# **CHP Neuro News**

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#### MULTIPLE SCLEROSIS AND NON-MULTIPLE SCLEROSIS DEMYELINATING DISEASE IN CHILDREN

We hear a lot about multiple sclerosis (MS) in adults, but did you know that 15,000 children in the U.S. today have MS? MS is a disease that affects the myelin - the insulation around nerves – in the brain and spinal cord. When this myelin is damaged or removed from nerves, it causes a kind of short circuit, just as it does in an electrical appliance. Whatever function is normally served by the nerves that lose their myelin is not able to be carried out properly once the myelin is lost. In most cases, the myelin can regenerate or reform; but in children and adults who have MS, the destructive process repeats itself, often in another part of the brain and/or spinal cord, and new symptoms of myelin injury appear. Sometimes the myelin destruction is severe enough that the symptoms do not completely go away between attacks.

When children under the age of 12 years get a sudden attack of demyelination, especially if that attack comes within two or three weeks of a viral infection, that attack is unlikely to represent the first attack of MS. In most such cases, that demyelination comes about because the immune system that is trying to fight the virus gets overactive or a bit confused and attacks the child's myelin as well. These children are much less likely to have recurrent attacks, and most never have another episode again. This disease is called acute disseminated encephalomyelitis (ADEM) because it is a sudden and widespread immune system attack (itis) on the brain (encephalo) and/or spinal cord (myel)

CHP Neurology has begun a White Matter Disorders Clinic that includes dedicated time and resources for children with MS or ADEM (among other disorders of myelin) and their families. This clinic is directed by Dr. Gulay Alper who sees patients with nurse practitioner Caroline Roche. To schedule an appointment in the White Matter Disorders Clinic please call 412-692-5520 and press "1" any time during the recorded message.

#### DR. SCHOR ELECTED NEUROLOGY REPRESENTATIVE TO NATIONAL SOCIETY FOR PEDIATRIC RESEARCH COUNCIL

The Chief of the CHP Division of Child Neurology, Dr. Nina F. Schor, was elected the Council member from Child Neurology for the Society for Pediatric Research (SPR). The SPR is the only national organization devoted solely to research in Pediatrics. Its members come from many countries in addition to the U.S., and convene annually to present and discuss research of relevance to the development and diseases of childhood.

#### Headaches in Children and Adolescents: Strategies for Diagnosis and Treatment

A Symposium for Medical Professionals and Trainees Wednesday, May 28, 2003.
Children's Hospital of Pittsburgh,
McCluskey Auditorium.
Call 412-647-8216 or -8232 for registration details.

# A Sampling of Internet Resources

These sites are merely examples of a host of internet sites available for information. Each has been reviewed by at least one member of the Division of Child Neurology for accuracy and helpfulness. No financial remuneration was received by CHP Neurology or any of its members for inclusion of any of these websites in this list; no endorsement of particular commercial products that may be mentioned therein is either intended or implied.



# General Child Neurology

<u>www.familyvilliage.wisc.edu</u> - Developed by the University of Wisconsin; Education regarding a wide range of disabilities and specific diseases

www.nyneurosurgery.org - Developed by the Institute of Neurology and Neurosurgery; Provides information on neurological and neurosurgical conditions; While on the home page, click on the "pediatric diseases" which will drop down a list of specific conditions.

# **Specifically for Parents**

<u>www.kidshealth.org</u> - Developed by the Nemours Foundation Center for Children's Health Media; Provides a wide range of information regarding children and teenagers, including specific medical topics

<u>www.zerotothree.org</u> - Information on development from ages 0 to 3 years

<u>www.brainconnection.com</u> - Offers a wide range of brain-related topics, such as learning, development and specific topics www.pbs.org/wgbh/pages/frontline/shows/teenbrai
 n/ - PBS Educational show titled "Inside the Teenage Brain"; Looks at teenage brain development and covers topics such as sleep,

memory, and emotions

<u>www.ama-assn.org</u> - American Medical Association; Offers accurate and up-to-date information on a wide variety of health topics and issues; click on the "patient" option

<u>www.helmets.org</u> - Bicycle Helmet Safety Institute; Offers consumer information including reports on specific products, fitting and wearing helmets effectively, and safety tips

# Specifically for Kids and Teens

<u>www.howstuffworks.com/brain</u> - Anatomy and function of the brain

<u>www.faculty.washington.edu/chudler/neurok</u> - Neuroscience for Kids

<u>www.kidshealth.org</u> - Educational site for kids and teens, includes a wide range of health-related topics

<u>www.epilepsy.org.au</u> - Great resource for kids and teens

# **Epilepsy and Seizures**

<u>www.epilespyfoundation.org</u> - Epilespy Foundation Home Page

<u>www.efwp.org</u> - Epilepsy Foundation of Western Pennsylvania Home Page (includes Pittsburgh region)

<u>www.epilepsy.org.uk</u> - Epilepsy Action Home Page

<u>www.epilepsy.org.au</u> - Epilepsy Association of Australia Home Page

## Headache

<u>www.achenet.org</u> - American Counsel for Headache Education Home Page

<u>www.headaches.org</u> - National Headache Foundation; Educational site and support group

<u>www.migrainhelp.com</u> - Sponsored by Imitrex; Offers education regarding migraine triggers and treatment

<u>www.excedrine.com</u> - Sponsored by Excedrine Migraine; Headache Resource Center

<u>www.mhni.com</u> - Developed by the Michigan Head Pain and Neurological Institue; Offers information on headaches, pain, and includes links to further resources

### **Neurofibromatosis**

<u>www.nf.org</u> - National Neurofibromatosis Foundation; Provides information and support for families affected by NF and physicians and researchers with an interest in this disorder.

<u>trfn.clpgh.org/nfca</u> – Neurofibromatosis Clinics Association; Greater-Pittsburgh organization that provides information and support for families affected by NF.

# **Tuberous Sclerosis**

<u>www.tsalliance.org</u> - Tuberous Sclerosis Alliance; National consortium of regional organizations providing information and support for families affected by TS and physicians and researchers with an interest in this disorder.

www.tsalliance.org/Volunteer%20Ops/pittsburgh. asp — Western Pennsylvania Chapter of the TS Alliance; Greater-Pittsburgh organization that provides information and support for families affected by TS.

#### **Multiple Sclerosis**

<u>www.nmss.org</u> - National Multiple Sclerosis Society; Provides information and support for patients with MS and their families.

<u>www.msaa.com</u> - MS Association of America; Provides information and support for patients with MS and their families.

Note: Neither of these websites is specifically geared towards childhood MS, but both give a general background on this disorder. Ask you child's doctor about specific aspects of MS in children that may differ from what's described on these websites.

#### Mitochondrial Diseases

<u>www.umdf.org</u> - United Mitochondrial Disease Foundation; Provides information and support for families affected by mitochondrial disease

#### Genetic and Rare Disorders

 $\underline{www.geneticalliance.org}$  - Educational resources and additional links for genetic disorders

<u>www.gig.org.uk</u> - Genetic Interest Group; Provides support and information for genetic disorders

<u>www.rarediseases.info.nih.gov</u> - Sponsored by the National Institutes of Health; Offers up-to-date information on rare diseases, including current research and links to further educational sites.

Thanks to all of you who have called us at least a day ahead of time when you were unable to keep an appointment!

In so doing, you have made that slot available to another child and family in need of CHP Neurology services.