



FONDAZIONE
INTERNAZIONALE
MENARINI

Focus on Fabry Nephropathy
**Biomarkers, Progression and
Disease Severity**

Official Satellite of the World Congress of Nephrology

Bergamo (Italy), May 27th – 28th, 2009

Organized by

MARIO NEGRI INSTITUTE

BAYLOR RESEARCH INSTITUTE (USA)

MEDICAL UNIVERSITY VIENNA (AUSTRIA)

HOPE HOSPITAL (UK)

WÜRZBURG UNIVERSITY (GERMANY)

UNIVERSITY OF ALABAMA AT BIRMINGHAM (USA)

FONDAZIONE INTERNAZIONALE MENARINI

PROGRAM

Aula Alabastro
Congress Center Giovanni XXIII
Viale Papa Giovanni XXIII, 106

The notion that the study of rare diseases sometimes tells us more than that of common ones is not new, and dates back as early as 17th century, as we learned from a famous letter of William Harvey to a Dutch physician. This is particularly true in the field of kidney diseases. During the last few years we have witnessed a tremendous increase in knowledge of the genetic nature of a number of rare kidney diseases. The investigation of the role of genetic disruption at the basis of pathological processes in the kidney has helped not only in understanding these disease states but also has high-lighted developmental issues, and revealed novel insights into kidney function.

By organising the Focus on Fabry Nephropathy: Biomarkers, Progression and Disease Severity as an Official Satellite of the World Congress of Nephrology, we have aimed to bring together research geneticists, nephrologists and clinicians, and experts from related specialties. The format of the conference is focussed to provide a cutting edge view of the field and to stimulate discussions, novel insights and consensus positions. The conference speakers will cover a variety of aspect of Fabry Nephropathy: natural history, factors that drive progressive loss of kidney function and responses to therapy, biomarkers for understanding the progression of disease and response to therapy, special issues for pediatric patients and patients on dialysis or with transplantation, pathology of Fabry nephropathy, and developing treatment options for Fabry Nephropathy. The plenary invited lectures include Professors Giuseppe Remuzzi (Molecular Basis of Glomerular Permselectivity and Proteinuria), Barry M. Brenner (Fetal Origins of Kidney Disease in Adults) and Christof Westenfelder (Stem Cell Therapies for CKD. Of special note will be concurrent workshops organized by Adeera Levin that will address: Biomarkers of Fabry Nephropathy and Progression; Enzyme Replacement Therapy; Dialysis and Transplantation in Fabry Patients; and Children with Fabry Disease which we intend to publish as consensus statements after the conference.

All of the presentations, and the incomparable venue provided in Bergamo will ensure a very successful meeting.

David Warnock and Christoph Wanner

Meeting Co-Chairs

Giuseppe Remuzzi
Mario Negri Institute
Bergamo, Italy

Gere Sunder-Plassmann
Medical University of Vienna
Vienna, Austria

Christoph Wanner
Würzburg University
Würzburg, Germany

Raphael Schiffmann
Baylor Research Institute
Dallas, USA

Stephen Waldek
Hope Hospital
Manchester, UK

David G. Warnock
University of Alabama
at Birmingham
Birmingham, USA

Steering Committee

M. Beck (Mainz, Germany), **D. Bichet** (Montreal, Canada),
B. Brenner (Boston, USA), **A. Fogo** (Nashville, USA),
A. Levin (Vancouver, Canada), **R. Mignani** (Rimini, Italy),
M. Mauer (Minneapolis, USA), **A. Mehta** (London, UK),
J.P. Oliveira (Porto, Portugal), **M. West** (Halifax, Canada),
C. Westenfelder (Salt Lake City, USA).

Organizing Secretariat

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Wednesday, May 27th, 2009 – Morning
Aula Alabastro “A”, Congress Center Giovanni XXIII

07.45 **Registration**

08.30 **Welcome to the Satellite: D.G. Warnock** (Birmingham, USA)

08.40 **Opening Lecture**
G. Remuzzi (Bergamo, I)
Molecular Basis of Glomerular Permeability and Proteinuria

Plenary Session I

Chairmen: **J. P. Oliveira** (Porto, P)
 M. West (Halifax, CDN)

09.25 **R. Schiffmann** (Dallas, USA)
 Fabry Nephropathy: natural history and predictors
 of disease progression

10.10 **C. Auray-Blais** (Sherbrooke, CDN)
 Biomarkers and Fabry Disease

10.55 *Coffee Break*

11.15 **A. Rosenberg** (Bethesda, USA)
 Antibodies to Therapeutic Enzymes

12.00 Chairman: **M. Beck** (Mainz, D)

U. Ramaswami (Cambridge, UK)
 Fabry Nephropathy in Children

12.45 Chairman: **G. Remuzzi** (Bergamo, I)

Keynote Lecture
 B. Brenner (Boston, USA)
 Fetal Origins of Kidney Disease in Adults

13.30 *Lunch*

Wednesday, May 27th, 2009
Congress Center Giovanni XXIII

12.30 – 14.30

POSTER PRESENTATION

*Will be selected among the abstracts submitted by participants.
There will be a poster session during lunch-time of each day.
During that time posters should be attended by the Authors.*

Wednesday, May 27th, 2009 - Afternoon
Aula Alabastro “A”, Congress Center Giovanni XXIII

Plenary Session II

Chairmen: **B. Brenner** (Boston, USA)
R. Schiffmann (Dallas, USA)

14.30 **C. Ruiz de Valbuena** (Porto, P)
Renal Biopsies in Women with Early Fabry Nephropathy

15.15 **M. Mauer** (Minneapolis, USA)
Structural/function relationship in Progressive
Fabry Nephropathy

Wednesday, May 27th, 2009 - Afternoon
Congress Center Giovanni XXIII
Parallel Sessions

16.00-18.00 **Workshop/Discussion Groups**
Chair: A. Levin (Vancouver, CDN)

Sala Alabastro “A”

Workshop 1 “Biomarkers of Fabry Nephropathy and Progression”

Chair: **R. Schiffmann** (Dallas, USA)

Co-chair: **S. Waldek** (Manchester, UK)

Co-chair: **A. Benigni** (Bergamo, I)

Sala Alabastro “B”

Workshop 2 “Enzyme Replacement Therapy (ERT)”

Chair: **M. West** (Halifax, CDN)

Co-chair: **D.G. Warnock** (Birmingham, USA)

Co-chair: **E. Daina** (Bergamo, I)

Sala “Novelli”

Workshop 3 “Dialysis and transplantation in Fabry Disease patients”

Chair: **G. Sunder-Plassmann** (Vienna, A)

Co-chair: **R. Mignani** (Rimini, I)

Co-chair: **P. Ruggenti** (Bergamo, I)

Sala “Stucchi”

Workshop 4 “Children with Fabry Disease”

Chair: **D. Bichet** (Montréal, CA)

Co-chair: **U. Ramaswani** (Cambridge, UK)

Co-chair: **A. Schieppati** (Bergamo, I)

Thursday, May 28th, 2009 - Morning
Aula Alabastro “A”, Congress Center Giovanni XXIII

Plenary Session III

Chairmen: **D. Germain** (Paris, F)
D.G. Warnock (Birmingham, USA)

08.30 **Keynote Lecture**
C. Westenfelder (Salt Lake City, USA)
Stem Cell Therapies for CKD

09.30 **D. Germain** (Paris, F)
Chaperone Therapy for Fabry Disease

10.00 **J. Shayman** (Ann Arbor, USA)
Glucosyl Ceramide Synthase Inhibitors in LSDs

10.30 *Coffee Break*

Session IV

Chairmen: **G. Sunder-Plassmann** (Vienna, A)
S. Waldek (Manchester, UK)

11.00 **J.P. Oliveira** (Porto, P)
The Role of Renal Biopsy in the Diagnosis and Management of
the International Study Group of Fabry Nephropathy (ISGFN)

11.30 **Panel Discussion on Kidney Biopsy**
J.P. Oliveira (Porto, P), **A. Fogo** (Nashville, USA),
E. Svarstad (Bergen, N), **M. Mauer** (Minneapolis, USA)
and **I. Maya** (Birmingham, USA)

12.00 **A. Levin** (Vancouver, CDN)
Concurrent Workshops Reports

12.45 **C. Wanner** (Würzburg, D)
Conclusions and Summary

13.00 *Lunch*

GENERAL INFORMATION

Meeting venue

The venue for the Meeting will be Congress Center Giovanni XXIII Viale Papa Giovanni XXIII, 106 I-24121 Bergamo, Italy. Phone: +39 035 236435

Secretariat during the Meeting

The Secretariat will be open at the following times:

Wednesday, May 27th, from 07.45 a.m. to 06.00 p.m.

Thursday, May 28th, from 08.00 a.m. to 02.00 p.m.

Official language

The official language of the Meeting will be English.

CME Credits

The Meeting earned n° 8 CME Credits from the Italian Health Authorities for Physicians.

European CME credits (ECMEC's)

European CME credits have been applied for from the European Accreditation Council for Continuing Medical Education (EACCME).

Registration

The Meeting is free to attend. Please confirm your participation to the Organizing Secretariat (Fondazione Internazionale Menarini

Phone: +39 02 55308110 – Fax: +39 02 55305739

E-mail: milan@fondazione-menarini.it) **by Monday, May 11th, 2009.**

Hotel accomodation

For information regarding the hotel accomodation in Bergamo please contact our Agency:

Servizi CEC (Mrs. Katia Gissi) Via Verdi, 18 – I-24121 Bergamo, Italy

Tel: +39 035 249899 – Fax: +39 035 237852 – E-mail: k.gissi@servizicec.it

Posters

Will be selected among the abstracts submitted by participants (deadline **Monday, May 4th 2009**).

The posters could be mounted before the Meeting starts and attended by the Authors during the lunch time. Three winners and prizes will be announced later in the Meeting.

Technical facilities

Facilities will be available for computer presentations and overhead projections.

A business center with PC (Powerpoint for Windows) will be available for check and preview of presentations. It is essential that speakers take their CD to the business center at least one hour before the session starts.

The center will be open at the following times:

Wednesday, May 27th, from 07.45 a.m. to 04.00 p.m.

Thursday, May 28th, from 08.00 a.m. to 02.00 p.m.

Lunches and coffee breaks

Lunches and coffee breaks will be served in the Meeting area.

Abstracts book

Participants will receive the Abstract book at the Meeting.

Thanks for their support to:



LIST OF SPEAKERS AND CHAIRMEN

Christiane Auray-Blais

Provincial Mass Urine Screening Program
Service of Genetics
Department of Pediatrics
Sherbrooke (QC, Canada)

Michael Beck

Universitäts-Kinderklinik
Mainz (Germany)

Ariela Benigni

Department of Molecular Medicine
Pharmacological Research Institute Mario Negri
Bergamo (Italy)

Daniel Bichet

Department of Physiology
University of Montréal
Canada Research Chair on Genetics of Kidney Disease
Montréal (Canada)

Barry Brenner

Brigham and Women's Hospital
Boston (MA, USA)

Erica Daina

Clinical Research Center for Rare Diseases "Aldo e Cele Daccò"
Pharmacological Research Institute Mario Negri
Ranica (Italy)

Agnes Fogo

Vanderbilt Medical Center
Nashville (TN, USA)

Dominique Germain

University of Versailles St Quentin
Hôpital Raymond Poincaré
Garches (France)

Adeera Levin

University of British Columbia
St. Paul's Hospital
British Columbia Provincial Renal Agency
Vancouver (Canada)

Michael Mauer

University Of Minnesota
Minneapolis (MN, USA)

Ivan Maya

Associate Professor of Medicine and Radiology
University of Alabama at Birmingham
Birmingham (USA)

Atul Mehta

Consultant Haematologist
Royal Free Hospital
London (UK)

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Nephrology and Dialysis
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Rimini (Italy)

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Porto (Portugal)

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Paediatric Metabolic Unit
Department of Paediatrics
Addenbrooke's Hospital
Cambridge (UK)

Amy Rosenberg

Food and Drug Administration
Division of Therapeutic Proteins
Bethesda (MD, USA)

Carmen Ruiz de Valbuena Bueno

Hospital de São João
Porto (Portugal)

James Shayman

Professor of Internal Medicine and Pharmacology
Associate Vice President for Research, Health Sciences
University of Michigan
Ann Arbor (MI, USA)

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Vienna (Austria)

Giuseppe Remuzzi

Department of Immunology and Clinical Transplantation
Mario Negri Institute
Bergamo (Italy)

Piero Ruggenti

Renal Research Department
Mario Negri Institute
Bergamo (Italy)

Arrigo Schieppati

USC Nephrology Dialysis Transplantation
Ospedali Riuniti di Bergamo
Bergamo (Italy)

Raphael Schiffmann

Institute of Metabolic Disease
Baylor Research Institute
Dallas (USA)

Einar Svarstad

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Würzburg (Germany)

David G. Warnock

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Michael West

Division of Nephrology
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Christof Westenfelder

Renal Section VA Medical Center
University of Utah
Salt Lake City (UT, USA)



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REGISTRATION FORM

Family name _____

First name _____

Title _____ Institute/Organization _____

Mailing address _____

Postal code _____

City _____ Country _____

Telephone _____ Fax _____

e-mail _____

The Meeting is free to attend. Please confirm the participation to the Organizing

Secretariat: Fondazione Internazionale Menarini - Phone: +39 02 55308110

Fax +39 02 55305739

E-mail: milan@fondazione-menarini.it, **within Monday, May 11th, 2009.**

Date _____

Signature



