

O|X|A|L|EUROPE

The European hyperoxaluria consortium primary
hyperoxaluria registry

Bernd Hoppe, MD

Disclosure: no financial interests to declare

To make a long story short:

OxalEurope had decided to built up a pan European database on patients with primary hyperoxaluria

Obviously this was a great challenge

We received generous sponsorship from the OHF

Future aim: merging current databases into an international PH registry

What did we achieve now:

We now have an SQL based online PH registry

We have full support and maintenance and monitoring opportunities

We got all our “old” 526 PH I patient (retrospective) data into the database and included new, also PH II and III patients

We got a positive IRB vote and positive vote of the security control services in the land of registration (here Germany)

Future plans:

Delivery of all PH II and PH III datapoints into registry

Addition of routine follow up data into the registry

Make upload of follow up data, e.g. imaging available

Produce interchange with RKSC (and CERTAIN) registries

Enable members of OxalEurope to use registry data for studies/research

First steps

Inform patient and/or parents about the registry and its purposes

Receive signed informed consent

Country specific

Physician's registration to registry via website

Get login details via email



The screenshot shows the website **ph-registry.net**. At the top, there are navigation links for "Startseite", "Impressum", and "Login/Logout". Below the header, the text "Kontaktieren zur Studie" is followed by a message in German: "Liebe Kollegen und Kollegen. Herzlichen Dank, dass Sie an der Studie teilnehmen möchten! Bitte füllen Sie folgende Daten vollständig aus. Die abgefragten Informationen sind zur Sicherung der Qualität- und Authentizität der Daten erforderlich." Below this is a form for "Ärztin/Arzt:" with input fields for "Titel:", "First name:", "Surname:", "E-mail:", "Clin:", "City:", and "Country:". At the bottom of the form are "Senden" and "Zurücksetzen" buttons. On the right side, there is a logo for "Division of Hypertrophia Foundation" and "OXIAL EUROPE". At the bottom of the page, it says "Wir support: www.kidneyweb.de".

ph-registry.net

Login Studie

Dear colleagues,

we appreciate, that you would like to participate in the OxalEurope primary hyperoxaluria registry. This registry is open for all patients with either form of primary hyperoxaluria, wherever they reside and wherever they are treated.

Please register first to be eligible for data input. The information you have to provide for registration is necessary to ensure quality and authenticity of the data input. After registration, you will receive an email from us indicating your login details.

Many thanks for your interest and help,

Bernd Hoppe, Coordinator

[Registration](#)

[Login](#)

With kind support of



and

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Organization

All participants can see their own data input

Summary and data overview provided



The screenshot displays the 'ph-registry.net' website. At the top, there is a blue header with the text 'ph-registry.net'. Below the header, the page is titled 'OxalEurope PH-Registry'. There are three main sections, each with a table and a 'New' button:

- Visits:** A table with columns 'ID', 'Date_of_visit', 'Age', 'Sex', and 'Timestamp'. It contains 10 rows of data.
- Transplantation:** A table with columns 'ID', 'Number_of_transplants', 'Type_of_transplantation', and 'Timestamp'. It contains 2 rows of data.
- BB Trial:** A table with columns 'ID', 'Date_of_start', 'Sex', 'Trial_name', and 'Timestamp'. It contains 2 rows of data.

On the right side of the page, there is a logo for 'OxalEurope' with the text 'With kind support of Children & Hyperendokrinology Foundation'.

One country specific supervisor can see all country specific data

OxalEurope steering committee will receive overview of all data entries

Quarterly newsletter (planned)

How does it look like:

www.oxalEurope.eu/studie2/phregresult4.php5

ph-registry.net

OxalEurope PH-Registry
Thank you for participating in the OxalEurope primary hyperoxaluria registry.

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Visits

Transplantation

B6 Trial

Further Patient

Clinical Trial

My Patient-Data

LogOut

www.oxalEurope.eu/studie2/b6.php?id=321

ph-registry.net

OxalEurope PH-Registry

Pyridoxal phosphate is an essential cofactor for aminotransferases such as AGT, and pharmacologic doses of pyridoxine are able to significantly reduce (by at least 30%) hyperoxaluria in one-third of patients. For assessment of pyridoxine responsiveness, reliable baseline values (a minimum of three) for urinary oxalate excretion are required. Pyridoxine medication is then installed with stepwise increases of 5 mg/kg (from 5 to 20 mg/kg body weight per day) and urinary oxalate excretion, or plasma oxalate levels are determined consecutively. Please also determine the serum pyridoxine level to acknowledge correlation of serum B6 with urinary or plasma oxalate levels. Significant reduction of oxalate levels show response to dosage and help to calculate the necessary daily dosage.

Mit freundlicher Unterstützung von

und
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B6:	
Date of start B6:	
B6 trial done:	.select: <input type="checkbox"/>
Date of end of trial:	
Response to B6:	.select: <input checked="" type="checkbox"/>
Uox before B6:	
Unit:	.select: <input checked="" type="checkbox"/>
Ucreat before B6:	
Unit:	.select: <input checked="" type="checkbox"/>
Uox with 5 mg/kg/day/B6:	
Unit:	.select: <input checked="" type="checkbox"/>
Ucreat with 5 mg/kg/day/B6:	
Unit:	.select: <input checked="" type="checkbox"/>
Uox with 10 mg/kg/day/B6:	
Unit:	.select: <input checked="" type="checkbox"/>
Ucreat with 10 mg/kg/day/B6:	
Unit:	.select: <input checked="" type="checkbox"/>
Uox with 15 mg/kg/day/B6:	
Unit:	.select: <input checked="" type="checkbox"/>

Current numbers

Database PH-Registry					
Country	PH type 1	PH type 2	PH type 3	unknown	total
France	162	0	2	3	167
Germany	133	5	23	0	161
UK	137	21	0	2	160
Italy	74	0	0	0	74
Netherlands	75	0	0	0	75
Spain	15	0	0	0	15
Poland	8	0	4	0	12
Sweden	3	0	0	0	3
Total in registry					667

Message for patients and parents:

Such a registry will help to better understand the primary hyperoxalurias

It will help to foster further research and enables to better recruit and find patients for studies

It will, when merged with other databases, bring all PH researchers together for the benefit of the patients

It will help pharmaceutical companies to gain long term follow up data needed for their own regulatory requirements

Hence,

please support our OxalEurope
PH registry in any matter....