

Family Voices of Wisconsin

*The Home of Wisconsin's Family to Family Health Information and Education Network
in Partnership with the Wisconsin Children and Youth with Special Health Care Needs Program*

Back to School for Children with Special Health Care Needs *Communicating with Your School Nurse is Key to a Healthy Year*

This is an exciting time of year for school age children and their families. A new school year means new teachers, a new classroom and new routines which can be exhilarating for students. However, it can also be challenging for families who have children and youth with special health care needs and disabilities.

While you may have met your child's new teacher, making time to meet the school nurse is equally as important to ensuring a successful school year. Establishing open communication with the school nurse will decrease misunderstandings if your child needs medication or treatment during the school day and will allow your child's school team to more effectively serve the health and educational needs of your child. According to Ann Riojas, RN, President of the Wisconsin Association of School Nurses, *"The goal of school nurses is to help remove the barriers to learning for all children. They are an important partner with parents and physicians to advocate for the health needs and accommodations for students with special needs and students with chronic illnesses such as diabetes, asthma, or seizures."*

If your child has an IEP or 504 Accommodation Plan, consider including the school nurse on the team and as a "related service" in the plan. The school nurse may also be able to assist you in adding health outcomes to your child's IEP (go to the Waisman Center website to learn more www.waisman.wisc.edu/wrc/cdrom.htm). The nurse should also be involved with helping

to develop an Emergency Care Plan if your child has a condition that could require emergency care during the school day. While some schools have a nurse on staff full time, most districts will have only a few nurses that cover many schools and have limited time at each school. You may want to contact your child's school and set up a meeting with the school nurse.

Questions to Ask the School Nurse:

- Is the school nurse in the building all day, or only during certain hours?
- Who is back up if the nurse is not available?
- If someone other than the school nurse will be giving your child medication or performing a treatment or procedure, has the school nurse trained this person?

What are the roles and responsibilities of the school nurse? The school nurse will determine whether or not a treatment, procedure or medication can be given by someone other than a nurse (a delegate) and the nurse is responsible for the decision, training and assessment of competency regarding that delegation.

Federal law requires school districts to provide necessary medications and nursing services for students to receive a free appropriate public education (FAPE). School districts are required to provide training to school staff who administer medications or perform procedures (e.g., seizure medication, respiratory care or Gastronomy tube feedings). On-line resources are available on the DPI website, dpi.wi.gov/sspw/medtraining.html.

NEW FAMILY VOICES TRAINING ON TRANSITION

We are rolling out our new training series, *WHAT'S AFTER HIGH SCHOOL? Everything You Need to Know About Supports and Resources for Youth with Disabilities and Special Health Care Needs*. All trainings will be held from 5:00 - 8:00 PM and include dinner. Trainings are free.

Dates/Locations: Oct. 6 in Burlington, Oct. 18 in Racine, Oct. 20 in Lake Geneva, Nov. 1 in Elkhorn

How do I Register? Call 608-220-9598 or email Lynn at Lynn@fvofwi.org, or go to www.fvofwi.org.





WEB WATCH

For additional resources related to the articles in this newsletter, you can visit the following sites:

Family Voices of Wisconsin

www.fvofwi.org

(note new address!)

National Office of Family Voices

www.familyvoices.org

Lead Poisoning Prevention Program

dhs.wisconsin.gov/lead

Autism Speaks

Autismspeaks.org

Healthiest WI 2020

www.dhs.wisconsin.gov/hw2020

Health Care Reform

www.familiesusa.org/health-reform-central/

www.healthcarereform.wisconsin.gov

www.HealthCare.gov

Did You Know? Now You Know!

Is Your Family Affected by Lead Poisoning?

Do you live in a home or does your child attend a daycare built before 1978 in which lead-based paint would have been used? Does a family member work or have a hobby that uses lead?

Lead poisoning has devastating effects on health and development. Children of all ages can become lead poisoned, but children under age six are especially vulnerable because their nervous systems are developing. For example, lead poisoning in children can result in a lowered IQ, behavior problems such as aggression and hyperactivity, shortened attention span, speech and language problems, hearing

loss, and learning difficulties. The majority of children diagnosed with lead poisoning in WI are poisoned from fine lead dust particles from chipping or peeling paint, lead contaminated soil or during renovation of older homes. Children with lead poisoning rarely show any symptoms and can only be diagnosed through a simple blood test.

If you have questions, contact your local health department or contact: WI Childhood Lead Poisoning Prevention Program, 608-266-5817 (dhs.wisconsin.gov/lead), Adult Blood Lead Epi. Surveillance (608-266-5817), Renovation, Repair and Painting Rules (608-267-3862), www.hud.gov/offices/lead/training/LBPguide.pdf.

Resources for Families and Providers

Shared Participation: Strategies to Increase the Voice of Families from Diverse Backgrounds as Partners and Advisors

A report released by Family Voices of Wisconsin documents conversations with Latino, African American and Native American families who have children with special health care needs. This report has received national attention! Copies are available from Family Voices (contact Lynn@fvofwi.org) and it can be downloaded from our website (www.fvofwi.org).

Dental Toolkit for Children with Autism

Autism Speaks, one of the nation's largest autism advocacy and science organizations, has developed a dental toolkit for families who have a child with Autism. A downloadable dental guide and video are available which provide tips for improving oral hygiene at home and information on how parents and dental professionals can make a visit to the dentist less stressful and more productive. Go to autismspeaks.org and click on "dental toolkit."

Healthiest Wisconsin 2020

The state's public health agenda for the next 10 years, Healthiest Wisconsin 2020, is now available on-line at www.dhs.wisconsin.gov/hw2020. Developed by the WI Department of Health Services, with the input of over 100 individuals and organizations, the plan declares, "Everyone Living Better, Longer" which reflects the plan's goals: improving health across the lifespan; eliminating health disparities (including health disparities for people with disabilities); and achieving health equity.

Opportunities Around the State

3rd Annual Statewide Self-Determination Conference

This year's conference will be held Nov. 8 - 10 at the Kalahari Resort, WI Dells. The focus will be the need to strengthen self-determination so that people are in control of their supports and their lives. For more information, go to www.wi-bpdd.org and click on "SD Conference."

21st Annual Children Come First Conference

Wisconsin's premiere child and adolescent behavioral health conference will be held Nov. 8 & 9 at the Kalahari Resort, WI Dells. For more information and registration, go to www.wifamilyties.org.

SAVE THE DATE! Circles of Life 2011

The 2011 Circles of Life Conference will be held on April 28 & 29, at the Hyatt Regency Hotel in Milwaukee. This is the state's largest conference for families of children with disabilities and special health care needs. Its an event not to be missed! Visit www.colwisconsin.org for more information.

Children and Youth with Special Health Care Needs News

“Did You Know? Now You Know!”

Family Voices training on health care and community services and supports will be held around the state this fall. For more details go to our website (www.fvofwi.org/training).

Dates/Locations

October 12, 5:30 - 8:30 PM, Redeemer Lutheran Church, Plymouth
Oct. 14 & Nov. 4, 5:30 - 8:30 PM, Marshfield Public Library, Marshfield
October 25, 5:30 - 8:30 PM, Thompson Community Center, Appleton
Nov. 13 & 20, Milwaukee - Our training partner is Alianza Latina Aplicando Soluciones (ALAS) and the training will be held in Spanish.

Traducelo Ahora - Spanish Translation Program

As a Family-to-Family Health Information Center, Family Voices and our members (that's YOU!) have access to a powerful new resource for Spanish speaking families. Traducelo Ahora! (Translate Now) is software developed by IBM that will translate documents, emails and websites for free. This software has been thoroughly tested and received great reviews. Whether you are using your home computer or searching the Internet at a public library or school, you can use Traducelo Ahora. Registration is required the first time. To learn more about Traducelo Ahora and how to access the software go to our website at www.fvofwi.org or contact Lynn at Lynn@fvofwi.org.

Your Voice is Needed!!!

Do you receive diapers or other incontinence products from J & B Medical Supply? Are you having problems getting the right products for your child?

Family Voices wants to hear about your concerns. We will bring this information to the Wisconsin Medicaid Program and to J & B Medical Supply. We want to make sure that families receive the diapers and other incontinence products that are most appropriate and work best for their child. To learn more about Medicaid's new provider of incontinence products, see our fact sheet at www.fvofwi.org/Publications/FactSheets/Incontinence.pdf.

***To take a survey and give us your feedback, go to www.fvofwi.org.
The survey is linked to our homepage.***

HEALTH REFORM UPDATE

On September 23, many of the provisions of the new federal health care reform law, called the Affordable Care Act, took effect. A great source of information for this new law and how it impacts families is Families USA, www.familiesusa.org/health-reform-central. Other good sources of information are Wisconsin's new Office of Health Care Reform www.healthcarereform.wisconsin.gov and the new national website, HealthCare.gov. Examples of changes that impact children and youth with disabilities and special health care needs are: insurance plans will no longer be able to deny or exclude coverage to a child due to a pre-existing condition; insurance companies can't include lifetime limits on coverage; and preventive health care services for children must be covered completely without a charge to you (no co-pay).

OTHER NEWS

The Wisconsin Board for People with Developmental Disabilities is developing their 5-year state plan and wants to hear from families about their ideas for ways to make Wisconsin a better place for people with disabilities. Input can be provided by filling out an on-line survey or by participating in state plan *Input Cafes*, to be held in several locations around Wisconsin. For information go to www.wi-bpdd.org.



Children and Youth with
Special Health Care Needs

CYSHCN CENTERS

**Call with your
questions!**

Northeast Region

Children's Hospital of
Wisconsin - Fox Valley

1.877.568.5205

Northern Region

Marathon County Health
Department

Wausau

1.866.640.4106

Southeast Region

Children's Hospital

Milwaukee

1.800.234.5437

Southern Region

Waisman Center

Madison

1.800.532.3321

Western Region

Chippewa County Dept of
Public Health

Chippewa Falls

1.800.400.3678

Great Lakes Inter-Tribal Council

(GLITC)

Lac du Flambeau

1.800.472.7207



Family Voices of Wisconsin

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About Family Voices of Wisconsin

Family Voices of Wisconsin is the home of the Wisconsin Family to Family Health Information and Education Network. Family Voices of Wisconsin is part of a national grassroots network of families and advocates who support children with disabilities and/or special health care needs. We provide information, training and support around health care and community supports to families throughout Wisconsin, including the well received "Did You Know? Now You Know!" training program. Family Voices is dedicated to strong collaborative partnerships between families and essential allies to improve the systems of supports and services for children. A core commitment of Family Voices is to involve and support parents in decision making roles that affect program design and policy recommendations on local, regional and statewide levels.

Feedback Welcome

We want to make sure that this newsletter is an effective resource for you. If you have any comments, or wish to provide news and information for us to publish, please contact Barbara at barb@fvofwi.org. We look forward to your ideas and suggestions!

Do you have an address change or want to be taken off this mailing list? Contact the Family Voices newsletter editor at Lynn@fvofwi.org or call 608-220-9598.