

# Follow-up and Treatment Workgroup for ACHDNC

Stephen McDonough, MD  
Retired Pediatrician  
Bismarck, North Dakota November 4, 2016

# New members to workgroup

- **Jeffrey P. Brosco MD PhD**
  - Professor of Clinical Pediatrics
  - University of Miami School of Medicine
  - Department of Pediatrics
- **Annamarie Saarinen**
  - Co-founder, CEO
  - Newborn Foundation

# 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, Senior Scientific Policy Analyst, Office of Dietary Supplements, National Institutes of Health**

# Medical Foods sub-workgroup

## ● Members

- Deborah G. Badawi , MD, Behavioral and Developmental Pediatrics, University of Maryland Medical Center.
- Kathryn L. Hassell, MD, 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

- 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
- Jana Monaco, Advocacy Liaison, Organic Acidemia Association
- Annamarie Saarinen, Co-Founder, CEO, Newborn Foundation

# Medical Foods sub-workgroup

## ● Members

- Joan A. Scott, MS, CGC, 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, MPH, 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
  - October 13, 2016



# Medical Foods sub-workgroup

- **August 25, 2016 meeting**
  - Discussed issue brief on medical foods
- **November 3, 2016**
  - Discussed executive summary
  - Plan is to present report for Committee vote in February 2017 meeting

# 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 , MD, 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, MD, University of Colorado School of Medicine, Professor of Medicine

# Quality measures sub-workgroup

## ● Members

- Christopher Kus, MD, MPH, 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
- Jeffrey Brosco, MD, PhD, Professor of Clinical Pediatrics, University of Miami School of Medicine.
- Nancy Green, MD, Associate Dean for Clinical Research Operations, Division of Pediatric Hematology, Columbia University Medical Center

# 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
- Terese Finitzo, PhD, clinical pediatric audiologist and CEO of OZ Systems
- John Eichwald, MA, 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)
- Kamila B. Mistry, Senior Advisor, Child Health and Quality Improvement, Agency for Healthcare Research and Quality (AHRQ)

# 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
  - September 15, 2016
  - October 20, 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
- **November 3, 2016 meeting**
  - Three domains of public health, clinical care and children/families
  - Plan is report to be approved by Committee in May 2017



# Thank you!

- David Flannery
- Brad Therrell
- Rebecca Goodwin
- Catherine Riley
- Lisa Feuchtbaum
- Alex Kemper
- Debie Badawi
- Celia Kaye
- Terese Finitzo
- Nancy Green
- Marci Sontag
- John Eichwald
- Rani Singh
- Debbie Freedenberg

# Workgroup changes

- I argued against removing 14 workgroup members in August 2016 conference call and again in October 2016 conference call
- In true Stephen McDonough fashion, I was ineffective and I failed. The bureaucracy won another battle but the struggle continues
- Yesterday, I apologized to the workgroup members who will be leaving and I hope that they will continue to assist us as non-workgroup members

# Thank you!

