

**MEMORANDUM
DEPARTMENT OF COMMUNITY HEALTH
LANSING, MICHIGAN 48909-7979**

DATE: October 2004
TO: Families of Children with Special Needs
FROM: Mary Marin, Executive Director, Parent Participation Program (PPP)
Children's Special Health Care Services (CSHCS) Division
SUBJECT: Heart-to-Heart Information Updates

This edition is historic. It's our first one ever to be distributed to all CSHCS members. Enclosed with our *new CSHCS Family Guide*, we thought we'd give every CSHCS family a sample of this resource.

For years, we've mailed it 11 times a year. If you are not a regular "subscriber" and want future *Updates* by postal mail, you'll need to join our mailing list. Join by calling us toll-free at 1-800-359-3722 or by e-mailing your name and address (postal or electronic) to PPP Secretary Leah Waters at waterslea@michigan.gov. There is no cost to subscribe.

To broaden access, we are posting *Heart-to-Heart Updates* on the Internet at www.michigan.gov/cshcs.

Forced by budget constraints to make tough choices, we have reorganized our *Family Support Network of Michigan* (FSN). Former FSN District Coordinator Randy Krause is now in charge of FSN statewide. She leads some 300 volunteers, offering parent-to-parent support activities plus one-to-one matches of parents of children with special needs. The "re-org" means we have sadly said goodbye to FSN District Coordinator Stacey Diekevers. Stacey did a fine job of expanding our pool of volunteers in West Michigan. She remains a valued resource, especially to fellow "mothers of multiples." ♥

PPP Update

Parent-gathered **resources on Cornelia de Lange Syndrome (CdLS), Fragile X Syndrome, Joubert Syndrome, PKU and Metabolic Disease, and Prune Belly Syndrome** are available for loan from PPP. Parent scholarship recipients collected them at national conferences over the summer.

The scholarship requires a conference report from the parent. The report often conveys a parent's excitement about gaining new information. A father who attended a Lowe Syndrome conference wrote, "*There have been boys discovered that have the Lowe Syndrome gene, but were not born with cataracts in their*

eyes! We all thought that being born with cataracts was a major part of the syndrome. What a shock. This has led researchers to believe that there may be an additional piece of the puzzle..."

To borrow conference resources files, parents may phone PPP Information and Resource Specialist Dianna Rigato at 1-800-359-3722. ♥

Note: Michigan families may apply for a parent scholarship to attend a conference related to the diagnosis, care or treatment of their child's special health need. For details and an application, phone PPP Administrative Assistant Jean Rennie at 1-800-359-3722.

High Expectations: Playgrounds for Children of ALL Abilities is a new book in PPP's *Lending Library*. We

have the 2003 early childhood edition. Families may borrow it and other titles by phoning PPP Secretary Leah Waters at 1-800-359-3722. ♥

CSHCS Update

The **two CSHCS Special Health Plans** (*Children's Choice of Michigan* and *Kids Care of Michigan*) **are no longer in operation**. The change took place Oct. 1. All Special Health Plan (SHP) enrollees can continue coverage through traditional CSHCS. The change means that statewide CSHCS members all have the same traditional coverage. CSHCS Director Kathy Stiffler's letter to SHP members explained:

"The decision to end the SHPs was not easy. The reason for this change is that the state does not have the staff or resources to run two different systems – one for the traditional CSHCS program and another for the SHPs. Of the 30,000 persons enrolled in CSHCS, about 5,000 are in the SHPs. CSHCS needs to focus its energies on how best to serve all 30,000 CSHCS families."

Former SHP families may get help on the CSHCS Family Phone Line, 1-800-359-3722. ♥

Our state website has a shortcut to CSHCS: www.michigan.gov/cshcs. It is one of 30 quick links to specific topics on MDCH's website. See the full list at www.michigan.gov/mdch. ♥

FSN Events

Family Support Network of Michigan (FSN) chapters in Detroit, Livingston County and Macomb County host ongoing meetings. FSN parent-to-parent volunteers are available throughout the state. For details, phone the CSHCS Family Phone Line: 1-800-359-3722.

Sensory Learning is the focus of the **Oct. 19** meeting of the *Family Support Network of Michigan* (FSN) and the *Arc of Livingston* in **Howell**. The topic is a drug-free alternative to improve perception, understanding and the ability to learn for children with disabilities. For details, reach Livingston FSN Coordinator Kathy Maher at 1-800-359-3722, (517) 546-8825 or kmaher2@sbcglobal.net. ♥

Other Events

Siblings of children with special needs are welcome to join **Sibshops in Detroit's Downriver Area**. A group for seven- to 12-year-olds meets at 6:30 p.m. on Wednesdays every other month. A group for teens is forming. Phone Program for Exceptional Families Social Worker Michelle Teklinski at (313) 294-1531 for more information. ♥

Youngsters age 18 and under can play **Wheelchair Basketball** in local games and regional tournaments organized by the newly formed *Junior Michigan Thunderbirds*. So far, games are set in **Southfield** (Oakland County) on Wednesdays and in **Ann Arbor** (Washtenaw County) on Thursdays. Adult *Michigan Thunderbirds* are part of the *National Wheelchair Basketball Association*. Phone (586) 412-0851 or go to www.michiganthunderbirds.org for details. ♥

Dose of Humor

circulating on the Internet

Excerpts of the **Modern Wife's Housecleaning Oath**

- I don't do windows because . . . I love birds and don't want one to run into a clean window and get hurt. (*I am compassionate.*)
- I don't disturb cobwebs because . . . I want every creature to have a home of their own and my family loves spiders. (*I am kind.*)
- I don't mind dust bunnies because . . . they are very good company. I have named some of them, and they agree with everything I say. (*I am imaginative.*)♥

Resources

DisabilityInfo.gov is an Internet gateway to federal information and services for persons with disabilities and their families. Topics include health, independent living, housing, employment, civil rights and technology. ♥

The Parent Participation Program (PPP) is a section of the Children's Special Health Care Services Division (CSHCS) of the Michigan Department of Community Health (MDCH). CSHCS is part of MDCH's Bureau of Children and Family Programs. CSHCS primarily provides medical specialty care to children with a qualifying diagnosis. PPP serves families of all children with special needs. The Family Support Network of Michigan (FSN) is PPP's parent-to-parent support arm.

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CSHCS Family Phone Line

1-800-359-3722

8 a.m.-5 p.m., Monday – Friday

CSHCS online:

www.michigan.gov/cshcs

Events and Resources are compiled by PPP from a variety of sources. A listing does not denote endorsement.

If you receive multiple copies of this memo by mail, please let us know.

To add your name to our postal mailing list or to remove it, *families* may call our toll-free CSHCS Family Phone Line. Others, please phone (313) 456-4376.