

Follow-up and Treatment Workgroup for ACHDNC

Stephen McDonough, MD
Retired Pediatrician
Bismarck, North Dakota August 26, 2016

Medical Foods sub-workgroup

- **Charge from ACHDNC**
 - Draft white paper/issue brief including a review of past actions that the full committee made to the previous Secretary and her responses.
 - Include Department of Labor Survey and IOM report have now been completed
 - Focus on maternal PKU syndrome, suggest options for coverage via Bright Futures in the ACA; and look at best practices concerning Medicaid.

Medical Foods sub-workgroup

- **Chair- Susan Berry MD, Director, Division of Genetics and Metabolism, University of Minnesota
Department of Pediatrics**
- **Co-chairs**
 - **Christine S. Brown, MS, Executive Director, National PKU Alliance**
 - **Carol Greene, MD Professor of Pediatrics, University of Maryland Medical Center, Clinical Medical Genetics**
 - **Kathryn Camp, MS, RD, CSP (C) Senior Scientific Policy Analyst, Office of Dietary Supplements, National Institutes of Health**

Medical Foods sub-workgroup

● Members

- Deborah G. Badawi M.D. Medical Director, Office for Genetics and People with Special Health Care Needs, Prevention and Health Promotion Administration, Maryland Department of Health and Mental Hygiene
- Kathryn L. Hassell, M.D. University of Colorado School of Medicine, Professor of Medicine
- Kamila B. Mistry, PhD, MPH, Senior Advisor, Child Health and Quality Improvement, Agency for Healthcare Research and Quality (AHRQ)
- Robert Ostrander MD, Valley View Family Practice Associates, Rushville, New York

Medical Foods sub-workgroup

● Members

- Catharine Riley, PhD, MPH, Rare Disorders and Health Outcomes Team, Division of Human Development & Disability, National Center on Birth Defects & Developmental Disabilities, CDC
- Rani Singh, Ph.D., Professor, Director, Division of Medical Genetics, Nutrition Section, Emory University School of Medicine
- Janet Thomas MD, Pediatrics and Genetics, Colorado Children's Hospital
- Klaas Wierenga, MD, Department of Pediatrics and Genetics, University of Oklahoma College of Medicine
- Jana Monoco, Advocacy Liaison, Organic Acidemia Association

Medical Foods sub-workgroup

● Members

- Joan A. Scott, M.S., C.G.C., Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Division of Services for Children with Special Healthcare Needs, Chief, Genetics Services Branch
- Debi Sarkar, M.P.H., Health Resources and Services Administration, Maternal and Child Health Bureau, Genetic Services Branch, Designated Federal Official
- Jill F. Shuger, ScM, Genetic Services Branch, HRSA/Maternal and Child Health Bureau
- Stephen McDonough, MD, retired (or tired) pediatrician, Bismarck, North Dakota

Medical Foods sub-workgroup

- Phone call meetings
 - June 9, 2016
 - July 14, 2016
 - August 11, 2016

Medical Foods sub-workgroup

- August 25, 2016 meeting
 - Discussed issue brief on medical foods

Quality measures sub-workgroup

● Charge from ACHDNC

- Prepare a report to the full advisory committee highlighting the state of the art and identifying opportunities to apply quality measures to long term follow-up of newborn screening.
- Develop a set of case studies illustrating the use of quality measures for long term follow-up of newborn screening.
- Prepare a brief how to guide illustrating the process of developing and implementing quality measures and identifying resources for assistance.

Quality Measures sub-workgroup

- Chair- Alan E. Zuckerman , M.D., Assistant Professor, Community and Family Medicine; Assistant Professor, Department of Pediatrics, Georgetown University Medical Center
- Co-chairs
 - Amy Brower, PhD, National Coordinating Center, Newborn Screening Translational Research Network, American College of Medical Genetics
 - Jana Monaco, Advocacy Liaison, Organic Acidemia Association
 - Kathryn L. Hassell, M.D. University of Colorado School of Medicine, Professor of Medicine

Quality measures sub-workgroup

● Members

- Christopher Kus, M.D., M.P.H., Associate Medical Director, Division of Family Health, New York State Department of Health
- Rebecca Goodwin, JD Project Manager and Special Assistant to the Director of the Lister Hill National Center for Biomedical Communications
- Catharine Riley, PhD, MPH, Rare Disorders and Health Outcomes Team, Division of Human Development & Disability, National Center on Birth Defects & Developmental Disabilities, Centers for Disease Control and Prevention
- Marci Sontag, PhD, Associate Professor, MPH, Epidemiology, Colorado School of Public Health
- Susan Berry MD, Director, Division of Genetics and Metabolism, University of Minnesota Department of Pediatrics

Quality measures sub-workgroup

● Members

- Celia Kaye, MD, PhD, Professor Emerita, Pediatrics-CHA/PA Program Consultant, Education Office, UCD School of Medicine Senior Genetics Advisor
- Dr. Terese Finitzo, clinical pediatric audiologist and CEO of OZ Systems
- John Eichwald, M.A., branch chief Child Development and Disability (CDD) Division of Human Development and Disability (DHDD) National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC)
- Janet Thomas MD, Pediatrics and Genetics, Colorado Children's Hospital
- Stanley Sciortino, PhD, California Department of Public Health
- David B. Flannery, MD, FACMG, FAAP Medical Director, American College of Medical Genetics and Genomics (ACMG)

Quality measures sub-workgroup

● Members

- Joan A. Scott, M.S., C.G.C., Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Division of Services for Children with Special Healthcare Needs, Chief, Genetics Services Branch
- Debi Sarkar, M.P.H., Health Resources and Services Administration, Maternal and Child Health Bureau, Genetic Services Branch, Designated Federal Official
- Jill F. Shuger, ScM, Genetic Services Branch, HRSA/Maternal and Child Health Bureau
- Stephen McDonough, MD, retired pediatrician, Bismarck, North Dakota

Quality measures sub-workgroup

- Phone call meetings
 - July 21, 2016
 - August 18, 2016

Quality measures sub-workgroup

- August 25, 2016 meeting
 - Key findings for Executive Summary
 - Case studies of existing quality measures and projects
 - Other items to include in the report to the advisory committee

Other Events outside ACHDNC

- American Medical Association- resolution 122 - health coverage for nutritional products for inborn errors of metabolism
- Resolution of the New York State Academy of Family Physicians
- United States Senate passed S. 2943 Authorizing Medical Foods Coverage for the Military in National Defense Authorization Act

Measurement

- If you can measure it and don't measure it, it is NOT important
- How many states do not do long term follow up?
- What percentage of pregnant women with PKU have good control during pregnancy?
- Are there areas of the United States or within states where outcomes are better and why, what are best practices?

Thank you

