

Working Together

Summer 2012



A Note from the Office Director, Donna Harris

As we welcome in summer, the **Office for Genetics and Children with Special Health Care Needs (OGCSHCN)** has many



exciting new developments to announce. This current newsletter, our second edition, highlights many of these updates. These transformations may not have come to fruition without the benefit of our partners. Through strong, effective partnerships, we can conserve financial and other resources, avoid duplication of services, accomplish more, and reach more people. As an Office, we are particularly interested in collaborating with organizations that serve CYSHCN especially affected by disparities, including diverse audiences (linguistic and cultural), particularly the Latino community; underserved regions of the state (especially Southern, Western and Eastern Maryland); low-income communities; and CYSHCN with severe and/or complex conditions. Through partnerships, we can further our impact on CYSHCN.

A Word from the Medical Director, Deborah Badawi, MD

Newborn screening continues to be an active area of development in the OGCSHCN. As of July 1, 2012 the short term follow-up of infants identified on blood spot screening will become part of our office once again. We are looking forward to having **Johnna Watson, RN** join our

team and to welcoming another nurse in the near future. The OGCSHCN is working collaboratively with the Laboratories Administration to make this a smooth transition.

A new screening program will also be initiated by September 1, 2012 – newborn screening for Critical Congenital Heart Disease (CCHD)! The OGCSHCN worked with the Advisory Council on Hereditary and Congenital Disorders to convene an expert panel that evaluated this new program which uses pulse oximetry to screen for CCHD. A legislative report was prepared for the Maryland Legislature and can be accessed at <http://fha.dhmh.maryland.gov/genetics/docs/CCHDLegisRpt.pdf>. The panel includes cardiologists, nurses, pediatricians, administrators and members of the public, and is now working on drafting regulations for implementation.

Maryland is one of the first states to implement newborn screening for CCHD. A diverse group

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A Word from the Medical Director *Continued*

of four health leaders formed the Newborn Screening for Critical Congenital Heart Disease group and has been selected to participate in the National Leadership Academy for the Public's Health (NLAPH) program, funded by the Centers for Disease Control and Prevention (CDC), Office of State, Tribal, Local and Territorial Support (OSTLTS). The leadership program will provide training and support to assist the team, which includes myself, in successfully addressing the implementation of this newborn screening program.

If you have any questions about CCHD please feel free to contact **Debra Harper-Hill, RN** at 410-767-6625, or me at 410-767-5592.

Transition Conferences

The OGCSHCN, in partnership with **The Parents' Place of Maryland (PPMD)**, sponsored three FREE full-day health care transition conferences for families, youth, and providers! Teens with special needs ages 12 to 17 were invited to attend with a parent. The conferences were held in March of this year in Annapolis; in April in Salisbury, and May in Cumberland, Maryland. The conferences offered information, ready-to-use planning tools, and resources for youth, families and providers. Attendees found the resources and information shared to be very useful.

Local Health Department (LHD) Spotlight



The Local Management Board (LMB) for Children's and Family Services of Kent County was contracted by the Kent County Health Department to complete a needs assessment for CYSHCN. In the fall of 2011, the LMB and the Kent County Health Department formed a work group of medical providers (Kent County Public Schools Head Nurse), agency representatives (Kent County Public Schools Supervisor of Special Education, Kent County Director of Social Services, Maryland Coalition of Families Family Navigator, Department of Developmental Disabilities) and parents to evaluate the needs assessment, identify priorities, and to learn about and develop resources to meet the needs of families for CYSHCN.

The group's top recommendation was to obtain funding for a care coordinator, who would assist families in obtaining needed medical care, in building partnerships with medical providers, and navigating the medical system (including insurance). Using the information gathered from the comprehensive assessment and prioritization of needs, Kent County developed an implementation plan and subsequently applied for and received local health department funding. The Kent County

CYSHCN Needs Assessment is an excellent example of the effective use of partnerships and collaboration.

Healthcare Transition to Adulthood

We are pleased to welcome **Antoinette W. Coward** as OGCSHCN's new health care transition coordinator. Antoinette has in-depth experience in program planning, health education, and policy. She is responsible for the development and coordination of educational, service and outreach activities involving transition of youth with special health care needs to the adult health care system. To prevent duplication of services by accessing existing resources, the office will utilize existing youth advisory councils/boards in Maryland to continue to obtain information about the needs of youth with special health care needs. If you know of any youth advisory councils/boards in Maryland that deal with youth transition to adulthood or youth self-advocacy, please e-mail Antoinette at cowarda@dhhm.state.md.us. For questions or more information, contact Antoinette at 410-767-5602.



Children's Resource Line

The Children's Resource Line helps parents/caregivers and providers find the resources they need to successfully care for their children with special health care needs, from birth to age 21. The information line, 1-800-638-8864, can accommodate both English and non-English speaking families. Parents/caregivers may also contact **Angela Sittler**, Resource Coordinator, by e-mailing her at asittler@dhmh.state.md.us.

Ms. Sittler is the mother of two children with special health care needs and has a wealth of information across a variety of topics, such as financial assistance and information/support.



Sickle Cell Awareness Month

In celebration of **Sickle Cell Awareness Month**, the Office for Genetics and Children with Special Health Care Needs is partnering with the Board of Directors of Sojourner-Douglass College to hold a community health fair on Saturday, September 22, 2012 from 10:00 a.m. until 2:00 p.m. The event takes place at Sojourner-Douglass College's Academic Hall building located at 200 N. Central Avenue, Baltimore, MD 21202.

Statewide Planning to Improve Services for Children and Youth with Autism and other Developmental Disabilities

Through support from a federal grant from HRSA, the OGCSHCN and The Parents' Place of Maryland (PPMD) are developing a plan to improve Maryland's system of care for CYSHCN with autism spectrum disorders (ASD) and other developmental disabilities (DD).

The first stage of work involved conducting a comprehensive needs assessment of CYSHCN with ASD and DD in Maryland – the needs assessment will be available on OGCSHCN's and PPMD's websites by Summer 2012. A report on the results of a statewide stakeholder poll on priorities for this population is available now at: http://www.marylandcoc.com/uploads/2011_Maryland_Children_and_Youth_with_ASD_and_DD_Priorities_Poll_Results_Final_03.09.12.pdf.



Now is the time to get involved in the planning process! We will be conducting day-long strategic planning meetings in each region of the state, so if you are a family member of or an adult with ASD or DD, or if you work with CYSHCN with ASD or DD and their families, please consider attending a meeting in your area. This phase of work has already begun – the first regional planning meeting was held at the Southern Maryland Higher Education Center on March 29; there are upcoming meetings scheduled on the Eastern Shore, Western Maryland, the Capital Area, and Central Maryland.

Please contact **Meredith Pyle** at OGCSHCN (mpyle@dhmh.state.md.us; 410-767-5185) or **Josie Thomas** at PPMD (josie@ppmd.org; 410-768-9100), and visit http://www.marylandcoc.com/ASD_DD_Planning_Grant.html for more information on how you can get involved.

The purpose of the community health fair is twofold: 1) to promote awareness and provide information to health care providers and the public on prevention and health maintenance for people with sickle cell disease, and 2) to address the social, mental, nutritional, and physical well-being of children with sickle cell disease and their families. The event will include presentations, educational workshops, and group fitness sessions.

For more information on the event, please contact Debra Harper-Hill, Program Chief, at 410-767-6625 or DHarperHill@dhmh.state.md.us.

Parent Connections: Parents Mentoring Parents of Newly Diagnosed Infants and Children with Hearing Loss



Learning that your child is deaf or hard of hearing can be a traumatic experience. Parents may have many questions and concerns in coping with their child's needs and their own feelings. Through a grant sub-award to the **Parents' Place of Maryland**, the newly established **Parent Connections Program** provides personal support to parents by matching parent mentors with families of infants and young children who are newly diagnosed with a hearing loss.

Nine parent volunteer mentors are available to parents of newly diagnosed children to answer questions, share experiences of parenting a child who is deaf or hard of hearing, connect families with resources, and discuss options for communicating with their children. Parent mentors are uniquely equipped to serve families of newly diagnosed children because of their own personal experience of having a child with a hearing loss, an understanding of the unique needs of these children, and knowledge of local and regional resources. In addition to parent mentoring opportunities, parents of newly diagnosed infants and children will also be invited to participate in a regional parent meeting.

For more information on Parent Connections, and/or be connected with a parent mentor, please contact **Cheri Dowling** by email at CAD800@aol.com or by phone at 443-277-8899. This is a free service, available to any family residing in Maryland.

New Database Manager at OGCSHCN



We are pleased to welcome **Katyayani Bhide**, a new Database Manager, to our staff. With her extensive experience in implementing web based solutions for the public and private sector, Kay brings her expertise for strategic solutions to our office.

With a dedicated IT person on board, we are working on building web-based infrastructure for all our programs to bring efficiency in data gathering, analysis and information dissemination. Through funding provided to the Maryland Center for Developmental Disabilities/ Kennedy Krieger Institute, the OGCSHCN is gathering information about regional services and supports through community resource mapping. The outcome of the mapping will be the development of a database, and the OGCSHCN hopes to have the database online next year, 2013.

The database, which will be accessed by parents/ caregivers and providers from the Office website, will allow users to search for and identify resources according to multiple factors, including type of resource and county.

Children's Medical Services Program Update

REVAMPING is happening with the **Children's Medical Services Program**. The CMS Program is now issuing ID cards to eligible applicants, similar to an insurance card. The cards are **purple** (so guess what team we love). First time eligible applicants will receive their ID cards and a "Welcome Packet".

This packet will contain the ID card, approval letter, CMS covered services and other pertinent information. Renewing applicants will get their ID cards when eligibility is renewed.

Focus on a Systems Development Grant

This year the OGCSHCN is funding a new systems development grant, *Practice-Based Implementation Support to Enhance Medical Homes for Children with Special Health Care Needs*. Tracy King, M.D., M.P.H., from the Johns Hopkins University, is spearheading this project, which focuses on improving and institutionalizing developmental screening and referral among primary care providers, as well as adapting a medical home implementation model to support transition of YSHCN to adult primary care. The grant will address three of the six shared outcomes for CYSHCN,:

- 1) "children are screened early and continuously for special health care needs";
- 2) "children and youth with special health care needs receive coordinated ongoing comprehensive care within a medical home"; and
- 3) "YSHCN receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence."

More information on the Maternal and Child Health Bureau's six core outcomes can be found at: <http://mchb.hrsa.gov/cshcn05/MI/cokmp.pdf>. The OGCSHCN is looking forward to the start of this program at the beginning of Fiscal Year 2013, which starts on July 1 of this year.

Latino Family Support Consortium

The **Parents' Place of Maryland** held their first meeting of the *Latino Family Support Consortium* on March 22 at the Meeting House in Columbia, Maryland. The mission of the Consortium is to bring together groups and agencies that serve Latino families of children with special needs, to share resources and to help improve services.

The meetings will be conducted on a quarterly basis, with the next meeting taking place on June 21, 2012. Meetings are conducted in English and interpreters are available for monolingual Spanish speakers. Please contact **Zayli Bocanegra** by email at zayli@ppmd.org or by phone at 410-768-9100 x 105.

BDRIS

The Birth Defects Reporting Information System (BDRIS) is a program in which hospitals report all infants born with an anomaly. After the information is received by the OGCSHCN, the family is sent specific educational information regarding their child's condition, as well as a list of available support groups and online resources.

To raise public awareness regarding birth defects, the BDRIS program participates in Birth Defects Prevention Month, which is celebrated in the month of January. During this time, educational information is made available to the general public. The BDRIS department has a nurse available to answer any questions that families, providers or the general public may have regarding birth defects.

We look forward to continuing to provide services to Maryland families. For more information, please contact **Debra Harper-Hill**, R.N. at 410-767-6625.



Looking for Data on CYSHCN?

Secondary data, or data that has already been collected by another organization, is more cost-effective and easier to collect than having your organization collect the data. Secondary data may also help your organization determine what data are missing on a particular issue. The source of the data is important, since it can indicate the accuracy and reliability of the data.

An excellent link to multiple sources of data, including the Maryland Title V Needs Assessment Report and the 2012 Report on Priorities for Children and Youth with Autism and Developmental Disabilities, can be found at http://fha.dhmh.maryland.gov/genetics/SitePages/data_info.aspx. Recently, data briefs on how Maryland is performing on each of the core outcomes for CYSHCN were added to our website.

OGCSHCN Contacts

<i>Program</i>	<i>Name</i>	<i>Phone</i>
Grants Management	Lynn Midgette	410-767-6749
Birth Defects and Reporting System Sickle Cell Disease Program	Debra Harper-Hill	410-767-6625
Children's Medical Services	Patricia Williamson	800-638-8864 <i>or</i> 410-767-5588
Healthcare Transition to Adulthood	Antoinette Coward	410-767-5602
Infant Hearing Program	Tanya Green	800-633-1316 <i>or</i> 410-767-5603
Community Resources	Angela Sittler	800-638-8864 <i>or</i> 410-767-1063



ChopChop

ChopChop Maryland is a program run by the Maryland Department of Health and Mental Hygiene, in partnership with ChopChop Magazine. The program provides a new, fun, family-friendly recipe each month.

To receive the recipes, text CHOPMD to code 43186. For Spanish, text CHOPES to code 43186. (Message and data rates may apply). Learn more about the program by visiting www.chopchopmd.com.

Race to the Top Grant

The OGCSHCN was pleased to be able to collaborate with the **Maryland State Department of Education (MSDE)** on a portion of the Race to the Top Grant that addresses developmental screening. Training will be provided by MSDE to child care providers across the state in doing developmental screening and communicating the results to parents.

The OGCSHCN will receive a small amount of funding to continue training for primary care providers (pediatric and family physician practices) on how to incorporate developmental screening in their practices. If you are interested in finding out about this training, please contact **Debbie Badawi, MD** at dbadawi@dhmh.state.md.us.

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