

MEMORANDUM
DEPARTMENT OF COMMUNITY HEALTH
LANSING, MICHIGAN 48909-7979

DATE: March 2005
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

If you've ever phoned our CSHCS Family Phone Line, Jean Rennie may have helped you. For years, "Jeannie" has been the voice of PPP. Our office family mourns the February death of Jeannie's dad, James "Don" Rennie. Our hearts go out to Jeannie and her 10 siblings. Many of them are long-time child-care volunteers at our *Relatively Speaking* conference. Notably, at all ten events, Beth has been our on-site registered nurse.

Correction of last month's memo: *Relatively Speaking* takes place Friday-Sunday, **Nov. 4 – 6**. To join the "Relatively" postal mailing list, phone Jeannie at 1-800-359-3722 or send e-mail to renniejea@michigan.gov. ♥

PPP Update

CSHCS urges **youth or family members who haven't mailed in their medical transition survey to call in their responses** at 1-800-359-3722. Survey responses help CSHCS evaluate the transition process for youth with special health care needs who are moving to adult services. The two-page survey was mailed in February to the 7,000 homes of 14- to 21-year-olds in CSHCS. Major concerns of the first 450 respondents include prescription and health care coverage plus independent living needs. ♥

CSHCS Updates

Families may submit **summer camp scholarship applications** to the *Children with Special Needs (CSN) Fund* starting April 1. For the sixth year, the fund will award up

to \$500 to allow a camper with special needs to attend any licensed Michigan camp.

The camper must be under age 21 and enrolled in --or medically eligible to enroll in-- CSHCS. For now, to allow more children to benefit, a camper may only receive a CSN Fund scholarship every other year. If funds are still available on June 15, the CSN Fund will begin to accept applications from 2004 scholarship campers.

Starting on March 21, download the application at www.michigan.gov/csnf. Or, get it by mail by phoning 1-800-359-3722. Families also may pick up an application and get help with filling it out at the CSHCS office in your local health department. ♥

The CSN Fund also **invites health care professionals who work with children with special needs to apply** for a

three-year term on its *Advisory Committee*. The committee promotes public awareness of the fund and of CSHCS, develops funding guidelines and initiatives, and establishes policies and procedures for administering the Fund.

The Advisory Committee's six to eight volunteers also include family members of persons with disabilities and members of the general public who have an interest in improving the lives of children with special health care needs.

The committee meets every other month, mostly in Lansing. For a full job description and application directions, phone CSN Fund Executive Director Lisa Splawn at (517) 241-7420. ♥

Two persons joined CSHCS. The new application services unit manager is **Jim Beaver**. Previously, he focused on *Healthy Kids* and *MiChild* as a

MDCH program specialist. Earlier, he worked for 13 years in the CSHCS Grand Rapids Regional Office.

Faith Goins is the new general office assistant. Her 23 years of administrative support experience includes work for the Michigan State Police, Sparrow Hospital and Ingham Regional Hospital. ♥

Events

A **Mom's Night Out** for mothers of children with disabilities takes place **March 9** in **Brighton**. Dads are welcome, too. Get details from *Family Support Network of Michigan* Livingston County Coordinator Kathy Maher at 1-800-359-3722, (517) 546-8825 or kmaher2@sbcglobal.net. ♥

The **Down Syndrome Association of West Michigan** holds a **free conference March 19** in **Grand Rapids**. It includes resources for new parents "in a very relaxed atmosphere." Register at www.dsawm.org. ♥

A **free concert features Chris Burke**, a TV star who has Down syndrome, on **March 22 in Port Huron** (phone: 810-985-8900) and on **May 6 in Grand Rapids** (toll-free phone: 1-866-665-7451). ♥

Wayne State University's **diagnostic and treatment clinic for children and adolescents with diabetes** is in **Port Huron** on **March 23 and 24**. For details, phone 1-888-324-6852. ♥

Resource

Attached is a first-hand account of how a *Community Action Agency* can help young adults with special needs. ♥

Call for Advocates

from CSHCS Advisory Committee Member Linda Potter

"Years ago, Children's Special Health Care Services established an Advisory Committee made up of parents of children who get CSHCS services, professionals who serve them, and people who are advocates for children with special health needs. It advises CSHCS about its activities.

"The Advisory Committee recently discussed the fact that, as a result of term limits, very few legislators even know what CSHCS is, much less how critical its services are to families. Given severely increasing cuts to government and competition for scarce revenues, a group of parents and advocates felt that action needs to be taken to assure the future of this and other key programs.

"It is critical, given the effects of term limits that parents and families of children who depend on state and federal services create and maintain the capacity to communicate effectively with policy makers at all levels. In that context parents in the MDCH networks (as well as Education, Mental health and others) need to be identified, recruited and empowered to take on this advocacy work. The Michigan Council for Maternal and Child Health, partnering with other interested groups, is willing to develop supports for parents about being effective advocates for their children and the programs that serve them.

"Because Advocacy can be confused with Lobbying, it is important that the work of parents in politically supporting publicly funded programs be kept distinct from the roles of parents as members of formal advisory bodies.

"If you are interested in advocacy on behalf of vulnerable kids, contact Linda Potter. You can reach her at 1-800-828-2714 or by email at potter@ucpmichigan.org. ♥"

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.

Mary J. Marin
Executive Director

Lisa Cook-Gordon
Transition Consultant

Linda Lyles Daniels
Parent Communications Consultant

Randy Krause
FSN Coordinator

Jean Rennie
Administrative Assistant

Dianna Rigato
Information & Resource Specialist

Rebecca Start
Program Specialist

Nelinda Treviño
Phone Line Operator

Leah Waters
Secretary

Early On Liaison to CSHCS
Penny Verran

CSHCS Family Phone Line
1-800-359-3722
8 a.m.-5 p.m., Monday – Friday

CSHCS online
www.michigan.gov/cshcs

Free online course on CSHCS
www.training.mihealth.org

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 Family Phone Line. Others, please phone (313) 456-4381.

Dose of Humor

From "Anonymous" on the childhood beliefs site, iusedtobelieve.com

"When I was in kindergarten I used to believe that whenever we would sing "If You're Happy and You Know It, Clap Your Hands," the teacher was making a specific reference to something. In fear of her asking me what "it" was, I never clapped my hands. Now I know why my teachers spent so much extra time with me." ♥