Advisory Committee on Heritable Disorders in Newborns and Children

Audio Conference Call August 7, 2008

THURSDAY, AUGUST 7, 2008

1:00 P.M.- 1:15 P.M. WELCOME

- ROLL CALL
- APPROVAL OF MINUTES, JANUARY 14-15, 2008

R. RODNEY HOWELL

COMMITTEE CHAIR

DENNIS P. WILLIAMS

DEPUTY ADMINISTRATOR

HEALTH RESOURCES AND SERVICES ADMINISTRATION

1:15 P.M. – 1:30 P.M. COMMITTEE NOMINATION AND REVIEW PROCESS—A REVIEW

NANCY GREEN

DIVISION OF PEDIATRIC HEMATOLOGY

ASSOCIATE DEAN FOR CLINICAL RESEARCH OPERATIONS

COLUMBIA UNIVERSITY MEDICAL CENTER

1:30 P.M. – 2:15 P.M. DECISION CRITERIA AND PROCESS WORKGROUP

BRUCE CALONGE

COMMITTEE MEMBER

2:15 P.M. – 3:00 P.M. NOMINATION REVIEW AND PRIORITIZATION WORKGROUP: REPORT

ON CANDIDATE NOMINATIONS: KRABBE DISEASE AND FABRY

DISEASE.

PIERO RINALDO

COMMITTEE MEMBER

3:00 P.M.- 3:45 P.M. EVIDENCE REVIEW WORKGROUP: REPORT ON THE CANDIDATE

NOMINATIONS: SEVERE COMBINED IMMUNODEFICIENCY (SCID) AND

POMPE DISEASE

JAMES PERRIN

PROFESSOR OF PEDIATRICS, HARVARD MEDICAL SCHOOL DIRECTOR,

DIVISION OF GENERAL PEDIATRICS

DIRECTOR, CENTER FOR CHILD AND ADOLESCENT HEALTH POLICY,

HARVARD MEDICAL SCHOOL

MASSGENERAL HOSPITAL FOR CHILDREN

3:45 P.M. – 4:15 P.M. NEWBORN SCREENING SAVES LIVES ACT 2008- NEW LEGISLATION

PETER VAN DYCK
COMMITTEE MEMBER

4:15 P.M – 4:30 P.M. COMMITTEE DISCUSSION

4:30 P.M. – 5:00 P.M. PUBLIC COMMENTS

5:00 P.M. ADJOURN