

Neurosciences Family Advisory Council



FALL, 2017

SHARING WISDOM, PARENT TO PARENT:

In late 2011, our twin boys ended up in the hospital for over a month with RSV. It wouldn't be the last time both boys would be admitted simultaneously, and we've learned a few things that have helped during those times. Most of it applies even when only one of our kids is admitted to the medical center, but even more when both are.

Ask for help. If you are fortunate enough(as we have been) to have a good support system of family and friends, don't be shy about asking for their help , whether that means bringing clothes, delivering food, or just sitting with one of your children while you take a break or get some sleep. One of the medical center's volunteers may be able to stay with one of your children while you step out for a bit .

Know the schedule and take notes. Ask staff about the times the doctors are more likely to come around to see patients. Although the timing may vary considerably, there is often a period when you are more likely to see the doctor and have a chance to discuss your child's condition in person. Just as with visits to the clinic, take notes on what the doctors and nurses tell you about your child's plan of care, including times for food, medicine, x-rays, changes in treatment, etc. If you observe anything about your child's condition that may be important, write that down as well so you can inform the staff.

Make time for yourself. It's harder to participate in the care of your child when you aren't taking care of yourself. Getting sleep, eating properly, taking breaks, and even exercising can help you focus and reduce some of your stress. If you get help from others and know your child's schedule , you'll be better able to make time for your own needs.

Matt Cobb—Father of William and John-Raven and member of the Neurosciences Family Advisory Council.

Having a critically ill child is challenging, so we're here to help ease the way as much as possible. The Neurosciences Family Advisory Council is made up of parents and primary caregivers who, along with Cook Children's neurosciences staff, work to improve our family-centered care and the experiences of patient families.

Our council meets every month to discuss initiatives and offer suggestions and feedback to Cook Children's staff members. They then work with staff members to help make these projects happen. If you are interested in joining the Neurosciences Family Advisory Council or have something to share, we're here to listen, and to make sure your voice is heard.

For more information call 682-885-7123 or email parents@cookchildrens.org

Getting to know Neurology Staff



SPOTLIGHT ON:

Jessica Holy

Registered Dietitian



Jessica Holy has worked as a Registered Dietitian since 1997. She started her career managing the nutrition care of adults who were

hospitalized in long-term acute care settings. Jessica completed her undergraduate degree in nutrition at Texas Christian University and a few years later completed her Master's degree at Texas Woman's University.

After completing graduate school, Jessica began working at a Long Term Acute Care (LTAC) hospital in the Arlington and Fort Worth areas. She monitored patients on tube feedings and IV nutrition to ensure their nutrition needs were met. She also participated on wound care teams, making recommendations for supplemental nutrition to maximize wound healing. After 9 years, she was looking for a new challenge and found just that at Cook Children's.

Jessica has been at Cook Children's for almost 11 years. Her first role was as Renal Dietitian for the Nephrology/Dialysis Clinic. Within a few years, she had the opportunity to learn about ketogenic diets and was soon taking on the role of our Ketogenic Dietitian. About 4 years ago, Jessica was able to transition into a full time position within the Neurosciences Department. Now, she dedicates most of her time to the ketogenic diet - teaching families how to start their children on ketogenic diets and then supporting them on their journey. Jessica also sees a variety of patients in clinic, providing education and support on weight gain, weight loss and tube feeding management.



UPCOMING EVENTS!

October

*FAMILY CENTERED CARE MONTH

Oct 13-15: Camp E.E.G. (Epic Epilepsy Gathering) - Camp John Marc. Contact the eftx.org for info.

Oct 14: Sib2Sib Camp Courage (8 – 12 year olds)

November

*EPILEPSY AWARENESS MONTH

Nov 2: Dr. Keator- 6:00 to 7:00 **Sudden Unexplained Death in Epilepsy (SUDEP)**. South Tower # 1163

Nov 9: **Epilepsy Support Group meeting** 5:00 to 7:30 Kat Davitt-**The Who, What, Where, and How of Getting a seizure Dog**. Pavilion 4 & 5

Nov 16: Dr. Perry- Hochberger 6:00 to 7:00 **Update on Cannabidiol (CBD) for the treatment of intractable childhood epilepsy**

Nov 30: Dr. Kadiwala- 6:00 to 7:00 Pavilion 4 & 5
Parent Talk Adult transitional epilepsy clinic

December

Dec 14: Neurofibromatosis, Epilepsy &

Tourette Syndrome
Support Groups

HOLIDAY PARTIES



Do you have topics that you would like to see covered in future newsletters?

Please email us at parents@cookchildrens.org and join the Neurosciences & Neuro FAC FB Groups



HOW TO MAKE THE BEST EXPERIENCE AT THE NEUROSCIENCES CLINIC

Be prepared to provide details about all the patient's health care providers

Take advantage of the complimentary valet parking service and registration on the West side of the 1st floor of the Dodson Building, accessible from Cooper Street.

When discussing your child's condition, medication side effects, compliancy and other sensitive matters, carefully consider how much to include your child in the conversation.

Do you have a medically complex Child? Get a free copy of "Your Child's Health Care Note-book" from our Family Health Library.

Sign up for the Cook Children's Patient Portal at mycookchildrens.org to communicate with your child's health care team in a secure and confidential manner.

Parents or guardians of adult patients 18 year old+ must provide legal documentation regarding guardianship or supportive decision.

~ RESOURCES TO SHARE ~

PLEASE NOTE: Cook Children's does not endorse these resources or businesses. They are shared by parents for your convenience as a helpful guide. This information is subject to change:

Texas Parent to Parent

txp2p.org
Toll free 866-896-6001

Texas Dept. of Aging & Disabilities

dads.state.tx.us/providers/communications

Epilepsy Foundation of Texas

eftx.org

Texas Health and Human Services Commission STAR Kids program

<http://www.hhsc.state.tx.us/medicaid/managed-care/mmc/star-kids.shtml>

Child Study Center Diagnosis Treatment & Education for Complex Developmental Disabilities

cscfw.org

Partners Resource Network - Path Project

partnerstx.org
Region 9 & 11 - Wichita Falls & Ft. Worth
Shannon Rosson (817) 988-7717

The ARC of Greater Tarrant County

arcgctc.org

MHMR of Tarrant County

mhmrarrant.org



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WISHING YOU A HEALTHY, HAPPY, SAFE FALL !