

UPDATE IN THE MANAGEMENT OF GAUCHER DISEASE AND OTHER LYSOSOMAL DISORDERS

PROGRAMME

September 6-9th, 2010

Co-Directors Program

Pilar Giraldo MD, PhD - Miguel Servet University Hospital. CIBERER
Miguel Pocovi, Profesor - Zaragoza University. CIBERER
Zaragoza, Spain

September 6th 2010 (Monday)

Centro de Docencia Hospital Universitario Miguel Servet.
Aula Edificio Consultas Externas. C/. Cardenal Gomá, 4

To all attendees

16:00-16:10

. Welcome/ Opening

Pilar Giraldo and Miguel Pocovi

16:10-16:30

. Lysosomal Diseases: An overview, emerging new treatments

Pilar Giraldo

16:30-17:00

. Introduction to enzymatic and genetic diagnosis of Lysosomal Diseases

Miguel Pocovi

. Coffee Break

17:20-17:45

. Evaluating Gaucher Disease by imaging techniques

Mercedes Roca

17:45-18:00

. Biomarkers in the diagnosis and follow-up of Gaucher Disease

Pilar Irun

18:00-18:40

. Neurological complications of Gaucher Disease

. Neurophysiological exam in Gaucher Disease

Alicia Saenz de Cabezón

18:40-19:00
. Discussion

September 7th 2010(Tuesday)

Group 1

Laboratorio de Bioquímica, Biología Molecular y Celular
Facultad de Ciencias. Universidad de Zaragoza
Campus Pza San Francisco

9:00-13:30

. Tour to Laboratory and Practices:
Enzymatic Diagnosis of Gaucher, Fabry and Niemann-Pick A/B Diseases
Coordinated by Dr Pilar Alfonso (CIBERER)

Group 2

Hospital Universitario Miguel Servet
Servicio de Hematología
Pº Isabel la Católica 1-3

9:00-13:00

. Clinic Tour and Hospital Installations
Pilar Giraldo

Clinical training:

. Clinical evaluation of Gaucher Disease patients
Pilar Giraldo

. Neurological exam of Gaucher Disease patients
Neurologist

. Neurophysiological examination of Gaucher Disease patients
Alicia Saenz de Cabezón

. ORL evaluation
Jesús Fraile

14:00-16:00

Expert Meeting Lunch

To all attendees

FEETEG

Gral Sueiro, 35 2º izda
50008. Zaragoza

Evaluation of liver deposits by RM

Luis Sarria. S^o de Radiodiagnóstico. Hospital Universitario Miguel Servet

Evaluation of hearing loss in GD

Jesús Fraile. S^o ORL. Hospital Universitario Miguel Servet

16:00- 18:00

. FEETEG Registry and Clinical Trials

Pilar Giraldo

Paz Latre

September 8th 2010 (Wednesday)

Group 2

Laboratorio de Bioquímica, Biología Molecular y Celular

Facultad de Ciencias. Universidad de Zaragoza

Campus Pza San Francisco

9:00-13:30

. Tour to Laboratory and Practices:

Enzymatic Diagnosis of Gaucher, Fabry and Niemann-Pick A/B Diseases

Coordinated by Dr Pilar Alfonso (CIBERER)

Group 1

Hospital Universitario Miguel Servet

Servicio de Hematología

P^o Isabel la Católica 1-3

9:00-13:00

. Clinic Tour and Hospital Installations

Pilar Giraldo

Clinical training:

. Clinical evaluation of Gaucher Disease patients

Pilar Giraldo

. Neurological exam of Gaucher Disease patients

Neurologist

. Neurophysiological examination of Gaucher Disease patients

Alicia Saenz de Cabezón.

. ORL evaluation



www.feeteg.org

Jesús Fraile



14:00-16:00

Expert Meeting Lunch

To all attendees

FEETEG

Gral Sueiro, 35 2º izda

50008. Zaragoza

Bone density studies in Gaucher Disease

Ignacio Civeira. CEINOS

Functional Neuroimaging applications in GD

Javier Banzo. Sº de Medicina Nuclear. Hospital Clínico Universitario

16:00- 18:00

- . Evaluation of Quality of Life
 - . Gaucher Disease. Therapy Decisions.
- Case presentations and Discussion

Pilar Giraldo

Paz Latre

September 9th 2010 (Thursday)

To all attendants

Laboratorio de Bioquímica, Biología Molecular y Celular

Facultad de Ciencias. Universidad de Zaragoza

Campus Pza San Francisco

9:30-14:30

Practices:

- . Genetic Analysis of GD, Fabry, NPA/B and NPC
- . Biomarkers determinations

Coordinated by Dr Pilar Alfonso (CIBERER)

Practices:

Coordinated by Dr Pilar Alfonso (CIBERER)

14:00-16:00 Lunch

To all attendants

Centro de Diagnóstico Dra Roca



www.feeteg.org



C/. Carrera del Sábado, 4
50006 Zaragoza

16:30-19:30

. Practices of Radiological Studies: MRI, US Densitometry
Mercedes Roca

Faculties

Pilar Alfonso PhD
Research Lab. Miguel Servet University Hospital. CIBERER

Javier Banzo. MD PhD
Sº de Medicina Nuclear. Hospital Clínico Universitario

José Luis Capablo MD PhD
Neurology Department. Miguel Servet University Hospital. CIBERER

Ignacio Civeira Murillo. MD PhD
CEINOS

Jesús Fraile. MD PhD
Sº ORL. Hospital Universitario Miguel Servet

Javier Gervas Arruga. B.SC & M.SC Laboratorio de Investigación Molecular.
Hospital Universitario Miguel Servet

Pilar Giraldo MD, PhD
Haematology Department. Miguel Servet University Hospital. CIBERER

Pilar Irún PhD
Biochemistry and Molecular Biology Department. Zaragoza University
CIBERER.

Paz Latre MD
General Practitioner. CIBERER

Miguel Pocovi, Professor
Biochemistry and Molecular Biology Department.
Zaragoza University. CIBERER

Mercedes Roca MD PhD
International Skeletal Society. CIBERER

Alicia Saenz de Cabezón MD
Neurophysiology Department. Miguel Servet University Hospital. CIBERER

Objectives

The aim of this course is to provide an update in diagnosis, follow-up, monitoring and treatment of Gaucher disease and other lysosomal disorders. The training will be provided by experts in multidisciplinary areas related to the particular features of storage diseases. This course is directed to physicians with some experience in diagnosis and treatment of lysosomal diseases.

Admission is restricted to maximum of 6 people
Those interested will be admitted by order of registration

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