

MEMORANDUM
DEPARTMENT OF COMMUNITY HEALTH
LANSING, MICHIGAN 48909-7979

DATE: February 2006
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

Happy New Year! I hope that 2006 has been a good year for you so far. One brand new project plus an expanding one promise a bright year for the Parent Participation Program (PPP).

First, we are proud to implement Michigan's *Family-to-Family Health Education and Information* (F2F) grant. Our inaugural advisory meeting on Feb. 27 will bring together a broad array of agency partners. They include some entities we are collaborating with for the first time.

Secondly, we are part CSHCS's effort to expand the medical home concept in Michigan. A pilot project in the Grand Rapids area supports children with special needs transitioning from the pediatric to adult health care system. Key players include Dr. Wendy Burdo-Hartman, who also is leading a project on adolescent transition to adult providers. In the Detroit area, Dr. Tisa Johnson is head of medical home training in her practice and at Henry Ford Health System clinics.

Throughout the year, I look forward to keeping you informed of progress on those and other health issues of interest to families of children with special needs.♥

PPP Update

Statewide training sessions for parents of children with special needs start in spring. Topics include health and education, transition to adult mental health systems, mental health skills development and medical home.

The first one provides lifeskills training for families of children and youth with mental health disorders. It is set for March 29 in Taylor.

Four **Health Resource Parent Trainings** will cover public health care coverage, strategies for effective communication with health care providers, and educating youth on health care decision-making.

All sessions are offered through Michigan's new *Family-to-Family Health Information and Education Center*. For a schedule, phone 1-800-359-3722.♥

CSHCS Update

A survey of CSHCS family satisfaction with Private Duty Nursing (PDN) shows a mix of positive and negative experiences. PDN is a Medicaid benefit that CSHCS had administered. As of Feb. 1, MDCH's Medical Services Administration oversees it.

Among positives, more than 90 percent of the 22 families who responded feel that their child's nurse maintains confidentiality, is willing to provide care the

way the parent wants, and interacts acceptably with family members.

Among negatives, more than 70 percent of the 22 families who responded disagreed that there are always enough nurses available for them to use all PDN hours approved for the month. More than a third of respondents disagreed that new nurses are trained by an experienced nurse before providing care for their child, and that their nursing agency's supervisory staff is helpful in resolving a problem with their nurse.

CSHCS mailed the four-page survey in October to the 230 CSHCS families receiving PDN. As of early December, 22 families in 14 Michigan counties returned it.♥

A letter about **changes in the Payment Agreement (PA) policy** went to every CSHCS family in December. Changes created payments for some families while considerably lowering them for others. Modified PAs are no longer offered. Also, new PAs do not refund families who pay more for CSHCS coverage than the program spends on the program member.

Noted CSHCS Director Kathleen A. Stiffler, "Michigan's economy forced us to make very difficult decisions. At each decision step, we reminded ourselves of the importance of keeping medical coverage available to all CSHCS clients. For many, CSHCS is their only option to pay for part or all of the services they need."♥

Resources

Podcast interviews of **adults with cystic fibrosis (CF)**, physicians and others is at www.jerrycahill.com. Cahill is a 48-year-old who has CF.♥

Help is available to high-risk Ingham County children under age 18 with asthma or other respiratory illness. Healthy Homes University is a HUD-funded, MDCH project to reduce asthma triggers and injuries. A flier about the project is enclosed. For details, reach Linda Stewart at (517) 335-8867 or Stewartlin1@Michigan.gov.♥

Redesigned site **www.Abledata.com** covers 32,000 assistive technology products. Features include news and listings of disability-related conferences. Sponsor is the *National Institute on Disability and Rehabilitation Research*, a part of the U.S. Dept. of Education Office of Special Education and Rehabilitation Services (OSERS).♥

Financial education for teens and adults with disabilities is the aim of a new United Cerebral Palsy (UCP) of Michigan program. It includes a DVD, *Knowledge is Power: Building Your Financial Future*. One copy is in PPP's Lending Library. UCP also is hosting dozens of its MoneySmart workshops statewide. For details, phone 1-800-828-2714, e-mail to moneysmart@ucpmichigan.org or click to "Special Focus" at www.ucp.org/ucp_local.cfm/87.♥

Below is an excerpt of *Reference Points* (www.ncset.org), a project of the National Center on Secondary Education and Transition, funded by and a partner with the U.S. Department of Education OSERS:

Helping the Student with Diabetes Succeed: A Guide for School Personnel is downloadable at www.ndep.nih.gov. It includes *Actions for School Personnel, Parents and Students*. Publisher is the *National Institutes of Health* and the *Centers for Disease Control and Prevention*. Order a copy at 1-800-438-5383.♥

Dose of Humor

From Kathy Stiffler's year-end remarks to CSHCS staff

"The only person who truly welcomes change is a wet baby."

A quote from Mary Francis Henry, according to Barb Campbell of the *Winnipeg Ostomy Association* at www.geocities.com/mr-ostomy/Challenge1.htm

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 and this Update 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 CSHCS Family Phone Line or send e-mail to ppp@michigan.gov. Others, phone (313) 456-4381 or send e-mail to ppp@michigan.gov.