



European Reference Network
for rare or low prevalence complex diseases

Network
Endocrine Conditions (EN-ERN)



European Reference Network
for rare or low prevalence complex diseases

Network
Bone Disorders (ERN BOND)



European Reference Network
for rare or low prevalence complex diseases

Network
Kidney Diseases (ERKNet)



UNIVERSITÀ
DEGLI STUDI
DI PADOVA



Con il patrocinio di:

Padua
October 8th 2019

**AUDITORIUM BOTANICAL GARDEN
PADUA UNIVERSITY
ITALY**

**DISORDERS OF
PHOSPHATE
IMBALANCE:
A DYSREGULATION
OF THE FGF23
ENDOCRINE SYSTEM.
HOLISTIC MANAGEMENT
OF THE DISEASE.
FIRST JOINT MEETING
ENDO-ERN, ERKNET,
BOND ERN**

8.30 Authorities' greetings
C. Scaroni, R. Vettor, P. Facchin

8.45 Opening
*N. A. Greggio, L. Sangiorgi, F. Emma,
D. Taruscio, G. Lombardi, E. Terol*

Session 1

Chairs: L. Guazzarotti, S. Giannini, L. Murer

9.00 Genetics of hypophosphatemia
E. Pedrini

9.30 Hypophosphatemia and XLH in adult
ML. Brandi

10.00 Pathophysiology of FGF23 system
and differential diagnosis of renal
hypophosphatemia
F. Emma

10.30 1st Guest Lecture • *Chair N. A. Greggio*
Burosumab Therapy in children
*T. O. Carpenter, Yale University
(New Haven-Ct-USA)*

11.15 Coffee Break

Session 2

Chairs: V. Camozzi, MC. Salerno, G. Vezzoli

11.40 1st Clinical case
AM. Colao

11.50 2nd Clinical case
G. I. Baroncelli

12.00 2nd Guest Lecture • *Chair L. Sangiorgi*
Clinical practice recommendation for XLH
A. Linglart, Hopital Bicetre, Paris, France

12.30 Leading opinion from
Endocrinology experts
Pediatric: MC. Salerno & Adult: I. Chiodini
Bone metabolism experts
Pediatric: G. I. Baroncelli & Adult D. Gatti
Nephrology experts
Pediatric: F. Emma & Adult: G. Vezzoli

13.30 Light Lunch

Session 3

14.30 Round Table: Brainstorming INTER-ERN
*ML. Brandi, F. Emma, P. Facchin, N. A. Greggio,
G. Lombardi, M. Vaccarotto, L. Sangiorgi,
D. Taruscio, E. Terol*
Plenary discussion

16.00 Closing remarks and ECM

Presentation

The national and European ERN network aims to improve access to high quality health care for patients with rare disorders to provide them with appropriate diagnostics, treatment and quality of care.

In the case of hypophosphatemic rickets linked to the X chromosome (XLH), and more generally in the field of rare diseases, patients are forced to face many difficulties during their care pathways and this generates complications caused by delays in starting or discontinuing therapies.

In XLH, children and adults should be followed in a holistic way because they present endocrinological renal, dental, bone, orthopedic, pain, social and work problems.

As National Coordinators EndoERN, Bond-ERN and ERKnet we strongly wanted this multidisciplinary meeting which brings together national and international experts on hypophosphatemia XLH to discuss its management and for its greater dissemination.

A fundamental step for the dissemination of information useful to patients and families was the establishment in 2018 of the AIFOSF Association of Hypophosphatemic Patients.

Given the paucity of specialized centers in XLH we believe that the formation of a telemedicine network capable of guaranteeing better coverage throughout the Italian territory will be fundamental to avoid the migration of patients in search of the best cure.

Relatori e Moderatori

Baroncelli Giampiero Igli, Pisa
Brandi Maria Luisa, Firenze
Camozzi Valentina, Padova
Carpenter Thomas,
New Haven CT, USA
Chiodini Iacopo, Milano
Colao Annamaria, Napoli
Emma Francesco, Roma
Facchin Paola, Padova
Gatti Davide, Verona
Giannini Sandro, Padova
Greggio Nella Augusta, Padova
Guazzarotti Laura, Padova
Linglart Agnes, Parigi, Francia
Lombardi Gianni, Firenze
Murer Luisa, Padova
Pedrini Elena, Bologna
Salerno Mariacarolina, Napoli
Sangiorgi Luca, Bologna
Scaroni Carla, Padova
Taruscio Domenica, Roma
Terol Enrique, Bruxelles
Vaccarotto Manuela, Padova
Vettor Roberto, Padova
Vezzoli Giuseppe, Milano

INFORMAZIONI GENERALI

SEDE

Auditorium Orto Botanico

Prato della Valle 57/C - Padua

MODALITÀ D'ISCRIZIONE

L'iscrizione è gratuita ma obbligatoria compilando l'apposita scheda di iscrizione on-line, disponibile nel sito www.sabiwork.it

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SabiWork

Via Ospedale Civile 33, Padova

Tel. 049 7387069 - Fax 049 7387061

segreteria@sabiwork.it

CREDITI FORMATIVI ECM

I crediti ECM sono in fase di definizione

Il convegno è accreditato per le figure professionali di:

- Medico Chirurgo - discipline Endocrinologia, Genetica Medica, Laboratorio Genetica Medica, Malattie Metaboliche e diabetologia, Medicina Interna, Nefrologia, Pediatria
- Biologo

Presidenti del Congresso: Nella Augusta Greggio, Francesco Emma, Luca Sangiorgi

Segreteria scientifica: S. Azzolini, V. Camozzi, F. Emma, S. Giannini, N. A. Greggio, L. Guazzarotti, L. Murer, L. Sangiorgi

Con il contributo incondizionato di:

KYOWA KIRIN