



## **Parent to Parent Resources**

### **Projects/programs that *match families* (and more)**

**Family Support Network of Michigan**, This parent-directed section of Children's Special Health Care Services is named the *Family Center for Children and Youth with Special Health Care Needs*. We direct the Family Support Network of Michigan to provide health resource information and emotional support to **all** Michigan families of children with special needs. We are currently seeking Health Resource Support Parents volunteers to provide other parents with emotional support and information about critical resources for children with special health needs. Training is provided. To call on us, enrollment in CSHCS is not required. If you are a parent of a child with special needs seeking support or have questions or are willing to offer support to help families like yours meet their child's needs and their own, please contact us through the Family Phone Line at 1-800-359-3722.

**Friends' Health Connection**, PO Box 114, New Brunswick NJ 08903. Friends' Health Connection is a communication network whose goal is to alleviate the devastation illness can bring by providing one-to-one support for individuals with health problems and their families. For more information: (800) 48-FRIEND (800) 483-7436, Web site: [www.48friend.org](http://www.48friend.org) or E-mail: [info@friendshealthconnection.org](mailto:info@friendshealthconnection.org) Friends' Health Connection does not have bilingual staff.

**Mothers United for Moral Support (MUMS)**, 150 Custer Court, Green Bay, WI 54301-1243. MUMS matches families throughout the world. It is MUMS' hope that by matching families, parents can mutually support one another emotionally, exchange valuable medical information they have gathered, and alleviate the feelings of being alone. MUMS also refers families to existing support groups for specific rare disorders. For more information: (877)336-5333 (toll free, parents only please) or (920)336-5333, Web site: [www.netnet.net/mums](http://www.netnet.net/mums) or E-mail: [mums@netnet.net](mailto:mums@netnet.net), FAX: (920) 339-0995. MUMS does not have bilingual staff.

**National Organization for Rare Disorders (NORD)**, P.O. Box 1968, 55 Kenosia Ave., Danbury, CT 06813-1968, a federation of more than 140 not-for-profit voluntary organizations serving people with rare disorders and disabilities. NORD has a Networking Program and maintains a data base from which it can print reports regarding specific diagnoses, written in understandable language. The Networking Program also encourages the formation of mutual self-help support groups. For more information: (800) 999-6673 (voice-mail only); TDD Number: (203) 797-9590, FAX: (203) 798-2291; Web site: [www.rarediseases.org](http://www.rarediseases.org) or E-mail: [orphan@rarediseases.org](mailto:orphan@rarediseases.org).

If you have a question about a rare disease, available resources, or caring for a loved one, you can call or write to NORD's genetic counselor or registered nurse at [Genetic\\_Counselor@rarediseases.org](mailto:Genetic_Counselor@rarediseases.org), or [RN@rarediseases.org](mailto:RN@rarediseases.org), or call (800) 999-NORD.

**Parents as Teachers**, 2228 Ball Drive St. Louis, Mo. 63146 Parents as Teachers is here to help you! Parents as Teachers (PAT) is a parent education and family support program serving families throughout pregnancy until their child enters kindergarten, usually age 5. Parents are supported by PAT-certified parent educators trained to translate scientific information on early brain development into specific *when, what, how* and *why* advice for families. By understanding what to expect during each stage of development, parents can easily capture the teachable moments in everyday life to enhance their child's language development, intellectual growth, social development and motor skills. As a PAT family, you receive personal visits, parent group meetings, screenings, and a resource network. For more information: (866) 728-4968, web site <http://www.parentsasteachers.org> (click on Michigan to find Michigan programs) or E-mail [info@parentsasteachers.org](mailto:info@parentsasteachers.org)

**Parent to Parent of Southwest Michigan**, 406 E. Michigan, Kalamazoo 49007, is a non-profit community organization offering services at no cost to families who have children with disabilities or special needs. Parent to Parent serves families in 5 counties and collaborates with other organizations. Since our inception, we have assisted over 1200 families through mentor support, referrals, information, recreation opportunities, a bi-monthly newsletter, parent network meetings and informal social events. For more information: (269) 345-8950, Fax: (269) 345-5363, web site <http://www.p2pswmi.org/> or E-mail [p2pswmi@sbcglobal.net](mailto:p2pswmi@sbcglobal.net)

### **Other Michigan statewide parent projects/programs**

**Association for Children's Mental Health (ACMH)**, 100 W. Washtenaw St., Suite 4, Lansing MI 48933-2129. ACMH provides training, information, support and advocacy regarding children's mental health needs, and promotes collaborative partnerships between parents, professionals, agencies and the community. For more information: (888) 226-4543; Web site: [www.acmh-mi.org](http://www.acmh-mi.org) or E-mail: [acmhadmin@sbcglobal.net](mailto:acmhadmin@sbcglobal.net)

**Citizens Alliance to Uphold Special Education (CAUSE)**, 6412 Centurion Dr., Ste. 130, Lansing, MI 48917. CAUSE is Michigan's Federally funded Special Education Parent Training and Information Center, providing special education information and direct advocacy regarding legal rights and related issues. For more information: (800) 221-9105; Web site: [www.causeonline.org](http://www.causeonline.org) or E-mail: [info@causeonline.org](mailto:info@causeonline.org).

**Everyone Together Network**, United Cerebral Palsy of Michigan, 3401 East Saginaw Suite 216, Lansing, MI 48912. "All Children, All Together, All the Time. That is our mission." Everyone together local networks seek to educate parents to improve their ability to advocate for their children with special needs in the general education setting. Local networks join together to support one another and further work to advocate for inclusion of children with disabilities. Across the state, as a coalition of networks Everyone Together seeks system change and collaborates with other organizations "to advocate for the adoption of policies, legislation, and practices that support Universal Education." For more information: Web site: <http://everyonetgether.org/index.html> or E-mail: [info@everyonetgether.org](mailto:info@everyonetgether.org).

**Family Center for Children and Youth with Special Health Care Needs.** The Center's primary purpose is to help shape CSHCS policies and procedures and to help families navigate the CSHCS system. Services of the Family Center for Children and Youth with Special Health Needs include: answering the CSHCS Family Phone Line, distributing the *Heart-to-Heart Information Update*, a newsletter of interest to families of children with special needs; coordinating *Relatively Speaking*, a biennial conference uniquely for siblings of children with special needs; directing the Family Support Network of Michigan; administering scholarships to enable Michigan parents to attend conferences related to the diagnosis, care or treatment of their child's special health need; leading training and presentations related to children with special needs and to parent/professional collaboration; coordinating Michigan's **Family to Family Health Information and Education Center** - <http://www.bridges4kids.org/f2f/> - and assisting youth with special needs and their families in the transition to adulthood. For more information contact the Family Phone Line: (800) 359-3722.

**Family Voices, Inc.**, 2340 Alamo S.E., Ste. 102, Albuquerque, NM 87101. Family Voices is a national grassroots network of families and friends speaking on behalf of children with special health care needs. For more information: (888) 835-5669, FAX (505) 872-4780 Web site: [www.familyvoices.org](http://www.familyvoices.org) or E-mail: [kidshealth@familyvoices.org](mailto:kidshealth@familyvoices.org) In Michigan, we are thrilled that the Family Support Network (FSN) of Michigan was a successful applicant for a F2F HIC grant. Family Voices of Michigan (FV MI) is a long-term partner with FSN. For more information contact Bev Crider (313) 745-0197 or [bevcrider@gmail.com](mailto:bevcrider@gmail.com)

**Great Parents, Great Start** is a grant program to support Intermediate School District collaborative community efforts to develop parent involvement and education programs for families of young children birth to age five. To find resources in your county use the interactive Michigan map at <http://www.migreatparents.org/> or contact your Intermediate School District. **Project Great Start** is a statewide effort to coordinate both public and private efforts to ensure all children in Michigan have the opportunity for a Great Start and a Great Life. For more information, visit the web site at <http://www.michigan.gov/greatstart>.

**Michigan Alliance for Families** is a Michigan Department of Education IDEA Mandated Activity Project grant awarded to and coordinated by the Arc Michigan. The grant provides information, support, and education to Michigan families of children from birth to age 26 with disabilities and special needs. Other components are Regional Sites and Leadership Mentoring. For general information and specifics on regional sites and leadership mentoring contact the main office in Lansing at (800) 292-7851, E-mail [sherri@arcmi.org](mailto:sherri@arcmi.org) or web site: [www.arcmi.org](http://www.arcmi.org). For information and support call the Ann Arbor office (800) 552-4821, (734) 994-8100 x 1590, Fax: (734) 994-2203, E-mail [kmoler@arcmi.org](mailto:kmoler@arcmi.org) or web site: [www.michiganallianceforfamilies.org](http://www.michiganallianceforfamilies.org).

**Special Education Parent Advisory Committees – Local** Each intermediate school district is required to have a parent advisory committee (PAC) consisting of local parents of students with disabilities. The role of the parent advisory committee is to participate in the development of the district's plan for the delivery of special education programs and services. The committee may give advisory input on any matters that the committee deems appropriate to the improvement of special education services within the intermediate school district. Parents serving on local PACs who would like support and access to leadership development can contact the Michigan Alliance for Families at (800) 292-7851 or [ellen@arcmi.org](mailto:ellen@arcmi.org).

### **Other family friendly resources**

**Beach Center on Families and Disability**, University of Kansas, 1200 Sunnyside Ave., Room 3136 , Lawrence, KA 66045-7534, (785) 864-7600, TTY: (785) 864-3434, FAX: (785) 864-7605, Web site: [www.beachcenter.org](http://www.beachcenter.org) or E-mail: [beachcenter@ku.edu](mailto:beachcenter@ku.edu).

**Family Village**, Welcome to the Family Village! We are a global community that integrates information, resources, and communication opportunities on the Internet for persons with cognitive and other disabilities, for their families, and for those that provide them services and support. Our community includes informational resources on specific diagnoses, communication connections, adaptive products and technology, adaptive recreational activities, education, worship, health issues, disability-related media and literature, and much, much more! Web site: <http://www.familyvillage.wisc.edu/> or E-mail [familyvillage@waisman.wisc.edu](mailto:familyvillage@waisman.wisc.edu).

**Institute for Family-Centered Care (IFFCC)**, 7900 Wisconsin Ave., Ste. 405, Bethesda, MD 20814. IFFCC provides essential leadership to advance the understanding and practice of family-centered care. The Institute serves as a central resource for both family members and members of the health care field. For more information: (301) 652-0281, FAX: (301) 652-0186; Web site: [www.familycenteredcare.org](http://www.familycenteredcare.org) or E-mail: [Institute@iffcc.org](mailto:Institute@iffcc.org). IFFCC does not have bilingual staff.

**National Dissemination Center for Children with Disabilities (NICHCY)**, P O Box 1492, Washington DC 20013-1492. NICHCY is a national information and referral center that provides information on disabilities and disability-related issues. Children and youth with disabilities (birth to age 22) are their special focus. For more information: v/tty (800) 695-0285, FAX (202) 884-8441, Web site: [www.nichcy.org](http://www.nichcy.org) or E-mail: [nichcy@aed.org](mailto:nichcy@aed.org) NICHCY has Spanish bilingual staff and materials.

**National Lekotek Center**, 3204 W. Armitage Ave., Chicago, IL 60647. The National Lekotek Center is driven by the philosophy that children learn best when play is a family-centered activity that includes all children, regardless of their abilities or disabilities, in family and community activities. Many resources regarding toys, play and toy loan centers are available. Toy Resource Helpline: (800)-366-PLAY (800) 366-7529) or (773) 276-5164. Web site: [www.lekotek.org](http://www.lekotek.org) or E-mail: [lekotek@lekotek.org](mailto:lekotek@lekotek.org).

**Specialized Training of Military Parents (STOMP)**, Washington PAVE, 6316 S. 12<sup>th</sup> St., Tacoma, WA 98465-1900, is a federally funded Parent Training and Information Center established to assist military families who have children with special education or health needs. For more information: (800) 5-PARENT or (800) 572-7368 (v/tty), FAX: (253) 566-8052, E-mail [stomp@washingtonpave.com](mailto:stomp@washingtonpave.com) or Web site: <http://www.stompproject.org/about.asp> STOMP has Spanish bilingual staff. They also utilize volunteers for translation and interpreting of Korean, French, Laotian and German.



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