

Neurosciences Family Advisory Council (Neuro FAC)

Winter, 2015

Cook Children's Neuro FAC



Getting to know Neurology Staff **SPOTLIGHT ON:**



Julie Schmidt

Neurosciences Patient Liaison

How can we help your family?

We are dedicated to changing lives and improving outcomes for children and teens with neurological conditions. The following information is provided by our Neuro FAC to make things simple when things get complicated with your child's condition. We are here to help families bridge communication gaps and empower parents with tools to manage their child's healthcare.

Email us: neuro@cookchildrens.org

PHYSICIAN'S FORUM

Although summer seems far away, now is the time to begin preparing your child for spring break travel, summer activities, and the upcoming school year. Below is a list of tasks that can be completed now or in the near future that will decrease your stress level and help avoid the rush of last-minute preparation...

- Finalize spring break travel plans and request needed medical documents as soon as possible.
- Request medication refills well in advance of spring break and summer trips.
- Finalize summer camp plans and complete applications.
- Apply for private school admission for next school year.
- Request letters to initiate school evaluation process for IEP's and 504 Plans.
- Request neuropsychological evaluation and reevaluation appointments in order to complete the entire process prior to school resuming.
- Request ARD meetings now to make changes for next school year.
- Schedule well-child visits now because summer appointment slots fill quickly.
- Begin medication weaning/changes early in summer.
- Talk to the school nurse about potential medical needs in the upcoming school year.
- Update seizure action plans and school medication forms.
- Request updated letters documenting specific needs for school (e.g., special care or dietary requirements, activity limitations).
- Request a second labeled Rx bottle for medications administered at school.
- Set a reminder to ask for ADHD prescription medication refills well before school begins.
- Request summer biofeedback appointments to reinforce headache management techniques.
- Resume a typical school-year sleep/wake/activity schedule well before school resumes.
- For patients leaving town for college:
 - Request all high school records needed prior to high school graduation.
 - Create specific academic accommodations for college prior to high school graduation.
 - Consider identifying physicians in the city where the patient will be attending college to ensure easy access to healthcare.

Receiving a neurological diagnosis and managing treatment options can be overwhelming, even for strong individuals. My goal, as a patient liaison, is to help make things simple when life gets complicated by complex medical conditions. Faced with challenges at home, work, school, and in the community, some families need extra support. Other families require additional information or improved communication with staff. Navigating families to appropriate, helpful resources like Cook's Matusik Family Health Library or directing out-of-town caregivers to local resources are simple ways I can help improve patient experiences.

It is important for parents and staff to build trusted partnerships of care that benefits the patient and family. Cook Children's offers many tools to empower and uplift families. Many times, families are unaware of various services available to assist caregivers with unique family dynamics. For example, printed material is available near the check-out desks and in the Neuro Clinic waiting room. The "Patient & Family" tab on our Cook Children's website at www.cookchildrens.org/ForPatientsFamilies/Pages/default.aspx and the "Resources" tab on our Neurosciences website at www.cookchildrens.org/SpecialtyServices/Neurosciences/Resources/Pages/default.aspx also feature many upcoming events and appropriate resources for your convenience: child life specialists, support groups, camps, parent mentors, social workers, financial counselors, and more. If you are unable to find what you are looking for, please contact me. I am available to help you with your inpatient and outpatient needs.

Contact Julie Schmidt at: 682-885-7887

OR

julie.schmidt@cookchildrens.org



Upcoming events & Related resources :

January: Muscular Dystrophy Awareness

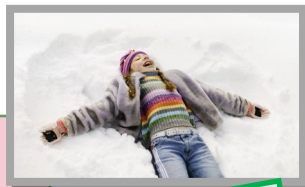
mda.org

January 8: Epilepsy Support Group at Cook Children's

[cookchildrens.org/
SpecialtyServices/Neurosciences/
Resources/](http://cookchildrens.org/SpecialtyServices/Neurosciences/Resources/)

February 7: Cook Children's Neuro FAC Parent Education Day

[cookchildrens.org/
SpecialtyServices/Neurosciences](http://cookchildrens.org/SpecialtyServices/Neurosciences)



Save the date:

April 18, 2015
Stroll for Epilepsy
at the Ft. Worth Zoo

March 26: National Wear Purple Day for Epilepsy Awareness

eftx.org

March: Brain Injury Awareness

Family Support Council of Tarrant County

March: National Multiple Sclerosis Education & Awareness Month

nationalmssociety.org/resources

We would love to hear from you! Do you have topics that you would like to see covered in future newsletters? Please email us at neuro@cookchildrens.org

NEURO PARENT EDUCATION DAY

Sponsored by Cook Children's Neurosciences Family Advisory Council

YOUR FAMILY'S JOURNEY THROUGH NEUROSCIENCES

February 7, 2015 (8 AM – noon)

Navigating the Top 10 Basics of Special Education

Shannon Rosson, PATH Project, Regional Coordinator-Partners Resource Network, Inc

Sorrow...Part of the Journey

Panel with parent, patient, and sibling perspectives

Hope for the Road

Nika Maples, MA, Stroke survivor, public speaker & author, [Twelve Clean Pages](#)

– Preparing Your Financial & Legal Roadmap

John A. Chalk, CPA, J.D., CFP, ChSNC, Chalk Cullum
Rick Weaver, J.D., partner Shannon Gracey
Kathleen F. Lehrmann, J.D., Kathleen F. Lehrmann, P.C.
Timothy J. Morand, CLU, ChFC, ChSNC, Mass Mutual
Matthew Reed, LCSW, Social worker, Cook Children's Neurosciences

– Travelers' Guide to Creative & Therapeutic Nourishment

Jessica Holy, RD, LD, Clinical Dietician, Cook Children's Neurosciences

– Strategies for Managing Behavioral Roadblocks

Complimentary Continental Breakfast, free Childcare with RSVP, Door Prizes

*Resource Fair with exhibitors and printed materials to research
a wide variety of options available in the Tarrant County area

Cook Children's Medical Center
Hochberger Auditorium
Please **RSVP** to Julie Schmidt at 682-885-7887
or neuro@cookchildrens.org

~ 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:

Facebook: Doctor Radio-SiriusXM81

Doctor Radio: Channel 81 on Sirius XM Radio

www.siriusxm.com/doctorradio

Facebook: Reaching for the Stars. A Cerebral Palsy Foundation

Reaching for The Stars Cerebral Palsy Foundation

www.reachingforthestars.org

Twitter: @Reach4Stars

Twitter: @NYUDocs

Texas Dept. of Aging & Disabilities
www.dads.state.tx.us/providers/communications

Facebook: Sensory Processing Disorder Parent Support

<http://sensoryprocessing.yolasite.com/>

Epilepsy Foundation of America

www.epilepsy.com

Epilepsy Foundation of Texas

www.eftx.org

www.cafetx.org



don't forget to

find us on...

Cook Children's

facebook

Children's @ Cook Childrens



Wishing you a healthy, happy and prosperous New Year!!