

Working Group
Nutrition and Diet in Surveillance and Registry Studies of Hemoglobinopathies
Natcher Building, National Institutes of Health, Bethesda MD

Agenda – 16 August 2010

Purpose

This Working Group will identify priorities for basic, clinical, translational, and population science research regarding nutrition and diet in individuals with sickle cell disease and thalassemias. Consumer priorities will be discussed during a morning session on the first day.

Working Group scientific presentations will focus on:

- 1) Nutritional physiology and clinical nutrition issues (including metabolism, nutrient requirements, nutritional status, growth and development, food intake, and use of nutritive and non-nutritive dietary supplements); and
- 2) Collection and analysis of dietary intake data, supplement intake data, and nutritional status data in surveillance and registry studies.

Sponsors

National Heart, Lung, and Blood Institute (NHLBI)
NIH Office of Dietary Supplements (ODS)
NIH Office of Rare Diseases Research (ORDR)
Centers for Disease Control and Prevention, Atlanta (CDC)

DAY ONE (Monday, August 23, 2010)

Consumer Meeting

10:00 **Discussion and Q& A about nutrition and diet-related concerns**
(Moderator: Kathleen Durst, MA, LMSW, Cooley's Anemia Foundation)

11:30 **Adjourn**

Working Group Meeting

11:30 **Registration and sign-in for Working Group Meeting**

12:00 **Welcome and Logistics**
(Abby Ershow, ScD, NHLBI; Ellen Werner, PhD, NHLBI; Rebecca Costello, PhD, ODS)

Session I. Overview

12:30 **Clinical dimensions of sickle cell disease and thalassemia**
(Thomas Coates, MD, University of Southern California)

1:15 **Animal models of sickle cell disease and thalassemia**
(Thomas Ryan, PhD, UAB)

Session II. Nutritional physiology in hemoglobinopathies

1:45 **Nutrient requirements, metabolism, and status assessment in sickle cell disease**

(Virginia Stallings, MD, University of Pennsylvania)

- 2:15 **Nutrient requirements, metabolism, and status assessment in thalassemias**
(Ellen Fung, PhD, Children's Hospital-Oakland Research Institute)
- 2:45 **Exercise physiology and physical activity in hemoglobinopathy patients**
(Robert Liem, MD, Northwestern University)
- 3:15 **One-carbon metabolism in hemoglobinopathies**
(Ralph Green, MD, PhD, University of California-Davis)
- 3:45 **Metabolic assessment using metabolomics**
(Steven Zeisel, MD, PhD, University of North Carolina)
- 4:15 **Endothelial dysfunction in sickle cell disease**
(Joseph Vita, MD, Boston University)
- 4:45 **Discussion**
- 5:30 **Adjourn**

DAY TWO (Tuesday, August 24, 2010)

Session III. Clinical nutrition in hemoglobinopathies

- 8:30 **Nutrition counseling and dietetics practice in sickle cell disease and thalassemias**
(Jean Ann Olds, RD, Colorado)
- 9:15 **Nutritional and non-nutritional dietary supplement usage patterns**
(Rebecca Costello, PhD, NIH Office of Dietary Supplements)
(Johanna Dwyer, DSc, RD, NIH Office of Dietary Supplements)
(Gina Cioffi, JD, Cooley's Anemia Foundation)
(Eric Kirkwood, Uriel Owens Chapter, Sickle Cell Disease Assoc of America)
- 10:00 **Food insecurity and its relationship with chronic disease**
(Barbara Laraia, PhD, RD, University of California San Francisco)
- 10:30 **Break**

Session IV. Surveillance and registry studies

- 11:00 **Principles and examples of surveillance studies and resources**
(Althea Grant, PhD, CDC-Atlanta)
- 11:20 **Principles and examples of registry studies and resources**
(Ellen Werner, PhD, NHLBI)
- 11:40 **Working Lunch**

Session V. Ancillary study designs and data collection models

- 12:15 **NHANES and other CDC surveys**
(Kathryn Porter, MD, MS, National Center for Health Statistics)

- 12:30 **Nested case-control designs**
(Lanetta Jordan, MD, MPH, Barry University)
- 12:45 **Patient-reported outcomes in nutrition and dietary intake research**
(W. Philip Tonkins, DrPH, National Institute of Arthritis and Musculoskeletal Diseases)
- 1:00 **Connection between WIC enrollment and sickle cell disease experience**
(Violanda Grigorescu, MD, MSPH, Michigan Department of Community Health)

Session VI. Research Priorities: Breakout Groups and Summary

- 1:30 **Healthy People 2020 Objectives for Hemoglobinopathies**
(Ellen Werner, NHLBI)
- 1:35 **Breakout Groups**
- Basic Science, Animal Models, and Preclinical Studies
 - Clinical Science
 - Population Science and Implementation Research
- 2:30 **Summary of Research Priorities and Publication Plans**
- 3:30 **Adjourn**