

Working Together

Winter 2012



A Note from the Office Director, Donna Harris

Welcome to the first issue of our newsletter, *Working Together*. I would like to share a little about the Office for Genetics and Children with Special Health Care Needs (OGCSHCN). We serve children and youth, from birth to age 21, with special health care needs.

We use the Maternal and Child Health Bureau definition for CYSHCN as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition, and who also require health and related services of a type or amount beyond that required by children generally.”

The six priorities that guide our work include:

1. Family/Professional Partnerships
2. Medical Home
3. Adequate Insurance and Financing
4. Early and Continuous Screening
5. Easy-to-use Community-based Systems and Services
6. Youth Transition to Adulthood

A Word from the Medical Director, Deborah Badawi, MD

Many of you may be aware that Maryland passed legislation this year pertaining to screening newborns for cyanotic critical congenital heart disease (CCCHD). An expert panel was convened by the Advisory Council on Hereditary and Congenital Disorders, and the legislative report is being finalized. There was agreement that newborns should be screened for CCCHD using pulse oximeter testing, and now that this testing has been adopted for newborn screening at the federal level, Maryland will initiate screening within the next year. Also, the Newborn Screening Program will soon be returning to OGCSHCN.

P.S. It's flu shot time!

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Grantee News

OGCSHCN provides funds to local health departments and private grantees to provide programs and services to children and youth with special health care needs and their families (CYSHCN). In addition, private grantees are funded to provide genetic services and/or develop systems and infrastructures to better meet the needs of CYSHCN.

Collaboration can be a tool for pooling financial resources to address an issue, to reach a new audience that has not been traditionally served by an organization, and/or to share resources and talents.

In addition to fostering collaborations between OGCSHCN



and other organizations/agencies, OGCSHCN encourages collaboration amongst its grantees whenever possible. If you are a grantee that would like to share a story of collaboration, particularly with another private grantee or health department, please email **Lynn Midgette** at lmidgette@dnhm.state.md.us.



Maryland Infant Hearing Program

The goals of the Maryland Infant Hearing Program are: to ensure that all newborns receive a hearing screen before they are one month of age, that identification of hearing loss occurs by three months of age, and that early intervention for those babies with hearing loss is initiated by six months of age. Early intervention is crucial to giving children the best chance to develop normal communication skills, and requires timely hearing screening and diagnostic evaluation.

Grants and Activities:

In July 2011, the Program was awarded grant funding from the Centers for Disease Control and Prevention. This funding will provide improvements to the OZ database system, which tracks newborn hearing screening results and diagnostic testing. The Program also received grant funding in October 2011 from the Health Resources and Services Administration to improve follow-up rates for infants who fail their newborn hearing screening.

Healthcare Transition to Adulthood

A new position has been added to the OGCSHCN team — a transition coordinator! **Stephanie Hood** officially became our health care transition coordinator during the first week of October. She has been attending the Interagency Transition Council (IATC) meetings, and presented on Health Care Transition with **Meredith Pyle** at the October 17 IATC conference in Ocean City. A Youth Advisory Council is also being formed for our office. For more information, contact Stephanie Hood at 410-767-5298.



Children's Medical Services

Children's Medical Services provide funding for uninsured or underinsured CSHCN in the State of Maryland to receive specialty care. For more information about the Program, please call toll-free 800-638-8864 or the local phone number 410-767-1359.

We welcome our new bilingual care coordinator, **Surayma Roberts**, and nurse consultant, **Monika Piccardi**, to the CMS team!

Community of Care

Maryland Consortium for Children with Special Health Care Needs

The Community of Care Consortium (www.marylandcoc.com), led by The Parents' Place of Maryland with the support of OGCSHCN, continues to thrive. The last meeting was held on October 26th. We look forward to having everyone join our consortium meetings in the future.

The next meeting is January 25, 2012 from 10:00 a.m. to 12:30 p.m. at The Meeting House in Columbia, 5885 Robert Oliver Place, Columbia, Maryland 21045. The focus of the next two meetings will center on information sharing and improving the system of insurance and financing for health care and related services for children and youth with special health care needs and their families.



My Health Care Notebook

We are excited to announce the creation of *My Health Care Notebook*, a resource for organizing important health information for children and youth with special health care needs. If you would like hard copies or the notebook on a bracelet flash drive, please call **Chevria Meekins** at 410-767-6730. Information and resources for creating a notebook are also available online: http://fha.maryland.gov/genetics/create_care_notebook.cfm.

Youth Advisory Council: Help Us Fill the Seats

A Youth Advisory Council is being developed for OGCSHCN. We are looking for youth and young adults, 14 to 22 years of age, who want to share their thoughts on issues that affect themselves, are able to participate in meetings, have a desire to make a difference, and are willing to share ideas for planning activities that address the needs of youth and young adults with special health care needs. For more information, please call Stephanie Hood at 410-767-5298. Upon request, all efforts will be made to make accommodations for participation.

Sickle Cell Disease Program

OGCSHCN's Sickle Cell Follow-up Program provides information and resources to families and providers regarding the care of young children with Sickle Cell Disease (SCD). For Sickle Cell Awareness Month in September, we provided DHMH employees with an educational display and hosted a contest to test their knowledge about SCD. We continue to work to improve the quality of life for children with SCD throughout the year. For further information, contact **Debra Harper-Hill**, RN, Sickle Cell Disease Program Chief, at 410-767-6625.

Birth Defects Reporting and Information System (BDRIS)

Our BDRIS Program has had a busy year sending letters to families of infants with a birth defect/congenital anomaly. Within six months of their birth, families of these children receive fact sheets and potential resources.

Funded by the Maryland Environmental Public Health Tracking Program, BDRIS created and purchased Provider Manuals for all Maryland birthing hospitals.

For more information about BDRIS, contact **Debra Harper-Hill**, RN, Program Chief, at 410-767-6625.

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> 410-767-1359
Healthcare Transition to Adulthood	Stephanie Hood	410-767-5298
Infant Hearing Program	Tanya Green	800-633-1316 <i>or</i> 419-767-5603
Community Resources	Angela Sittler	800-638-8864 <i>or</i> 410-767-1063

Community Resources

We welcome our new Parent Resource Coordinator, Ms. **Angela Sittler**, to OGCSHCN. She is ready to connect individuals with information and resources for children and youth with special health care needs. To request information or share a community resource to add to the Resource Directory, please call her at 800-638-8864 or her local phone number, 410-767-1063.



Top row, left to right: Barbara Greer; Deborah Badawi, M.D. (Medical Director), MD; Tanya Green; Erin Filippone; Monika Piccardi; Surayma Roberts; Debra Harper-Hill; Meredith Pyle; Stephanie Hood; Theresa Thompson; Angela Sittler; Stacey Richards.
Bottom row, left to right: Cheoria Meekins; Donna Harris (Office Director); Pat Williamson; Lynn Midgette.

Office for Genetics and
Children with Special Health
Care Needs

Maryland Department of Health and Mental Hygiene

201 West Preston Street,
Baltimore Maryland 21201

Martin O'Malley, *Governor*
Anthony G. Brown, *Lt. Governor*
Joshua M. Sharfstein, M.D.,
Secretary, DHMH
Donna X. Harris,
Director, OGCSHCN
410-767-6730

Fax: 410-333-7956

Toll Free Help Line:

1-800-638-8864

<http://fha.maryland.gov/genetics/>