Working Together

Office of Genetics and People with Special Health Care Needs

Fall 2016 Newsletter

About our Office

Purpose of this Newsletter

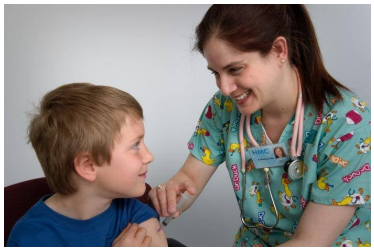
This newsletter is a platform for information sharing about the Office of Genetics and People with Special Health Care Needs. It will provide updates, resources, and general information to stakeholders

In This Issue:

Hello from Donna

As we welcome in Fall, the Office for Genetics and People with Special Health Care Needs has exciting news to share. During the past two years, the OGPSHCN has been working on its federal Title V Maternal and Child Health five-year action plan to improve Maryland's system of care for Children and Youth with Special Health Care Needs (CYSHCN). Building on the findings of our 2015 CYSHCN Needs Assessment, strategic planning meetings with state and local entities, medical providers and educators, community partners, and families, strategies were recommended to improve quality, efficiency and effectiveness of programs for children with special needs. The OGPSHCN Plan provides direction and guides our priorities, initiatives and activities.

During this next five-year cycle, we call to action the needs to improve system collaboration around care coordination and to develop a plan for effective coordination of services for our families. During the next few years, we will increase the capacity for regionalizing services and garnering support for regional initiatives. We will continue to broaden opportunities for youth and young adults to receive services necessary to make transitions to adult health care. Careful attention will be made to reduce health disparities by engaging communities and focusing on improving family involvement, ensuring inclusion and equity in its OGPSHCN programs. Please continue to read our newsletter for further details on our programs, services, and initiatives. You are encouraged to view the Title V MCH Report by clicking http://phpa.dhmh.maryland.gov/genetics/Pages/home.aspx.



CHANGING Maryland *for the Better*

Local Health Department

Carroll County Children's Smart Screening Program

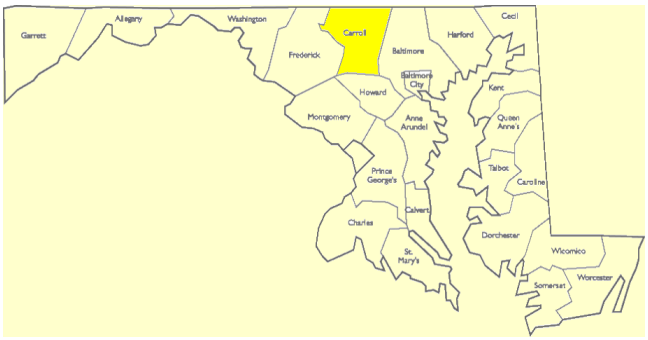
SMART (Screening, decision Making, Assessment, Referral and Treatment) is a systematic approach to identifying children at risk for developmental, behavioral and /or social/emotional problems ensuring their access to appropriate intervention and treatment. SMART aims to improve local access to diagnostic and treatment services, as well as provide integral early identification and intervention to children across the continuum of need. This is key for both overall prognosis and cost containment for the system.

Research indicates that early identification of children in need and connection to appropriate services improves long term outcomes (Dreyer, 2011). Additionally, there is evidence that offering families comprehensive services, including meeting parental needs, improves outcomes for children (Kilmer, Cook & Munsell, 2010). Moreover, findings suggest that county systems working together is economically beneficial (Karolyn, Kilburn, & Cannon, 2005) and improves family outcomes. Last, based on evidence that offering integrated community services through a localized collaborative model best serves families (Epps & Jackson, 2000) SMART is designed to address multiple family needs in one location.

Various community partners repeatedly identified children not selected for intervention through the existing county systems, including those with substance exposure, higher functioning special needs, delays below the threshold for early intervention and later emerging needs. SMART enacted a system of community partnerships to meet this need, knowing the health of the county depends upon the ability to work together across organizational and system boundaries. Collaborators include the Health Department, School System/Early Intervention, Home Visiting, Early Childhood Mental Health providers, and other community early childhood and family providers.

Furthermore, SMART goes beyond simply identifying needs. Family navigators assist families with resources (e.g. housing, food, clothing, entitlements) and linkage services (i.e., case management/parent mental health referrals). Families are followed and connections with services are facilitated.

For more information on Children's SMART in Carroll County, please contact: Dawn Brown, Director, Quality Improvement and Prevention, Carroll Co. Health Dept. 410-876-4800 Dawn.brown@maryland.gov.



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Making Moves:

2017 Maryland Parent Survey

The Office of Genetics and People with Special Health Care Needs has partnered with the Parents Place of Maryland and John Hopkins University to develop and conduct the 2016 Maryland Parent Survey. The Parent Survey records vital information about the needs of children with special health care needs and their families throughout the state of Maryland. The survey is provided in both Spanish and English and in both electronic and paper forms. The 2017 Maryland Parent Survey is expected to be disseminated January 2017. To ensure that responses reflect the needs of diverse families, we are looking for agencies to assist us in distributing the survey to parents of children with special health needs in Maryland.

If your agency is interested in distributing the Parent Survey to families, please contact Stacy Taylor at The Parents Place of Maryland, 410-768-9100, stacy@ppmd.org.

Making Moves:

Healthcare Transition to Adulthood

A True Test to Partnership and Collaboration:

Maryland was selected by the Maternal and Child Health Bureau Title V Program to sit on the State Title V Strategic Planning Group for healthcare transition, which includes the development of a state plan around Healthcare Transition. As a result, the Healthcare Transition Leadership Team was formed. Maryland's Healthcare Transition State Leadership Team is comprised of enthusiastic and dedicated stakeholders who work with children with special health care needs throughout the state. The goal of this team is to improve transition from pediatric to adult health care through the use of new and innovative strategies for health professionals and youth and families. Through a series of meetings and work groups, the leadership team developed a set of recommendations to improve Healthcare Transition for CYSHCN. Many of the recommendations have been incorporated into the OGPSHCN five-year action plan for Healthcare Transition. To see a list of the developed recommendations click here: http://phpa.dhmh.maryland.gov/genetics/Pages/Transition_Leadership_Team.aspx. For more information on Healthcare Transition or to discuss ways we can collaborate please contact Mary Price, DHMH- Health Care Transition Coordinator Office: 410-767-5581 or Email: mary.price@maryland.gov

Coordinating Center:
Transition Connection Initiative

Transition Connection Initiative

With the support of Title V funding through the Office of Genetics and People with Special Health Care Needs, The Coordinating Center launched their ***"Transition Connection Initiative (TCI)."*** This approach to health care transition was developed with the goal to improve healthcare transition from pediatric to adult healthcare systems for youth with special health care needs (YSHCN) and their families. The pilot project focused on a subset of youth, 12 to 25, with Rare and Expensive Case Management (REM) with cerebral palsy, congenital anomalies of the nervous system, hereditary neurodegenerative disorders and/or ventilator dependence living in Baltimore City and Baltimore County. Some of the learning objectives from this initiative are to use the transition readiness tools to help youth identify needs and develop goals for health care transition; and to document activities related to healthcare transition in the case management Information System, using CARMA.

TCI customized the Six Core Elements transition readiness assessment and is used with youths and parents/caregivers at 14 and older. The results will be incorporated into each client's care management plan, and Clinical Care Coordinators work with youths and families to gain needed self-care skills. A medical summary and emergency care plan is developed from the Coordinating Center's internal databases, and starting when clients are 16, the Clinical Care Coordinators will begin to discuss legal issues and decision-making capabilities to ensure that clients and families are prepared for adult care. The Coordinating Center assist in identifying adult primary and specialty providers and adult disability services and will work with pediatric providers to ensure that their transfer package is complete and shared with the new adult provider(s).

During the Transition Connection Initiative pilot, Coordinating Center surveyed pediatric and adult providers who care for 295 of their REM clients. They expressed an interest in continuing education on healthcare transition and on topics concerning the ongoing care of youth with complex childhood-onset illness and neurodevelopmental disabilities. The TCI also involves conducting outreach appointments with providers to share our transition policy, provide transition and disability resources, and identify adult provider referral options. The project aims to ensure that the Coordinating Center's REM participants have a well-planned HCT approach and continuous access to high-quality medical care that meets their medical and developmental needs.
For more information on this initiative, contact The Coordinating Center at 410-987-1048 and speak with Betsy Bernstein, ext. 160, or Kathy Rivers, ext. 269, or visit the Coordinating Center's webpage: https://www.coordinatingcenter.org/featured-programs/tci/

Making Moves:
Healthcare Transition to Adulthood

Community of Care Consortium (COC)

The Community of Care Consortium is a working group of diverse stakeholders, including families, providers, advocates, consumers, administrators and professionals from the public and private service systems. The COC is dedicated to improving systems of care for children and their families in the state of Maryland. Using the national agenda for CSHCN and core outcomes as a starting point, the COC works to create systems of care that promote optimal health, functioning, and quality of life for Maryland CSHCN and their families. The COC meets quarterly in January, April, July and October, and all are welcome to attend. To join the COC or for more information, visit their website at www.marylandcoc.com or contact Kelly Meissner at 410-768-9100 × 107 or kelly@ppmd.org. The COC October's Meeting showcased Health Care Transition initiatives and best practices from the Office of Genetics and People with Special Health Care Needs' grantees throughout the state. For more information on these new initiatives, please visit our website page at http://phpa.dhmh.maryland.gov/genetics/Pages/Health_Care_Transition.aspx

Fetal Alcohol Spectrum Disorders and continuing Medical Education (CME) and Continuing Nursing Education (CNE) Credits:

Are you ready to talk to patients about Fetal Alcohol Spectrum Disorders? The Office of Genetics and People with Special Health Care Needs is pleased to announce four CEU-accredited Fetal Alcohol Spectrum Disorder prevention online courses for physicians, nurses, medical and nursing students available through December 31, 2016. Participants will learn how they can help detect and address risky drinking in patients that are pregnant or of reproductive age. The Course is free of charge; courses are between 15 and 60 minutes; courses are available for CME and CNE credits, Physicians: Between .25 and 1.0 AMA PRA Category 1 Credit, Nurses Practitioners and Nurses: Between .25 and 1.0 contact hour, including up to 0.5 pharmacology hours, Pharmacists: 1.0 contact hour. The courses are available through December 31, 2016. These courses were developed by the Association of Reproductive Health Professionals and The Arc of the United States. For additional information, contact FASD@TheArc.org or visit The Arc's FASD Prevention Project to learn about additional for-credit webinars.

The Zika Virus and the role of birth facilities in reporting via Maryland's Newborn Screening Programs

Sickle Cell Parent Mentor Program

The Sickle Cell Disease Long Term Follow-up Program has been following up on all children born in Maryland since 1995. The program has been providing education to providers and families of these children in order to ensure adherence to the standards of care and knowledge of resources available in state and nationally. In order to expand our services, the program conducted a pilot "parent mentor" program with parents of newborns. This pilot ran from May to August 2015 and is being offered to all parents of newborns and those whom a provider has referred for parental education. The parent mentor program is now looking to add additional parents and young adults as mentors.

Sickle Cell Disease Long-Term Follow-Up Program Highlighted

In April, the Sickle Cell Disease program was asked to contribute to a special edition of the Southern Medical Journal. Monica Piccardi, RN, SCD, the program Chief, submitted an article describing the program and its growth and changes from 1995 to the present. The article can be found in the September issue of the Southern Medical Journal: http://sma.org/southern-medical-journal/article/state-of-maryland-sickle-cell-disease-follow-up-program-evolution-of-a-public-health-program/

CDC Awards Zika Grant

The Maryland Department of Health and Mental Hygiene, the Prevention and Health Promotion Administration, Maternal and Child Health Bureau, received a grant award of $400,000. This opportunity will allow the DHMH to expand its capacity from passive birth defect reporting to active surveillance of microcephaly and other central nervous system (CNS) defects that are possibly associated with Zika virus infection during pregnancy. Data will be used for public health monitoring, prevention, and intervention.

For more information, please contact

Monika Piccardi, RN, Program Chief at

410-767-6737.

Family Professional Parternships

Services that We Provide:

FAMILY SENSITIVITY TRAINING FOR PROVIDERS

We offer a free staff training for any organization that works with families of CYSHCN. It is geared to help your staff better understand the population they are dealing with and to develop a better family professional partnership. The training is about 1 ½ hours and includes information on caregiver stress, financial stressors, the family perspective, and the joys of special needs children. If you want more information on this training, please contact our Resource Coordinator.

FAMILY ENGAGEMENT STRATEGIES

The Office of Genetics and People with Special Health Care Needs is in developing its Family Engagement Initiative. This initiative focuses on inclusion of more diverse families of children with special health care needs in program planning, development, implementation and evaluation in a meaningful way. The results of this effort are a strengthened system of care that meets the needs of children and families. The OGPSHCN convened a stakeholder meeting with parent organization and representatives around the state to gather input and guidance on some best practices to be successful. Our goal is to create a statewide initiative that focuses on increased family outreach, family professional partnership, and family-centered care. We want to hear from you, so please fill out our family engagement form by clicking here .

Resource Locator

We welcome parents, caregivers, providers and youth to search through our comprehensive database of resources to find services for children with special health care needs and their families. The database consists of more than 1,000 resources with easy-to-use search options and interactive maps for each resource. It is accessible in more than 50 languages and is 508 compliant for those with visual impairments. Resources include respite care, financial assistance, education, family support services, behavioral health services, therapeutic services, transition and much more. You can access the database online at http://specialneeds.dhmh.maryland.gov or call (800) 638-8864 to speak to our parent resource coordinator for more assistance.

For more information, please contact:

Resource Coordinator, Angela Sittler at (410)767-1063 or (800) 638-8864.

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Extraordinary Cross-Grantee Partnerships That Help Our Children

Kinera Hub

Pursuing the mission to enhance the quality of life for children with special needs and their families, Kinera Foundation is proud to partner with the Office of Genetics and People with Special Health Care Needs to bring to the Eastern Shore a centralized, coordinated Hub of Patient/ Family Centered Care. The Kinera Foundation Eastern Shore Regional Hub unites providers, therapists, families and supporting agencies to ensure children with special health care needs on the Eastern Shore receive the level of care they deserve, within the region they reside. Offering a multitude of services within one building increases access to services for Eastern Shore families, reduces the cost of care drastically, while improving the overall health of the family.

The Kinera Foundation Eastern Shore Regional Hub provides speech therapy, occupational therapy, psychology, pediatric gastrointestinal services, vocational training, durable medical equipment outfitting, orthotics outfitting, assistive technology, resource and lending library, care coordination, collaborative care, parent/ caregiver support, is a family-friendly center, and boasts a sensory quiet room.

For more information about the Kinera Foundation Eastern Shore Regional Hub, or to request an appointment, please visit www.kinera.org, or

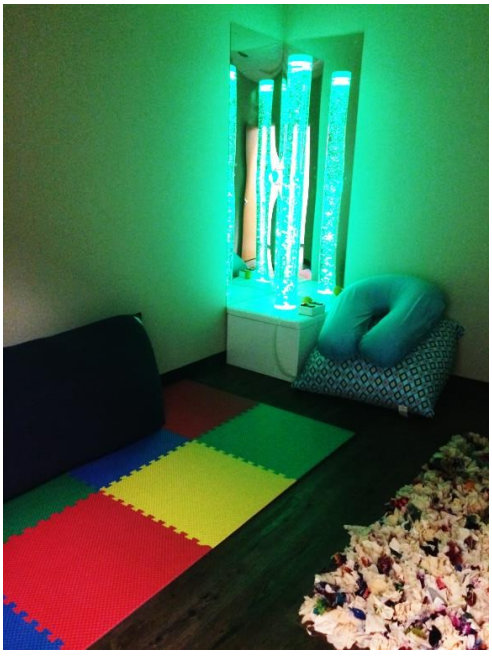
Kinera
115 Sallitt Dr., Suite C
Stevensville, MD 21666

Introducing Pediatric GI services at Kinera!

Kinera Foundation, in partnership with the Department of Health and Mental Hygiene, Office of Genetics and People with Special Health Care Needs is very pleased to announce that they have partnered with the University of Maryland, Baltimore, to provide services for children identified with feeding and nutritional issues at a regional clinic on the Eastern Shore. We are pleased to have this much -needed service provided regionally to offset the difficulties that the trip to Baltimore presents to many families!

To schedule an appointment please contact Conchetta Williams at 410-328-7351. All appointments take place at the Kinera Foundation Eastern Shore Regional Hub.

For more information, please contact Mary O'Brien 4104437977 or click here.



Early Hearing Detection and Metabolic Screening Program MD–EHDI

Parent Connections

The "Maryland Parent Connections" program is a parent-to-parent mentor program for families of children to 21 who are deaf or hard of hearing. When parents have questions and concerns about their child's needs, having a mentor who has had similar experiences can be a big help. "Parent Connections" provides emotional support from trained parent mentors, information and resources and regional social and informational events at no cost.

The program was established February 2012 and is funded by the HRSA Title V grant to the Maryland Department of Health and Mental Hygiene, Office for Genetics and People with Special Health Care Needs, and is administered by the Parent's Place of Maryland.

For more information or to be contacted by a parent mentor by phone or email:

Contact Cheri Dowling

443-277-8899 or cheri@ppmd.org

www.ppmd.org/programs/parent-connections All information is kept confidential.

Newborn Screening Program

In this past legislative session, HB 827 was passed. This bill states: "*The Department shall notify parents and guardians of newborn infants that laboratories other than the Department's public health laboratory may perform post-screening confirmatory or diagnostic tests on newborn infants for hereditary and congenital disorders.*" On the Federal level, the Advisory Committee on Heritable Disorders in Newborns and Children recommends conditions to the Secretary of the U.S. Department of Health and Human Services. This committee has developed a Federal Recommended Universal Screening Panel (RUSP). To view the RUSP, visit: (http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/recommendedpanel/index.html)

In Maryland, new conditions are reviewed by the State Advisory Council for Hereditary and Congenital Disorders. If the condition passes their review process, the recommendation for inclusion of a disorder on the Maryland Screening Panel is forwarded to the Maryland Secretary of Health, who makes the final decision. Maryland screens for the majority of the Core and Secondary Conditions on the RUSP. Some laboratories are screening for conditions that are not on the RUSP. These conditions, such as Krabbe and other lysosomal storage disorders, are very rare but can cause severe neurological problems or even death. The Office of Genetics and People with Special Heath Care Needs will be providing parents information advising about additional conditions that can be screened for that are not currently included in the Maryland Newborn Screening Panel. Parents can talk to their baby's doctor about having these additional screening tests after their initial screening is completed through the Maryland State Laboratory. This information will be made available in the parent brochures that are given to parents at the birth hospital and on our website.

For more information, please contact:

Johnna Watson at (443) 827-3189

Transformation:
Grant Opportunities for Systems Change

GENERAL INFORMATION ON SYSTEM GRANTS FOR STATE FISCAL YEAR 2017

In 2017 the Office of Genetics and People with Special Health Care Needs transformed the Title V funding opportunities for a local health department and system development grantee to develop and implement evidence-based strategy measures to improve outcomes for children and youth with special health care needs and their families in Maryland. This transformation was based on the needs assessment for the State of Maryland to address the priorities that aligned with the Office for Genetics and People with Special Health Care Needs five-year action plan, and national and state data. The Maternal Child Health Block Grant has identified two national priorities medical home and Healthcare transition to be addressed within the next five years. Maryland was given the flexibility to design and implement strategies on strengthening the infrastructure and improving the capacity of systems change and to continuously evaluate the effectiveness of the outcomes for these two priorities**.**

Look out for our 2018 Funding announcement coming soon. Visit our Grants and Partnership page for more information. http://phpa.dhmh.maryland.gov/genetics/Pages/Grants.aspx.

FOR MORE INFORMATION, CONTACT:
CLAUDETTE F. HARVEY, GRANT ADMINISTRATOR
Florence.harvey@maryland.gov 410-767-6749;

TITLE V CYSHCN PRIORITIES:

MEDICAL HOMES

Overall, 47% of children and youth with special health care needs successfully achieved and met the national medical homes core outcomes. These data are from the National Survey of Children Health (2011-2012 NSCH). The vision is for all Maryland children and youth with special health care needs to receive comprehensive care through a medical home partnership. The goal of the office is to increase the parent professional partnership in a medical home. Grant funds will support projects to increase awareness of the medical home model and ongoing comprehensive care within the medical home. Funds will be used to provide training to parents and professionals, to promote partnerships and, to address related issues such as care coordination, developmental screening and healthcare transition within the medical home.

HEALTH CARE TRANSITION

Overall, 40 % of YSHCN successfully achieved and meets the national transition core outcomes. These data are from the National Survey of Children Health (2011-2012 NSCH). The goal of the Office of Genetics and People with Special Health Care Needs is to increase the percentage of professional and youth with special health care needs and their families knowledge of Health-Care Transition. Grant funds will be used to support the development and implementation of new and innovative strategies to improved health care transition services to make all aspects of adult life, including adult healthcare, work and independence.