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Dell Children's Comprehensive Epilepsy Program

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Dear Colleagues,

We would once again like to share with you our program's newsletter in which we continue our dialog about treatment of our patients with epilepsy. In this newsletter, we introduce our colleague, Dr. Maureen Nelson, who joined us from the University of North Carolina in August 2011. She directs our physical medicine & rehabilitation department and will address how this specialty assists in the care of our patients with epilepsy.

We are also extremely excited and fortunate that the Institute of Medicine (IOM) has graciously allowed us to share with you their findings after examining the public health dimensions of the epilepsies. The IOM was asked by 24 sponsoring federal agencies and non-profit organizations to review both the clinical and research needs of the epilepsy population. We hope you take heed of their concerns and, as in our case, put their suggestions into action.

In an attempt to streamline care, we have created a clinical paradigm which should improve the care of our patients. It is diagramed at the back of this newsletter and we feel that this is a tool that can be utilized at all levels from family members through pediatricians, family practice providers and specialists.

We look forward to the entire community assisting us in our efforts to maximize positive outcomes for our children with epilepsy.

Dave Clarke, MD

Physiatry's Role in a Comprehensive Epilepsy Program

Dr. Maureen Nelson

Physical Medicine and Rehabilitation (PM&R), or Physiatry, is a medical specialty that deals with neuromuscular and cognitive deficits, both acute and chronic, from congenital issues, trauma, or disease processes. PM&R overlaps with multiple other medical specialties, including neurology, orthopedics, developmental pediatrics, pain management, gastroenterology, and urology. The main objective in PM&R is to maximize function, and for those of us in Pediatric PM&R that means working to improve function for both now and simultaneously aiming for the future when the child becomes an adult.

PM&R has three main areas of overlap with Epilepsy care. The first is that there is a significant population of children seen by both teams. The most common group seen by both teams are children with cerebral palsy (CP), but children with traumatic brain injuries (TBI), brain tumors, spina bifida, and other diagnoses are also commonly seen by both. Many of these children are followed long-term by both teams. The second area of overlap is that of cognitive dysfunction. Children with epilepsy may have cognitive issues from seizures, from the disease process that causes the seizures, or from a combination. The treatment goal for PM&R for this group of children is to maximize

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What's Going On?

Epilepsy Across the Spectrum: Promoting Health and Understanding

A Report Brief from the Institute of Medicine

Epilepsy is the nation's fourth most common neurological disorder after migraine, stroke, and Alzheimer's disease; but public understanding of epilepsy is limited. For example, many people do not know the causes of epilepsy or what they should do if they see someone having a seizure. Epilepsy is a complex spectrum of disorders—sometimes called the epilepsies—that affects millions of people in a variety of ways and is characterized by unpredictable seizures that differ in type, cause, and severity. Yet living with epilepsy is about much more than just seizures. For people with epilepsy, the disorder is often defined in practical terms, such as challenges in school, uncertainties about social situations and employment, limitations on driving, and questions about independent living.

An estimated 2.2 million Americans have epilepsy, with approximately 150,000 new cases diagnosed in the United States each year. Approximately 1 in 26 people will develop epilepsy at some point in their lives, and the onset of epilepsy is highest in children and older adults.

The Institute of Medicine (IOM) was asked by 24 sponsoring federal agencies and nonprofit organizations to examine the public health dimensions of the epilepsies, focusing on public health surveillance and data collection; population and public health research; health policy, health care, and human services; and education for people with the disorder and their families, health care providers, and the public. The IOM committee presents recommendations to improve the lives of people with epilepsy in its report, *Epilepsy Across the Spectrum: Promoting Health and Understanding*.

CLOSE THE DATA GAP AND PREVENT EPILEPSY

Data are lacking that could improve the lives of people with epilepsy, the committee concludes. Current data sources provide a patchwork of surveillance activity that, if coordinated and linked, could shed light on the full physical, psychological, social, and economic burdens of epilepsy and improve knowledge about its risk factors, associated health conditions, consequences, and health and community service needs. The committee calls for improved data collection on epilepsy to inform health policy and to identify opportunities for reducing the burden of the disorder.

Preventing epilepsy is possible for some causes of the disorder. Prevention efforts to reduce epilepsy's known risk factors, such as traumatic brain injury, stroke, and brain infections, will likely result in fewer new cases of epilepsy. Other opportunities exist to prevent the consequences of epilepsy, including interventions to improve seizure control in people who have both epilepsy and depression, to reduce internalized feelings of discrimination, and

to eliminate epilepsy-related causes of death, such as sudden unexpected death in epilepsy (SUDEP). The committee highlights the need for additional research, which will contribute to new insights and approaches to the prevention of epilepsy.

IMPROVE HEALTH CARE AND COMMUNITY SERVICES

Progress has been made in developing new seizure medications and refining medical devices and surgical techniques to reduce or eliminate seizures for many individuals with epilepsy. However, referrals to specialized care are often delayed, and access to these treatments fall short, particularly for rural and underserved populations and for people with persistent seizures. The committee outlines steps to expand access to high-quality, patient-centered health care that include focusing on timely identification and treatment of epilepsy and its associated health conditions, implementing measures that assess quality of care, and establishing accreditation criteria and processes for specialized epilepsy centers. The report stresses the importance of health systems collaborating with a range of community services to provide people who have epilepsy with the full spectrum of services they may need.

The wide variety of health professionals who care for those with epilepsy need improved knowledge and skills to provide high-quality health care. Building the health care workforce's knowledge base and skill sets in diagnosing, treating, supporting, and generally working with people with epilepsy is necessary to ensure that individuals and their families have access to high-quality, patient-centered care. Living with epilepsy includes not only dealing with seizures and their impact on health, but also involves developing knowledge and skills to manage the psychological and social challenges and co-existing health conditions associated with the disorder, side effects of medications, and fears of discrimination and prejudice—all of which can significantly affect quality of life. In addition, people with epilepsy are at risk for premature death and SUDEP. At the same time, they are faced with health care and community services that are often fragmented, uncoordinated, and difficult to obtain.

Family members may struggle with how to best help their loved one and maintain family life. The committee recommends that community services and programs be bolstered to ensure that they meet the needs of people with epilepsy and their families, are easily accessible, and work closely with health care providers. These services should take a whole-patient perspective by providing a range of resources and services, including support groups, vocational training, transitional care, assistance with independent living, and respite for caregivers.

¹ This summary of the Institute of Medicine's Report *Epilepsy Across the Spectrum: Promoting Health and Understanding* is being reprinted with permission from the National Academies Press. The full text of the report is available as a free PDF at www.iom.edu/epilepsy. The members of the report's authoring committee, the Committee on the Public Health Dimensions of the Epilepsies, are listed at the end of this summary.

RAISE AWARENESS, IMPROVE EDUCATION

Education for people with epilepsy and their families plays an important role in adapting to life with epilepsy, developing self-confidence, and competently managing the disorder and its associated health conditions. The committee recommends that educational opportunities be expanded and improved through the evaluation and updating of epilepsy websites and educational resources, among other efforts designed to increase knowledge and skills relevant to living with epilepsy.

Public misperceptions and misinformation about epilepsy have persisted over centuries. Inaccurate or sensationalized depictions of people with epilepsy, often used for dramatic effect in the entertainment media, have reinforced negative perceptions. To raise public awareness and reduce stigma, ongoing efforts are needed, using clear messages and diverse activities targeted to specific audiences through multiple media, including social media and the Internet.

STRENGTHEN STAKEHOLDER INVOLVEMENT

Currently, a number of organizations are engaged in efforts to advance research, improve health care and human services for people with epilepsy and their families, and increase knowledge about the disorder. Vision 20-20, a collaborative effort of more than 20 nonprofit organizations and 3 federal agencies, focuses its actions on moving the epilepsy field forward. The committee urges further partnerships and expanded efforts by working with groups within Vision 20-20.

Among the most persuasive advocates and educators are people with epilepsy and their family members. Individuals who are willing to speak out can provide a more complete picture of the disorder and its impact. While many people may be willing to play such a role, training and support will help them do so more effectively. People with epilepsy and their families also have the opportunity to advance knowledge about epilepsy and its treatment when they participate in clinical research, surveys, and other studies that investigate ways to improve care and increase understanding of how epilepsy affects individuals' lives.

CONCLUSION

Given the current gaps in epilepsy knowledge, care, and education, the committee believes there is an urgent need to take action—across multiple dimensions—to improve the lives of people with epilepsy and their families. The committee provides research priorities to further develop the evidence base, and it recommends realistic, feasible, and action-oriented steps for a variety of stakeholders to enable short- and long-term improvements for people with epilepsy.

HIGHLIGHTS FROM THE COMMITTEE'S RECOMMENDATIONS

- Validation and implementation of standard definitions and criteria for epilepsy case ascertainment, health care and community services use and costs, and quality measurement
- Continuation and expansion of collaborative surveillance efforts
- Development and evaluation of prevention efforts for epilepsy and its consequences
- Improvement in the early identification of epilepsy and its comorbid health conditions
- Development and implementation of a national quality measurement and improvement strategy for epilepsy care
- Establishment of epilepsy center accreditation and an Epilepsy Care Network
- Improvement in health professionals' education about the epilepsies
- Improvement in the delivery and coordination of community services
- Improvement in and expansion of educational opportunities for patients and families
- Provision of information to media to improve awareness and eliminate stigma
- Coordination of public awareness efforts
- Continuation and expansion of Vision 20-20 working groups and collaborative partnerships
- Engagement of people with epilepsy and their families in education, dissemination, and advocacy for improved epilepsy care and services

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Vision 20-20 nonprofit organization sponsors

American Epilepsy Society
Citizens United for Research in Epilepsy
Dravet.org
Epilepsy Foundation
Epilepsy Therapy Project
Finding A Cure for Epilepsy and Seizures
Hemispherectomy Foundation
International League Against Epilepsy
National Association of Epilepsy Centers
Preventing Teen Tragedy
Rasmussen's Encephalitis Children's Project
Tuberous Sclerosis Alliance

KETO CORNER

Fluids & the Ketogenic Diet – Hydration is Essential

Fluids are a key component to promoting the best outcomes while following the ketogenic diet. Without sufficient intake of fluids, the body is at increased risk for developing acidosis, constipation, and kidney stones. An intake of adequate fluids is necessary to maintain normal hydration during ketogenic diet therapy and to avoid potential complications.

Fluids recommended while on the ketogenic diet include: water, decaffeinated weak tea or coffee, and calorie-caffeine free diet soda. Heavy cream can be counted towards the fluid allotment. Tube feeding formulas are also included in the amount of fluid consumed. During an acute illness or exposure to warm weather, fluids should be liberalized in quantity. During periods of illness when children have decreased oral intake, fluids such as Pedialyte or broth can be used to help prevent hypoglycemia and dehydration.

Fluid goals are determined for each child using a mathematical calculation based on the child's desirable weight. When starting the diet, the dietitian will calculate the child's specific fluid goals to identify the quantity the child needs to consume daily. For some children, this volume of fluid may be too little or too much, therefore, the child's ability to consume the prescribed quantity of fluid may be altered.

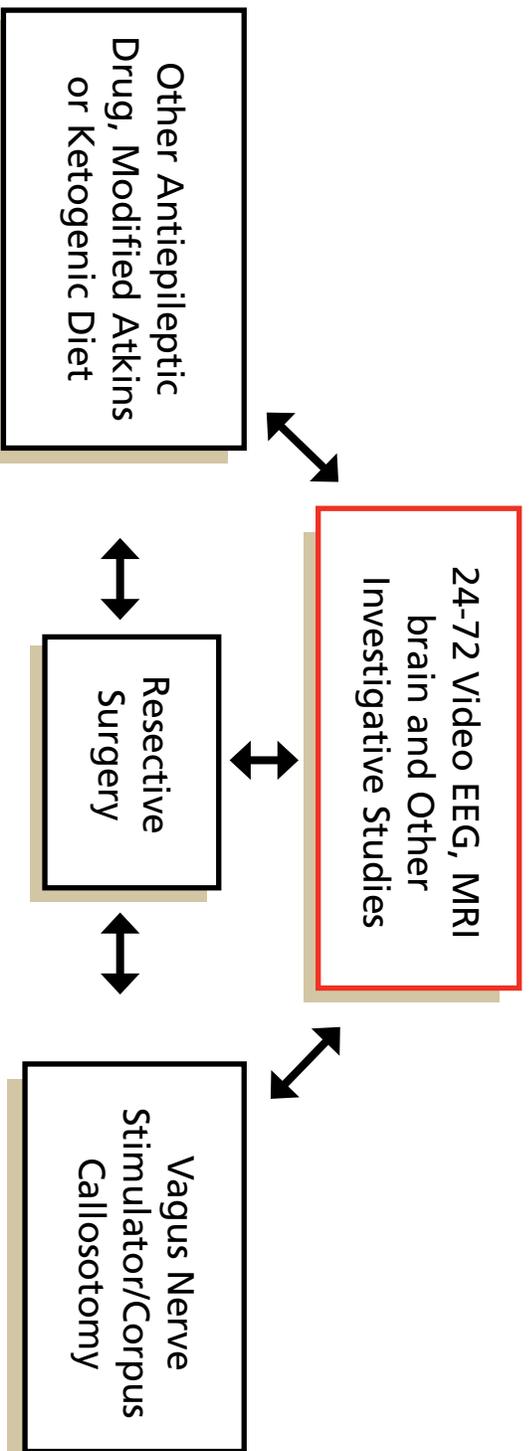
In addition to liquids that are safe to consume on the diet, as mentioned previously, there are other choices of beverages to help keep variety in the diet and promote adequate fluid intake. The Charlie Foundation approves the following beverages: O Clear Water, Aquafina Flavor Splash, Clear Fruit Lite, Dasani Natural Flavored Water Beverage, Fruit 2-O & Nestle Pure Life Natural Fruit Flavored Water.

For a special treat, making a ketogenic diet friendly version of an Italian cream soda may add a fun twist to consuming daily fluid requirements. To prepare an Italian cream soda, you simply need club soda, your favorite keto approved sugar-free syrup, crushed ice, and heavy whipping cream. To prepare the drink, pour club soda into a tall glass filled with ice. Add the sugar free syrup to taste. Slowly top the mixture with whipping cream. The cream may also be whipped and used as a garnish. Enjoy this delicious drink while helping to hydrate your keto kid!



Intractable Epilepsy Treatment Protocol

Fail 2 AEDs or after every 3 years
Refer to Epilepsy Monitoring Unit



Physiatry's Role in a Comprehensive Epilepsy Program

(Continued from front page)

cognitive function, particularly appropriate for school approach and school performance. The third area of overlap is with some of the children and teenagers who have intractable epilepsy and require surgery for optimal treatment. I have worked with this population of children elsewhere for many years in the inpatient rehabilitation setting, so it is exciting personally to be more involved throughout the process here at Dell Children's. For some of these children the surgical plan will include a temporary motor deficit. These are the ones who PM&R will work with closely and intensively. We will have physical therapy,

occupational therapy, and speech therapy working with the children and their families as soon as they are cleared by their neurosurgeon. We may need to get braces or other equipment to use early on in their recovery. Some of this group will require an inpatient rehabilitation unit stay to work aggressively on their rehab program, usually for three hours a day for a couple of weeks. They will then transition to an outpatient program several times a week, working to maximize function, in conjunction with their frequent new-found alertness related to decreased (or absent!) seizure activity!

Pediatric Specialty Services (PSS) is a multidisciplinary group of specialists committed to providing comprehensive care for kids. Our team supports the Comprehensive Epilepsy Program at Dell Children's Medical Center of Central Texas, providing a range of epilepsy services from drug treatment to neurosurgery. The program encompasses leading-edge diagnostic tools and offers the only dedicated pediatric Epilepsy Monitoring Unit (EMU) in Central Texas, which is staffed with specially trained medical, nursing and technical personnel monitoring patients around the clock.

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