

Research links sickle cell disease and sleep disorders, next step intervention

Studies show that a lack of quality sleep has been linked to an increased risk of numerous health issues such as attention deficit disorder, learning difficulties and high blood pressure. Research out of Le Bonheur's Neuroscience Institute is linking sickle cell disease and sleep-related disorders. Pediatric neurologist Dave Clarke, M.D., and hematologist Dr. Jane Hankins at St. Jude Children's Research Hospital recently finished one study and are working on a second. The two hope their research efforts will help decrease the morbidity and mortality of children with sickle cell disease while improving their quality of life and ability to learn.

The first study, which was presented at the American Sleep Society conference this summer, suggests that the prevalence of sleep-related disorders among children with sickle cell disease is very high. Conducted by questionnaire, the study asked 100 parents of children with sickle cell disease objective questions about obstructive sleep apnea, insomnia and restless leg syndrome.

These numbers were much higher than those of the general pediatric population. As opposed to 1-3 percent of well children, more than half of the subjects reported chronic snoring. Restless leg syndrome also affects sickle cell children at a higher rate – 11 percent met full criteria versus 0.5-1 percent of the general population. Of the study subjects, 22 percent indicated leg discomfort while sitting or standing.

About 40 percent had short term insomnia, 30 percent woke up more than twice a night (sleep maintenance insomnia) and 21 percent had chronic sleep insomnia for greater than six months.

"The next step is intervening with these children and conducting detailed sleep studies. We'll retest the children down the line to see if we were able to improve their sleep quality, hence quality of life," Clarke said.

The second study is investigating stroke risks in children with sickle cell disease. Also done in conjunction with hematologists at St. Jude, patients in this study will receive a high density EEG. Researchers will look retrospectively to see if it is possible to potentially determine a child's risk of stroke and allow for early intervention. The use of EEG could supplement other current methods such as transcranial doppler and functional MRI techniques, which are also being studied. The study is funded by the Shainberg Neuroscience Fund.

Le Bonheur's Pediatric and Adolescent Sleep Disorders Center is the only sleep center in the region dedicated to treating children from infancy to 18 years of age. The three-bed unit is open seven days a week for sleep studies and is accredited by the American Association of Sleep Disorders.

The polysomnography suite at the Sleep Disorders Center is equipped with 21-channel polygraph equipment and additional equipment for monitoring all sleep, respiratory and cardiac parameters.

The center maintains a home-like environment conducive to monitoring sleep on an inpatient or outpatient basis. Comfortable sleep accommodations are provided for one parent, and the child can bring books, stuffed animals, blankets or other familiar objects that are part of his or her usual bedtime routine.



Dave Clarke, M.D.

Sleep Center

- Evaluates common sleep disorders: insomnia, sleep apnea, narcolepsy, restless leg syndrome, hypoventilation/hypoxemia, abnormal sleep behavior, nocturnal enuresis and nocturnal seizures.
- 3- bed unit
- Open 7 days a week
- Medical Director:
Pulmonologist Robert Schoumacher, M.D.
- Associate Medical Director:
Neurologist Dave Clarke, M.D.
- Scheduling: 901-287-7870

Research site lists studies recruiting patients

Two new research studies recruiting patients have been added to Le Bonheur's Neuroscience Institute research Web site. Both studies are for drugs used as adjunctive therapy for children with seizures.

The Perampanel study is for children 12 years and older who have Refractory Partial Seizures. The study will evaluate the efficacy and safety of Perampanel used with other seizure medicines.

The Carisbamate, Topiramate and Levetiracetam study is recruiting individuals

16 years and older with partial onset seizures to evaluate retention rate, efficacy, safety and tolerability of the drugs as adjunctive therapy. Patients will receive one of the medications during a 48-week treatment period. Patients will then be given the option to continue in an open label study.

The Neuroscience Institute's research Web site includes more than a dozen studies that are currently recruiting patients by invitation, active and closed. All are listed at www.lebonheur.org/neuroscience under

"participating in our research." The site allows physicians and even families - to inquire about and eventually enroll in studies that may be applicable to them.

The site also includes publications and funded research at Le Bonheur in the fields of neurology, neuropsychology and neurosurgery.

For more information, contact Michelle Ellis, RN, Study Coordinator at 901-287-5330 or ellismi@methodisthealth.org.

Tidwell receives Family Choice Award

Brain Tumor Program Director Tracy Tidwell, PNP, is the recipient of Le Bonheur Children's inaugural Family Choice Award. The award is given by the Family Partner's Council to an individual who demonstrates a dedication to the principles of patient- and family-centered care.

In her interactions with patients and their families, "Tracy relates as well to the children as she does with their parents," read her nomination letter. "Parents feel that Tracy is their best advocate. She listens and does whatever she can to help meet their needs."

Principles of patient- and family-centered care, according to the Family Partner's Council, include respect for the patient's family, candid disclosure of information, family involvement in care planning and family collaboration with clinicians about policy decisions.

One of Tracy's many contributions to patient- and family-centered care is a new format for reporting between nurses at a patient's bedside in the neuro units. This ensures that information is shared openly between patients and their caregivers. Thanks to programs that Tracy helped



Tracy Tidwell, PNP, left, received the first Family Choice Award for her dedication to family-centered care at Le Bonheur.

implement, parents of hospitalized children are now able to schedule their child's medications and therapy, giving them greater control of their child's care.

In her work, Tracy takes these values to heart and practices these principles even under the most difficult circumstances.

"From the moment we stepped foot in the ICU from being life-flighted from Tulsa, Okla., Tracy was there to support us," said Michelle Perry, mother of brain tumor patient Allyson. "We are so grateful that Tracy has the gift that she does - the gift to be exactly what patients and families need in a time of chaos."

Richie joins neuropsychology staff



*Sarah Richie, Ph.D.
Clinical Neuropsychologist*

Sarah Richie, Ph.D., has joined Le Bonheur Children's neuropsychology team.

Richie serves as a clinical neuropsychologist and assistant director of training at the Center for Pediatric Neuropsychology under Dr. Vickie Brewer. She is an attending neuropsychologist for the Epilepsy Monitoring Unit and is involved in research projects studying autism and epilepsy within the Neuroscience Institute.

Richie is a graduate of Millsaps College. She received her doctorate in clinical psychology from the University of Mississippi and completed three years of

post-doctoral fellowship in neuropsychology with pediatric and adult populations, including two with Le Bonheur's Neuroscience Institute. She holds the titles of clinical assistant professor in the Department of Pediatrics, Division of Neurology at the University of Tennessee Health Science Center and adjunct professor in the department of Clinical Psychology at the University of Mississippi.

Nurse recognized as rising star

In just two years as the nurse practitioner with Le Bonheur's neurology service, Lai Brooks has already been recognized as a rising star in her field by the American Association of Neuroscience Nurses.

Brooks received the Rising Star of Clinical Practice Award from the AANN earlier this year. She was nominated by Davi Ledet, RN, MSN, MBA, who said Brooks demonstrates superior skills in managing basic neurological disease processes independently and plays a significant team role in the management of highly complex patients. "What separates Lai from other neuroscience nurses is the genuine care and compassion that she displays to all of her patients," Ledet, president of the Mid-South chapter of the AANN, said.

The nomination cited an instance in which Brooks was able to help a family come to terms with the fact that their child needed surgery. Despite intensive medical care an infant was experiencing hundreds of seizures each day. Extensive discussion between the family and physicians occurred on multiple occasions; however, the medical team was unable to convince the family of the importance of surgical intervention.

Brooks approached the family after multiple attempts by other team members. Through a very open, honest and candid conversation, she uncovered multiple misconceptions that were preventing the family from consenting to surgical intervention. Ultimately, the infant underwent surgery, and now at almost a year old, the baby is meeting developmental milestones.

"Lai is a tremendous asset to our inpatient service. She provides continuity of care for the patients and allows the doctors to work more efficiently. Most importantly she is friendly, caring and a knowledgeable advocate for our patients and our practice," said neurologist Robin Morgan, MD.

Brooks is also assisting the AANN in revising the clinical portion of the pediatric neurology guidelines that are distributed to nurses nationwide. She is a board certified Family Nurse Practitioner, and she will sit for the Pediatric Nurse Practitioner exam soon. Brooks is also continuing her education this fall by enrolling in the Doctorate of Nursing Practice program at the University of Tennessee Health Science Center.



Lai Brooks

Brain Waves is a quarterly publication of the Neuroscience Institute at Le Bonheur Children's Medical Center. The institute is a nationally recognized center for evaluation and treatment of nervous system disorders in children and adolescents, ranging from birth defects and learning and behavioral disorders to brain tumors, epilepsy and traumatic injuries.

James W. Wheless, MD, *Medical Director, Le Bonheur Comprehensive Epilepsy Program and Neuroscience Institute*

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Stephanie Einhaus, MD

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Kathryn McVicar, MD

Robin L. Morgan, MD

Michael S. Muhlbauer, MD

F. Fred Perkins Jr., MD

Sarah Richie, PhD

Robert Sanford, MD

Namrata Shah, MD

Save the Date

Greater Mid-South Pediatric Neurology Update April 9-10, 2010

The Le Bonheur Neuroscience Institute will host the fourth annual Greater Mid-South Pediatric Neurology Update April 9-10, 2010 at the Peabody Hotel in downtown Memphis. The seminar is designed to encompass state-of-the-art practices and trends in treating children with neurologic disorders. Seminar faculty will provide insight into common situations sub-specialists in pediatric neurology face, using case-based learned and didactic lectures with question and answer time. The course schedule will be announced this winter.