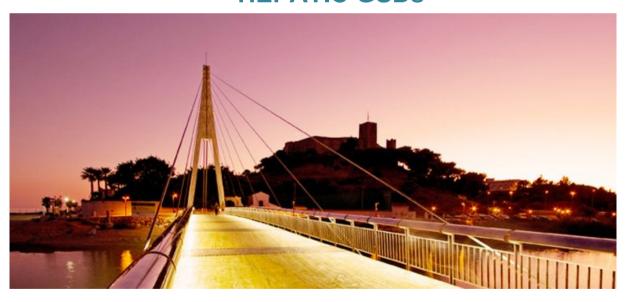




Hemos hecho mucho, queda mucho por hacer We have done a lot, a lot more can be done

IX International GSDs Congress

PROGRAM FOR MUSCULAR AND HEPATIC GSDs



Fuengirola, Málaga 10 – 13 October 2018

> Hotel IPV Palace Km 207 A-7 29640 Fuengirola, Málaga

Wednesday 10 October

First day of evaluation and counselling to patients

16:00-19:00 Evaluation and counselling to **Pompe** disease patients by the team of **Dr. Barry Byrne** (University of Florida)

Thursday 11 October

Second day of evaluation and counselling to patients

09:00-19:00 Evaluation and counselling to **Pompe** disease patients by the team of **Dr. Barry Byrne** (University of Florida)

Friday 12 October

Third day of evaluation and counselling to patients

09:00-19:00	Evaluation and counselling to Pompe disease patients by the team of Dr. Barry Byrne (University of Florida)
17:45-19:30	Physical Training to McArdle patients by Dr. Alfredo Santalla (Universidad Pablo de Olavide) and Dr. Ignacio Ara (Universidad de Castilla-La Mancha)

Activities of the IX Congress

Main Room		Multipurpose Room		
15:30-16:00 16:00-16:30	Reception and delivery of documentation and badge Opening acts President of the AEEG, President of Association of Glucolatino Spain and representative of Unicaja Foundation and representative of FEDER	16:30-18:15	Evaluations to Hepatic GSD, type 1B patients	
		18:15–19:45	Evaluations to Hepatic GSD, type 1A patients	
		19:45–20:30	Presentation : Advice on nutrition in McArdle disease by Dr. Alfredo Santalla (Universidad Pablo de Olavide)	
16:30-17:30	Presentation: Introduction: Benefits of physical activity throughout the life cycle in patients with McArdle disease by Dr. Ignacio Ara (Universidad de Castilla-La Mancha)	20:30-21:00	Natural isotonic design workshop for McArdle disease	
17:30-18:30	Presentation : Precision Medicine for Pompe Disease: Next Generation Therapy by Dr. Barry Byrne (University of Florida)			
18:30–19:45	Presentation: New tools for monitoring and treating Pompe disease by Dr. Jordi Díaz (Servicio Neurología Hospital Sant Pau; Barcelona)			
19:45–21:00	Presentation on gene therapy for GSD Type I and other hepatic GSDs by Dr. David Weinstein (U. Conn Health, Connecticut Children's Medical Center)			

Saturday 13 October

Fourth day of evaluation and counselling to patients

09:00 - 20:00	Evaluation and counselling to Pompe disease patients by the team of Dr. Barry Byrne (University of
	Florida)

09:00 - 14:00 Physical Training to McArdle patients by Dr. Alfredo Santalla (Universidad Pablo de Olavide) and Dr. Ignacio Ara (Universidad de Castilla-La Mancha)

Activities of the IX Congress

Main Daam		Multinum	- P	
Main Room 9:00-9:45	Presentation: Pathophysiology and therapeutic developments for Pompe disease by Dr. Marie-Anne Colle (National Veterinary School,	<u>Multipurpos</u> 9:00–9:45	Presentation: Liver GSDs and sports by Dr. Ulrike Steuerwald (UConn Health, Connecticut Children's Medical Center)	
9:45–10:30	Agribusiness and Food Nantes-Atlantique, France) Presentation: Pitfalls and pathways to diagnosis	9:45–10:30	Presentation on clinical aspects of Hepatic GSDs disease by Dr. Nerea López (Catalan Health Service)	
	of Pompe disease by Dr. John Vissing (Director, Copenhagen Neuromuscular Center)	10:30–11:00	Presentation on Juvenile onset of Pomp e disease in Spain: conclusions and challenges by Dr	
10:30–11:30	Presentation on Hepatic GSDs disease by Dr. David Weinstein (U. Conn Health, Connecticut Children's Medical Center)	11:00-11:30	Miriam Ley (Hospital Puerta del Mar, Cádiz) Presentation on Pompe disease on the current state of knowledge and future perspectives on the topic of muscle regeneration by Dr. Manuel Lorente (Andalusian Health Service, Granada) and María Berrio Miranda	
Main Room	11:30 - 12:00	Coffee br	reak	
12:00-13:00	Presentation on clinical management of Hepatic (Children's Medical Center)	GSD disease b	y Dr. Ana Estella (U. Conn Health, Connecticut	
13:00-14:00	Presentation on latest developments for Hepatic GSD disease by Dr. Kathy Dalhberg (U. Conn Health, Connecticut Children's Medical Center)			
	14:00 - 15:30	Lunch		
	Presentation: Cell-gene therapy using lentiviral vectors for Pompe disease by Dr. Pilar Muñoz (The Pfizer Center-University of Granada-Junta de Andalucía of Genomics and Oncology Research,	17:30-18:15	Presentation: Research utility to improve the quality of life in the McArdle disease by Dr. Alfredo Santalla (University of Pablo de Olavide)	
		Multipurpose Room		
16:45-17:30	GENYO) Presentation: Respiratory involvement of Pompe disease by Dr. Barbara Smith (University of Florida)	16:00-17:00	Presentation: Rare diseases in schools by Ms. Isabel Moráis	
		17:00–19:45	Presentation on Hepatic GSD disease by Dr. María José de Castro	
		19:45–20:20	Evaluations to Hepatic GSD, type 3 patients	

20:20-21:00 Evaluations to Hepatic GSD, type 4, 6 and 9

Presentation: Study of McArdle disease carriers by **Dr. Judit Nuñez** (Hospital German Trias I

Puiol. Barcelona)

19:00-21:00 AEEG Assembly

18:15-19:00

21:00 - 22:30 Dinner

patients

Sunday 14 October

Activities of the IX Congress

09:00 - 11:00 Meeting of the AEEG Governing Board

Multipurpose Room

9:00- 10:30 Evaluations to new patients with Hepatic GSDs

10:30–12:00 Doubts from associates affected by Hepatic GSDs

Organized by:





Sponsored by:





Contributors:











