

**National Coalition for PKU & Allied Disorders
Metabolic Conference for Parents, Professionals and Affected
Individuals
Friday and Saturday, June 25-26, 2004
Sheraton Novi Hotel
Novi, MI**

***Friday, June 25, 2004 6 Concurrent Sessions to choose from!
8:30 AM-4:30 PM***

Phenylketonuria Session

Richard Koch, MD, Children's Hospital, Los Angeles, CA
Maternal PKU

Dianne Sullivan, Sandwich, MA
Cooking with Dianne; A great low protein cooking demonstration

Emerging Therapies: BH4, PAL, and PreKUnil
Richard Koch, MD

Christineh Sarkissian, Ph. D.
The McGill University-Montreal Children's Hospital Research Institute

Elaina Jurecki, MS, RD, Kaiser Permanente, Medical Center, Northern California

Small Group Discussions: Breaking out into smaller groups according to age of person with PKU to discuss issues age related

Professional Panel: PKU Professionals will answer questions to the audience in an open discussion.

Organic Acidemia Session

Elaina Jurecki, MS, RD, Kaiser Permanente, Medical Center, Northern California
(Will speak on Organic Acidemia Treatments - unless other suggestions are noted)

Alexander Asamoah, MD, PhD, Pediatrics and Clinical Genetics, Henry Ford Hospital, Detroit, MI
(Hyperactive gag reflexes, oral aversions, swallowing difficulties, constipation, vomiting, GERD)

Lynne Wolfe, MS, ARNP, BC - Speaking on "Supplements and Cofactors in Treatment of Metabolic Disorders"

David Whiteman, MD, Metabolic Geneticist, Mayo Clinic, Rochester, MN -"Untangling the Spirals of Metabolic Disease: Primary Diagnoses and Secondary Effects: Implications of Treatment"

Piero Rinaldo, MD, Ph.D., Mayo Clinic, Patricia Stallings Story

Chuck Venditti, MD, Ph.D., Genetic Disease Research Branch, National Human Genome Research Institute, National Institutes of Health - MMA Research Study

Professional/Parent Panel: Professionals and parents answer questions from the audience in an open discussion

Fatty Oxidation Disorders Session

David Whiteman, MD, Metabolic Geneticist, Mayo Clinic, Rochester, MN

"Untangling the Spirals of Metabolic Disease: Primary Diagnoses and Secondary Effects: Implications of Treatment"

Mark Korson, MD, Metabolic Specialist, The Floating Hospital for Children at Tufts-New England Medical Center

"Adult Manifestations of Fatty Acid Oxidation Disorders" focusing on MCAD, VLCAD, and LCHAD deficiency

Alexander Asamoah, MD, PhD, Pediatrics and Clinical Genetics, Henry Ford Hospital, Detroit, MI

"Gastrointestinal problems in children with metabolic disorders" focusing on GE reflux, vomiting, anorexia, etc"

Lynne Wolfe, MS, ARNP, BC

"Supplements and Cofactors in Treatment of Metabolic Disorders"

Elaina Jurecki, MS, RD, Kaiser Permanente, Medical Center, Northern California

[Topic TBA]

Professional/Parent Panel: Professionals and parents answer questions from the audience in an open discussion.

Homocystinuria Session

Round Table Discussions; Time for families to introduce themselves, and address concerns, share ideas, etc.

Dianne Sullivan, Sandwich, MA

Cooking with Dianne; A great low protein cooking demonstration

Donald H. Chace, Ph.D. M.S.F.S.

Section Chief Division of BioAnalytical Chemistry and Mass Spectrometry; Pediatrics
Detecting Homocystinuria in Newborn Screening

Jonathan Picker, MD Children's Hospital, Boston, MA

Homocystinuria Topics to include: Betaine, Treatment, and Psychological Issues in late treated

Tyrosinemia Session

Round Table Discussions; Time for families to introduce themselves, and address concerns, share ideas, etc.

Grant Mitchell, MD

St. Justine Hospital, Montreal, Canada

Treating Tyrosinemia the Montreal approach

Dianne Sullivan, Sandwich, MA

Cooking with Dianne; A great low protein cooking demonstration

Donald H. Chace, Ph.D. M.S.F.S.

Section Chief Division of BioAnalytical Chemistry and Mass Spectrometry; Pediatrics
Detecting Tyrosinemia in Newborn Screening

***Newborn Screening Workshop, Friday, June 25, 2004
7:00PM-10:00PM***

Donald H. Chace, Ph.D. M.S.F.S.

Section Chief Division of BioAnalytical Chemistry and Mass Spectrometry, Pediatrics

Piero Rinaldo, MD Mayo Clinic, Minneapolis, MN

ACMG Recommendations and What They Will Mean for NBS

Charles Hehmeyer, Esq.

The End of the California Pilot Program and Legal Issues Faced by Hospitals and Physicians

Question and Answer Time: A Panel of Experts Answer Questions from the Audience

***Plenary Session for all Disorders, Saturday, June 26, 2004
8:30 AM- 4:30 PM***

Trish Mullaley, President

National Coalition for PKU & Allied Disorders

'We're All in this Together.'

Gerald T. Berry, MD

Jefferson Medical College, Philadelphia, PA

Topic: Liver Transplantation

Trica Luker

Topic: To be decided – possibly something on IEP/504 education plans

David Paolella, PKU Parent & Cambrooke Foods

School Lunch Program

Sandy Bulcher, RN & MSUD Parent

Federal Formula Legislation

Mark Korson, MD

Proposal on Metabolic Outreach Service

Professional Panel: Professionals from Plenary and Sessions to answer questions in an open forum.