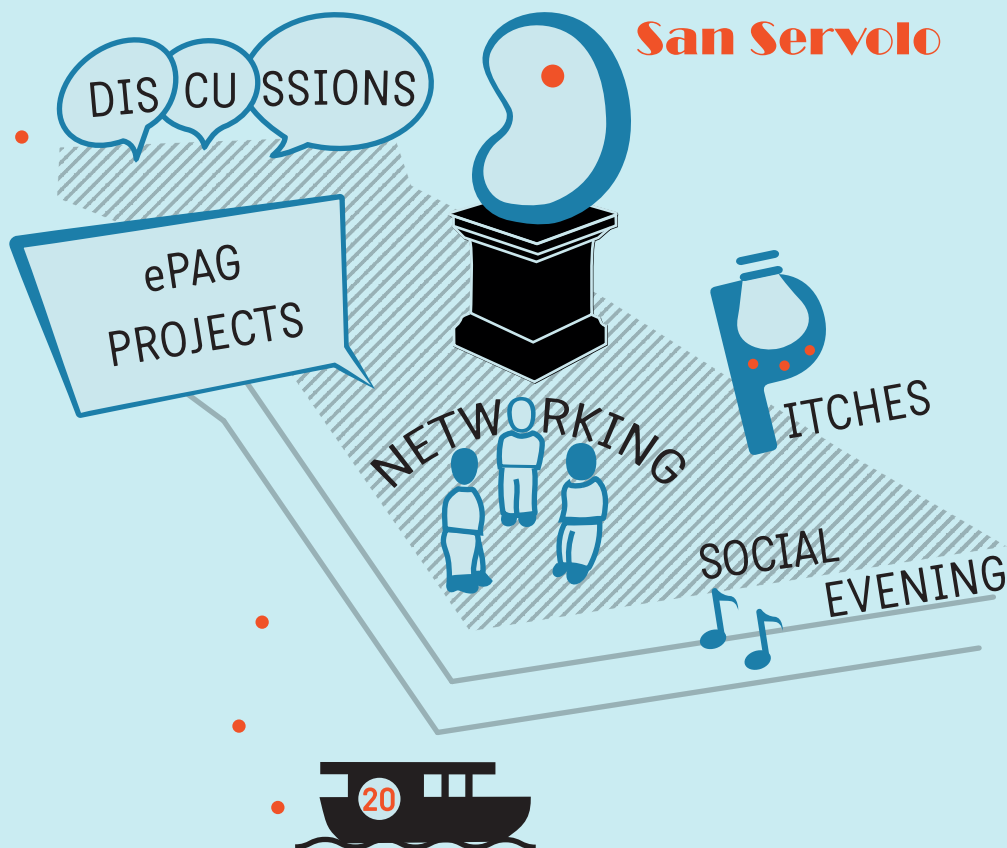


8th
Annual

ERKNet MEETING

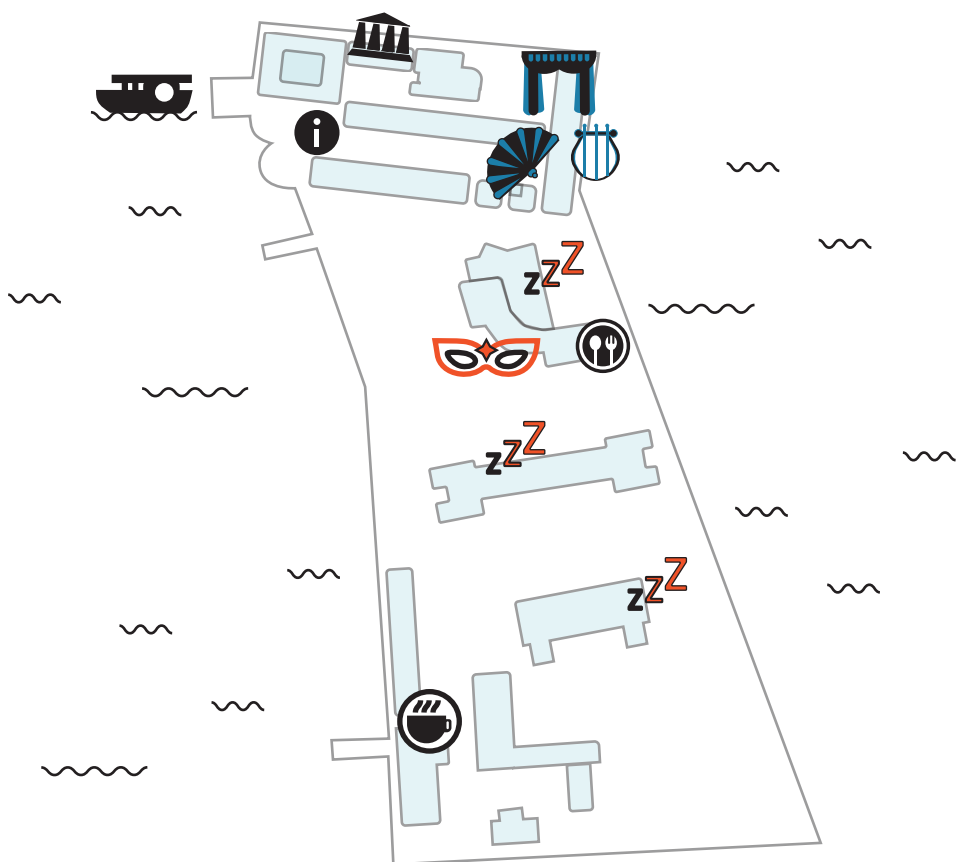
22.-24. APRIL 2024

San Servolo



• Lido

Mappa di San Servolo



Legenda della carta



Information



Waterbus Station



Auditorium



Restaurant



Hotel



Room 6



Breakfast



Social Evening



Room 7



Historic Museum



MONDAY, 22nd of April 2024

13:00 • • • 17:30

ePAG Meeting

ePAGs + Patient engagement managers



13:00 • • • 15:00

ERKReg Board

ERKReg Board members



15:00 • • • 15:30

COFFEE BREAK



15:30 • • • 17:30

ExCom Meeting

ExCom members



17:30 • • • 18:15

Patient Involvement in Guidelines

Matt Bolz-Johnson (EURORDIS)



TUESDAY, 23rd of April 2024

08:00 • • • 08:40

Network Board meeting

HCP Leads – 1 HCP representative only



08:55 • • • 09:20

Welcome and Overview

Franz Schaefer (15 min)

Susana Carvajal, Uwe Korst (10 min)



09:20 • • • 11:00

Updates on ERKNet activities I



09:20 • • • 09:40

ERKReg Update + registry analysis

Jose Ramirez, Jonas Hofstetter

09:40 • • • 10:05

Subregistry Update

Joanna Sladowska (CompCure + EscapeKD)

Dieter Haffner (SLE)

Aude Servais (EUROCYS)

Karl-Peter Schlingmann (Bartter)

Francesco Emma (dRTA)

10:05 • • • 10:15

Digital Histopathology Archive

Eyal Rahmani



TUESDAY, 23rd of April 2024

10:15 • • • 10:30

Clinical Exchange und Research Exchange - Concept
Stefanie Häberle

10:30 • • • 10:45

CPMS – ERKNet Hotline
Alicia Armbruster

10:45 • • • 11:00

Patient-initiated projects in ERKNet: past and future activities
ePAG Chairs

11:00 • • • 11:25

COFFEE BREAK + POSTER SESSION



11:25 • • • 12:45

Best Research Abstract session (~8 mins each)
Moderator: Karolis Ažukaitis



Childhood ADPKD: Insights from the ERKReg and ADPedKD registry
Djalila Mekahli

Kidney abnormality and outcome of renal function in patients with KABUKI syndrome
Eloise Colliou (virtual)

From Biomarker to Clinical Insight: The Role of Anti- β -2-glycoprotein I Domain 1 in LN with aPL-related Injuries
Savino Sciascia

Characterization of Monogenic Kidney Disease in Older Patients with CKD
Elhussein Elhassan

The role of genetics and environment in ADPKD course and Tolvaptan therapy: Real life monocentric experience
Floriana Secondulfo

Rapid Nephrogenomic for complement mediated TMA diagnosis and early intervention in a renal intensive care unit using Nanopore technology
Nadhir Yousfi

Exome sequencing in a cohort of patients affected with nephrono-phthisis-like NP identified 6 phenocopies and 1 candidate gene
Friederike Petzold

ADPKD-IFT140: clinical presentation and prognosis through a large European cohort
Nikola Zagorec



TUESDAY, 23rd of April 2024

PRPF8 and genes encoding for the EDD1-DYRK2 DDB1-VprBP-complex as potential novel ciliopathy candidate genes, phenocopying CAKUT

Floriana Secondulfo

Investigating genetic and environmental modifiers of ADPKD through a distinct PKD2-founder variant (p.Arg803*)

Julia Münster

12:50 ••• 13:00

GROUP PICTURE

13:00 ••• 13:50

LUNCH



13:50 ••• 14:25

Clinical Abstract Session (8 mins each)
Moderator: Jaap Mulder



Deep phenotyping by SAMS

Dominik Seelow

Ultra-rare monogenic kidney dysplasia mimicking salt-losing tubulopathy caused by TFCP2L1 gen pathogenic variants

Manuel Grana Vaqueiro

A case of AR tubular dysgenesis successfully surviving with neurosensory hearing loss due to two different and independent mutations

Maria-Paola Ferrante

SGLT2 inhibitors as a treatment for Fanconi-Bickel syndrome: a case report

Viola D'Ambrosio

14:25 ••• 16:00

Updates on ERKNet activities II



14:25 ••• 14:40

Social Media and Website

Anna Dengler, Hanna Azham

14:40 ••• 15:00

Patient Information

Stefanie Häberle, Alicia Armbruster

15:00 ••• 15:20

Evaluation (CEMS & CAMS)

Alicia Armbruster

15.20 ••• 15:45

Education

Stefanie Häberle



TUESDAY, 23rd of April 2024

15.45 ••• 16:00

Guidelines and Guideline App Update

Tanja Wlodkowski

16:00 ••• 16:30

COFFEE BREAK + POSTER SESSION



16:30 ••• 18:00

Working Group highlight project pitches (10 min each)
Moderator: Ana Teixeira



RHINE Project (Metabolic NP WG; virtual)

Shabbir Moochhala

Treatment pattern of HUS patients (TMA WG)

Alexandra Vujović

ADTKD project (AD structural disorder WG)

Jan Halbritter

NDI Guideline recommendations (Tubulopathy WG)

Elena Levchenko

NPHS2-related glomerulopathy (Hereditary Glomerulopathies WG)

Beata Lipska

Impact of Clinical Practice Recommendations on KPI (PedCKD & Dialysis WG)

Justine Bacchetta

Breaking news on IgA nephropathy (Immune Glomerulopathies WG)

Jürgen Floege

Incidence and time-varying determinants of graft failure after ped kidney re-transplantation in Eurotransplant area (PedTx WG)

Agnieszka Prytula

Patient education via ChatGPT? (CAKUT WG)

Stefan Kohl

19:00 ••• 21:30

**WELCOME RECEPTION WITH FREE
FOOD AND MUSIC**





WEDNESDAY, 24th of April 2024

08:00 • • • 09:30

Immune GP

Dieter Haffner, Jürgen Floege, Claire Dossier



Tubulopathies

Tom Nijenhuis, Gema Ariceta, Martin Konrad



AD Structural Disorders

Olivier Devuyst, Djalila Mekahli, Jan Halbritter



09:30 • • • 11:00

Hereditary GP

Kalman Tory, Roser Torra, Beata Lipska



Metabolic NP

Elena Levtchenko, Aude Servais, Jaap Groothoff



Ped CKD/Dialysis

Claus Peter Schmitt, Justine Bacchetta, Jerome Harambat



11:00 • • • 11:30

COFFEE BREAK + POSTER SESSION



11:30 • • • 13:00

CAKUT + Ciliopathies

Albertien van Eerde, Ana Teixeira, Stefan Kohl



TMA

Nicole vandeKar, Savino Sciascia, Marina Vivarelli



EURORDIS feedback session

Vera Cornelius, Valentina Neukel



13:00 • • • 13:15

WRAP UP

Franz Schaefer



13:15 • • • 14:15

LUNCH



Venezia

San Zaccaria



Waterbus Timetable

DEPARTURE TIMES ONLY

SAN SERVOLO 7:05 7:45 8:30 8:50 9:10 9:40 10:00 10:50 11:20 12:10 12:40 13:30 14:00 14:50
15:30 16:10 16:50 17:30 18:00 18:45 19:20 20:00 20:40 21:40 22:40 23:40 00:40

SAN ZACCARIA

SAN ZACCARIA 6:55 7:15 8:10 8:40 9:00 9:20 9:50 10:30 11:10 11:50 12:30 13:10 13:50 14:30
15:10 15:40 16:30 17:10 17:50 18:10 19:10 19:50 20:30 21:30 22:30 23:30 00:30

SAN SERVOLO

SAN SERVOLO 15:55 18:20

LIDO

LIDO 9:10 16:00 19:35

SAN SERVOLO

LINIA 20

10
MIN

DURATION EACH WAY



Funded by
the European Union



ERKNet

The European Rare Kidney Disease Reference Network