

III INTERNATIONAL CONGRESS ON GSD

June, 1st-3rd 2012

National Reference Care Centre for People with Rare Diseases and their Families (CREER), Burgos

FRIDAY 1ST, JUNE

Evening

17:30 *Arrival of participants*

18:00 *Welcome*

18:30 *Opening lecture*

Social models of care for people with rare diseases and their families*
National Reference Care Centre for People with Rare Diseases and their Families (CREER)
Miguel Ángel Ruiz (General Manager)

19:00 *Specific sessions with patients of each type of GSD*

GSD types I and III

Santiago Tomé Martínez de Rituerto (Complejo Hospitalario Universitario de Santiago de Compostela, Spain)

Emma Camarero González (Complejo Hospitalario Universitario de Santiago de Compostela, Spain)

GSD type V

Kathryn Birch

(Wolfson Centre for Inherited Neuromuscular Disease (CIND), Shropshire, UK)

Alfredo Santalla Hernandez. Spanish database of McArdle's patients

(McArdle group. Universidad Pablo de Olavide. Spain).

GSD type II

Barry Byrne

(University of Florida, USA)

Araceli Morales

(Universidad de La Laguna, Spain)

20:30 *Dinner*

SATURDAY 2ND, JUNE

Morning

09:00 *Cellular basis of Pompe disease.*

Araceli Morales and Jose Luis Herrera

(Cellular Neurobiology Laboratory, Universidad de La Laguna, Spain)

09:45 *Achieving a better quality of life in patients with glycogenosis*

Laura Fernández (Fundació Josep Laporte, Spain)

10:30 *Hepatic GSDs and its symptoms*

Santiago Tomé Martínez de Rituerto (Complejo Hospitalario Universitario de Santiago de Compostela, Spain)

11:15 Coffee break

11:45 *Update of gene therapy on Pompe disease*

Barry Byrne (University of Florida, USA)

12:30 *Early intervention in GSD*

Carmen de Linares Von Schmitterlow and Isabel Del Corral (Centro de Desarrollo Infantil y Atención Temprana "D. Miguel de Linares Pezzi", Spain)

13:15 *Clinical practice guidelines in Pompe disease.*

Julio Robles (Complejo Hospitalario Universitario de Santiago de Compostela, Spain)

14:00 Lunch

Afternoon

16:00 *Training workshops for AEEG associates.*

Francesc Cayuela (AEEG).

16:30 *Visit to Archaeological site of Atapuerca*

19:00 *Handbook on McArdle Disease. Spanish version.*

Kathryn Birch (Wolfson Centre for Inherited Neuromuscular Disease (CIND), Shropshire, Reino Unido)

19:45 *Nutritional criteria of GSD I and III.*

Emma Camarero González (Endocrinology Dept., Complejo Hospitalario Universitario de Santiago de Compostela)

20:30 *Closure of III International Congress on GSDs*



SUNDAY 3RD, JUNE

Morning

10:00 2012 AEEG's Ordinary Assembly

14:00 Lunch