit 316).
- Follow I-894 North to U.S. Hwy. 45 North.
- Continue on U.S. 45 North to Watertown Plank Road (Exit 40).
- Travel east (right) on Watertown Plank Road to the first stoplight (92nd St.).
- Follow the signs to the entrance of Children's Hospital of Wisconsin.

From Beloit:

- Take I-43 (Rock Freeway) to U.S. Hwy 45/I-894 North.
- Go north on U.S. Hwy. 45 (Fond du Lac) to Watertown Plank Road (Exit 40).
- Travel east (right) on Watertown Plank Road to the first stoplight (92nd St.).
- Follow the signs to the entrance of Children's Hospital of Wisconsin.

From Madison:

- Take I-94 East (Milwaukee) to U.S. Hwy 45 (Fond du Lac – Exit 305B). Exit from the left lane.
- Go north on U.S. Hwy. 45 (Fond du Lac) to Watertown Plank Road (Exit 40).
- Travel east (right) on Watertown Plank Road to the first stoplight (92nd St.).
- Follow the signs to the entrance of Children's Hospital of Wisconsin.

From Fox Valley cities:

- Take U.S. Hwy 41/45 South to Watertown Plank Road (Exit 40).
- Travel east (left) on Watertown Plank Road to the first stoplight (92nd St.).
- Follow the signs to the entrance of Children's Hospital of Wisconsin.



Children's Hospital
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