International Center for Studies and Training "Germana Gaslini"

Provider Nazionale Accreditato ECM n. 856 Certificazione ISO9001:2008





#### **CISEF Director: Antonio Infante**

### **AIMS**

The rationale of this Workshop is to share current experience of the Registry of paediatric patients on renal replacement therapy (dialysis and renal transplantation) held by the European Society for Paediatric Nephrology (ESPN) in collaboration with the European Renal Association - European Dialysis and Transplantation Association (ERA-EDTA) and operating at the European level, with that of other registries and study groups which are currently active in the field of renal diseases, both in paediatric and in adult nephrology.

The Workshop will be organized in strict cooperation with the Working Group on Inherited Kidney Disorders of the ERA-EDTA and will include a CME Course on "Nephrology registries and genetic renal diseases".

The main issues which will be addressed during the Workshop are represented by:

- Data from national and international registries and databases of patients affected by renal diseases: epidemiology, diagnosis, management and treatment.
- Update on the diagnosis of genetic diseases involving the kidney and the urinary tract.

The goals of the Workshop are:

- 1) To increase the participants' knowledge on rare kidney diseases and their ability to take care of affected patients.
- To facilitate the communication and the exchange of data and information between the existing registries in the field of renal diseases (with the ultimate goal of "merging" the different databases).

# **Scientific Committee of the Meeting**

Giovanni Capasso (Napoli, Italy)
Pierre Cochat, Lyon (France)
Rosanna Coppo (Torino, Italy)
Olivier Devuyst (Zurich, Switzerland)
Gianmarco Ghiggeri (Genova, Italy)
Kitty Jager (Amsterdam, The Netherlands)
Roberto Ravazzolo (Genova, Italy)
Franz Schaefer (Heidelberg, Germany)
Enrico Eugenio Verrina (Genova, Italy)

# **Organizing Secretariat**

#### Manuela Aloe

C.I.S.E.F. International Center for Studies and Training "Germana Gaslini". Genoa

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#### **GENERAL INFORMATION**

# Registration

The course is open to 60 nephrologists, pediatricians, medical genetists and biologists.

Applications will be accepted on a first come-first served basis.

Deadline for registration: March 15<sup>th</sup>, 2013.

Please, fill in the registration form to be downloaded from the course website and return it to the organizing secretariat.

# **Registration fees**

The fee of euros 100,00 (50,00 for PhD students and post-docs and for IGG personnel) covers: access to scientific sessions, the welcome cocktail of March 22, 2 coffee breaks and attendance certificate.

The fee can be paid after receiving confirmation from the organizing secretariat.

# **Italian CME credits**

The course "Nephrology registries and genetic renal diseases" has been accredited for Medical Doctors and Biologists (8 credits).

Discipline: Paediatrics, Nephrology, Medical Genetics.

# Official language

English

#### Venue

Villa Quartara, Badia Benedettina della Castagna Via Romana della Castagna 11 A, 16148 Genoa, Italy.

#### How to reach the venue

Plane: from the International Airport Cristoforo Colombo, shuttle bus n. 100 (runs every hour) takes you to Genova Brignole railway station, where you can take bus n. 17 to Via Romana della Castagna.

Train: get off at Genova Brignole railway station, take bus n. 17 and get off in Corso Europa, in front of Via Romana della Castagna.

Car: motorway exit Genova-Nervi, take Corso Europa westwards, take the overpass to change direction and drive eastwards, pass the Hotel AC and ESSO gas station on the right, after 50 mts. turn right into Via Romana della Castagna, go straight 80 mts., enter the gate and follow the dust lane up to the parking lot.

#### Accommodation

Please make your arrangement well in advance.

Special rates at the AC Marriot Hotel\*\*\*\* - Genova-Quarto +39-010-3071180 located at walking distance from the Badia as well as at the Hotel Iris \*\*\* - Genova-Quarto +39-010-3773914. Always mention the CISEF course.



# WORKSHOP ON NEPHROLOGY REGISTRIES

Including the CME COURSE:

"NEPHROLOGY REGISTRIES AND GENETIC RENAL DISEASES" dedicated to Rosanna Gusmano



Course Directors

G.M. Ghiggeri, E. Verrina

March 22-23, 2013

Villa Quartara, Badia della Castagna Genoa, Italy



G. Gaslini Children's Hospital Genoa



# **Faculty**

#### **Antonio Amoroso**

Transplantation Regional Centre, Piemonte Region "Città della Salute e della Scienza" Hospital, Torino, Italy

# **Corinne Antignac**

Service de Génétique, Hopital Necker–Enfants Malades, Paris, France

# Giovanni Capasso

Chair of Nephrology, Department of Internal Medicine II University of Naples, Naples, Italy

#### Pierre Cochat

Centre de référence des maladies rénales rares, Hospices Civils de Lyon and Université Claude-Bernard Lyon 1, Lyon, France

# Rosanna Coppo

Nephrology Dialysis and Transplantation Regina Margherita Children's Hospital, Torino, Itlay

### **Olivier Devuyst**

University of Zurich, Institute of Physiology Zurich Center for Integrative Human Physiology Zurich. Switzerland

#### Francesco Emma

Department of Pediatric Nephrology, Dialysis and Transplantation Bambino Gesù Children's Hospital, Rome, Italy

#### Giulio Gabbiani

Department of Pathology and Immunology University of Geneva, Geneva, Switzerland

#### Ali Gharavi

Division of Nephrology, Columbia University, New York, USA

## Gianmarco Ghiggeri

Pediatric Nephrology, Dialysis and Transplantation Department G. Gaslini Children's Hospital, Genoa, Italy

#### Jaap Groothoff

Department of Pediatric Nephrology, Academic Medical Center Amsterdam, The Netherlands

#### Jerome Harambat

Department of Pediatrics, University of Bordeaux, Bordeaux, France

#### Kitty Jager

ERA-EDTA Registry, Department of Medical Informatics Academic Medical Center, Amsterdam, The Netherlands

#### Martin Konrad

Department of General Pediatrics University Hospital Muenster, Munster, Germany

#### **Marina Noris**

Department of Molecular Medicine

"Aldo e Cele Dacco" Clinical Research Centre for Rare Diseases Bergamo, Italy

#### Luca Rampoldi

Dulbecco Telethon Institute San Raffaele Scientific Institute, Milano, Italy

# Simone Sanna Cherchi

Division of Nephrology, Columbia University, New York, USA

#### Gaia Scavia

Istituto Superiore di Sanità, Rome, Italy

#### Franz Schaefer

Division of Pediatric Nephrology KfH Kidney Center for Children and Adolescents University of Heidelberg, Heidelberg, Germany

#### Constantinos J. Stefanidis

Department of Pediatric Nephrology

"A. and P. Kyriakou" Children's Hospital, Athens, Greece

# **Enrico Eugenio Verrina**

Pediatric Nephrology, Dialysis and Transplantation Department G. Gaslini Children's Hospital, Genoa, Italy

# **PROGRAMME**

# Friday, March 22, 2013

11. 00 Get-together and briefing

11.30-15.30 Parallel sessions: Operative Meetings

- ESPN/ERA-EDTA Registry Committee meeting (Kitty Jager, Franz Schaefer)
- İtalian Registry of Paediatric Dialysis Scientific Board meeting (Enrico Verrina)
- Italian Registry of Haemolytic Uremic Syndrome Scientific Board meeting (*Gaia Scavia*)
- Italian Society for Paediatric Nephrology Council meeting (*Tommaso De Palo*)

# CME Course: "Nephrology registries and genetic renal diseases"

11.30-15.30 Registration of participants

#### 15.30-17.30 **I Session**

# Organization of renal disease registries and networks

Coordinator: *E. Verrina* Chairman : *P. Cochat* 

K. Jager The experience and organization of the ERA-EDTA and ESPN/ERA-EDTA Registry

- what to expect and what not to expect

from a registry.

**F. Schaefer** The experience and the organization of the International Paediatric Peritoneal Dialysis

Network.

J. Groothoff The extended registry: flaws and gains, experience from the RICH Q network.

**G. Scavia** The Italian haemolytic uremic syndrome

registry.

17.30 Tea/cookies break

17.45-19.15 II Session

Renal patient registries and rare diseases Coordinator: Constantino J. Stefanidis

Chairman: R. Coppo

P. Cochat Survival of children starting renal replacement therapy in the neonatal period.

J. Harambat Characteristics and outcomes of children with primary oxalosis requiring renal replacement

therapy: an ESPN/ERA-EDTA Registry study.

**F. Emma** Improvement in prognosis of nephropathic

cystinosis.

19.30 Welcome party

# Saturday, March 23, 2013

8.15-10.15 **III Session** 

Glomerular diseases
Coordinator: G.M. Ghiggeri
Chairman: A. Amoroso

C. Antignac News on podocyte inherited diseases.

**M. Noris** Cytoskeleton genes for nephrotic syndrome

**G. Gabbiani** Physiology and physiopathology of cytoskeleton.

10.15 Invited lecture

A. Gharavi Genetics of IgA nephropathy.

11.00 Coffee break

11.30-13.30 IV Session

Renal dysplasia/Inherited tubulo-interstitial fibrosis

Coordinator: *O. Devuyst*Chairman: *G. Capasso* 

S. Sanna Cherchi Molecular advances in renal dysplasia
L. Rampoldi Mechanisms of uromodulin-associated

kidney disorders.

O. Devuyst Insights into complex diseases: GWAS

and uromodulin.

M. Konrad Infantile hypercalcemia and related

disorders.

14.00 Closing Remark

Evaluation test for CME Italian credits and quality assessment questionnaire Release of certificates of attendance.