

# Cystinosis Research Network Family Conference

July 19-21, 2007

The Hotel Contessa, San Antonio, Texas  
Sponsored in part by Sigma Tau Pharmaceuticals

**DRAFT 7/03/07**

**“Searching for a Cure.....Deep in the Heart of Texas”**

## Poster Session Participants

### Research/Clinical

1. “Renal phenotype in the cystinosis mouse model is dependent upon genetic background”  
*Marie Chol, Nathalie Nevo, Anne Bailleu<sup>1</sup>, Andrea Onetti-Muda, Marie-Claire Gubler and Corinne Antignac*
2. “Gene Therapy Studies for Cystinosis”  
*V. Kalatzis, C. Hippert, C. Morin, O.Disson, C. Antignac, and E.J. Kremer*
3. “Design and Synthesis of Novel Prodrugs for the Treatment of Cystinosis”  
*Don Cairns, Ph.D.*
4. “Decreased intracellular ATP levels in conditionally immortalized proximal tubular cells from cystinotic patients”  
*Martijn Wilmer*
5. “Early Intervention Trial for Visual Processing Deficit in Cystinosis”  
*Doris A. Trauner, M.D., Kirsten P. Kung, Ph.D., Amy Spilkin, Ph.D., Angela Ballantyne, Ph.D., Mandy Brannen*
6. “Planning, Problem Solving, and Organizing Information: Executive Functioning in Cystinosis”  
*Amy M. Spilkin, Ph.D., Angela O. Ballantyne, Ph.D., Lynne R. Babchuck, Jennifer Williams & Doris A. Trauner, M.D.*
7. “Parent Ratings of Executive Functioning in Cystinosis: A Window into Behavioral Regulation and Problem Solving”  
*Angela O. Ballantyne, Ph.D., Amy M. Spilkin, Ph.D., Lynne R. Babchuck, Jennifer Williams, and Doris A. Trauner, M.D.*
8. “Analysis of the CTNS Gene in Nephropathic Cystinosis Mexican Patients”  
*Miguel Angel Alcantara-Ortigoza, Leticia Belmont-Martinez, Marcela Vela-AMieva, Ariandna Gonzalez-del Angel*
9. “Third Transplant of Kidney: A New Life for Gerardo: It is Possible”  
*Leticia Belmont, M.D., Victor Gomez*
10. “An Innovative Genomics Approach to Identifying Novel Genes Involved in Cystinosis”  
*K.A. Freed, E.K. Moses, J.E. Curran, M.P. Johnson, J. Charlesworth, T.D. Dyer, S.A. Cole, H.H.H. Göring, J. Blangero*

11. “Development of a Cysteamine *in situ* gelling system for the treatment of corneal crystals in Cystinosis”  
*Bola Lawal; Catherine Tuleu, PhD; Ken Nischal, MD; Olufemi Rabiou, PhD; Rajnish Sekhri, MD; William Van’t Hoff, MD.*

### **Industry/Advocacy**

1. Mexican Association of Cystinosis/Experience in Mexico  
*Victor M. Gomez Molina, President and Leticia Belmont Martinez, M.D., Medical Director*
2. Cystinosis Foundation Ireland  
*Mick Swift, Chairman, and Anne Marie O’Dowd*
3. AIRG  
*Francois Couppey*
4. Cystinosis Research Network  
*Marybeth Krummenacker, Vice President Education and Awareness*
5. Cystinosis Research Network Fundraising  
*John Shepperd and Frankie McGinnis*
6. Cystinosis Research Network Educational Scholarship  
*Sandy Glaize*
7. Cystinosis Research Network Sierra Woodward Sibling Scholarship  
*Pam Woodward*
8. Lynn Potts Education Scholarship/Cystinosis Foundation  
*Gail Potts*

### **Patient/Family**

1. Personal Health Records  
*Carol Hughes*
2. Feeding Issues/Oral Motor Exercises  
*Whitney Glaize*
3. Stages of Cystinosis:  
    Infancy/Preschool  
  
    Childhood  
  
    Adolescence  
  
    Adulthood
4. Managing the Psychosocial Effects of Cystinosis: A Family Systems Approach  
*Nick Smith, LMHC*