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EURODIS

Rare Diseases Europe



RARE DISEASE DAY.ORG



RareConnect.org
A EURODIS INITIATIVE



RARE
DISEASES
INTERNATIONAL

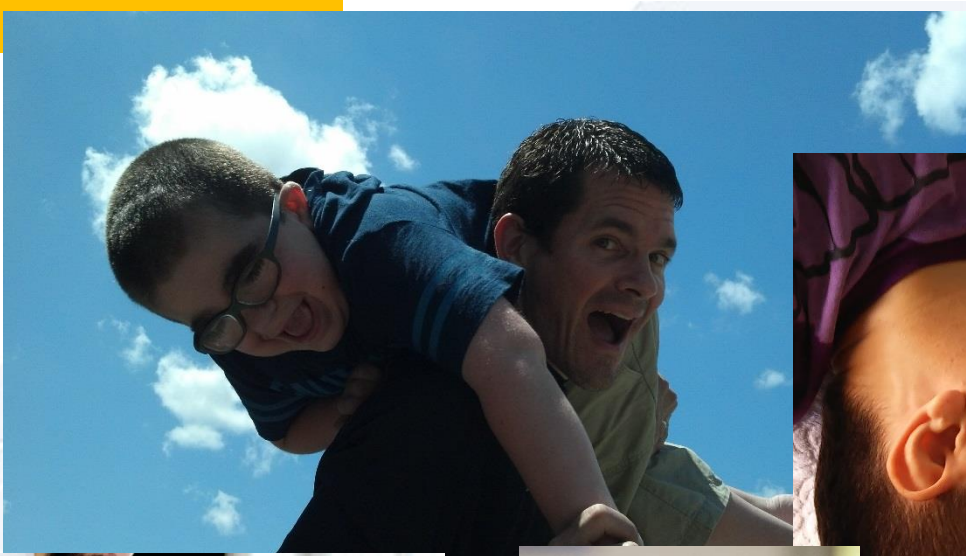
A EURODIS INITIATIVE



A EURODIS INITIATIVE



Photos submitted to the EURORDIS Photo Contest





EURORDIS Summer School 2016



EURORDIS Staff



European Conference on Rare Diseases & Orphan Products 2016



Rare diseases meeting, Barcelona, 2016



RARE DISEASE DAY 2017
28 FEBRUARY

[ABOUT THE DAY](#)

[EVENTS WORLDWIDE](#)

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117 DAYS
TO GO



RESEARCH BRINGS HOPE!

Find out more about this year's
theme: RESEARCH

[>> FIND OUT MORE](#)



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2017 EVENTS

Country



EURORDIS AWARDS

EURORDIS-Rare Diseases
21 Feb 2017 Brussels, Europe

[+ READ MORE](#)



MULTI-STAKEHOLDER SYMPOSIUM ON

This exceptional two-day
22 Feb 2017 - 23 Feb 2017 Brussels, Europe

[+ READ MORE](#)

BLACK DEADL EVENING



OUT NOW

2016 RARE DISEASE DAY VIDEO!

Rare Disease Day



- Held on the last day of February each year
- An occasion to raise public and policy-maker awareness of rare diseases
- Participation in 85 countries and regions in 2016 –
 - 9 new countries: Andorra, Aruba, Indonesia, Libya, Mauritius, Moldova, Tanzania, Uganda, Zimbabwe, Bolivia & Madagascar
- Rare Disease Day 2017 theme:

Research



JOIN NOW ▾

EN ▾



Connecting rare disease patients globally

START A COMMUNITY FOR A RARE DISEASE IN PARTNERSHIP WITH US.

JOIN NOW (it takes 30s)

SEE HOW IT WORKS

Search for a rare disease community or discussion group

Search

ABOUT RARECONNECT

A safe, easy to use platform where rare disease patients, families and patient organizations can develop online communities and conversations across continents and languages. RareConnect partners with the world's leading rare disease patient groups to offer global online communities allowing people to connect around issues which affect them while living with a rare disease. [More information](#)





RARE
DISEASES
INTERNATIONAL

A EURORDIS INITIATIVE



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discussion



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About RDI ▾

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News & Events ▾

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What is RDI

RDI is the global alliance of people living with a rare disease of all nationalities across all rare diseases.

RDI brings together national and regional rare disease patient organisations from around the world as well as international rare disease-specific federations to create the global alliance of rare disease patients and families.

RDI is an international network currently embedded in EURORDIS, which supports the development of RDI. It is governed by a Council, elected by RDI members in April 2016. In coming years the Council and members of RDI will decide if and when to register RDI as a separate organisation with its own legal identity. The initial focus is on taking action and gaining experience of working together.



Become a member

See [RDI Members](#)



Tweets by @rare diseasesint

RDI
@rare diseasesint
RDI Action Plan Webinar eurordis.org/tv?vld=1114&cl...
01 Nov

RDI
@rare diseasesint
A turning point in the history of SBH



- **What is Rare Diseases International (RDI)?**

An initiative aiming to create an informal network of rare disease patient organisations to form a **global alliance** representing patients & families of all nationalities across all rare diseases.

- **Who is involved?**

RDI is a EURORDIS initiative with National Alliances around the world with whom we have signed partnership agreements (MoUs).

Nearly 40 members around the world

- **Why Rare Diseases International?**

- To enhance capacities of *Rare Diseases International* members through information, exchange, networking, mutual support, joint actions
- To represent its members & people living with rare diseases internationally
- To promote RDs as an **International Public Health & Research priority** through public awareness and policy (+280 million people living with rare diseases around the world)

Rare Barometer Voices eurordis.org/voices

EURORDIS.org > [Rare disease Policy](#) > [Rare Barometer](#)

Choose language ▼



[Why join us?](#)

[Who can register?](#)

[How does it work?](#)



1

Register to Rare
Barometer Voices



2

Receive invitations
to surveys



3

Take part
in the surveys

[Register now](#)

Why join us?

The European Conference on Rare Diseases & Orphan Products

Rare-diseases.eu



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English

ECRD 2016 : The European Conference on Rare Diseases & Orphan Products

26 to 28 May 2016
Edinburgh



[Programme](#)

[Posters](#)

[Register](#)

[Hotel & Travel](#)

[Networking](#)

[Exhibits & Support](#)

[Infos & Downloads](#)

Game Changers in Rare Diseases
Delivering 21st century healthcare to rare
disease patients: Together we can
change the future!

[Videos of the plenary sessions and speakers' presentations](#)

[Posters available](#)

[Executive Summary ECRD 2016](#)

Search



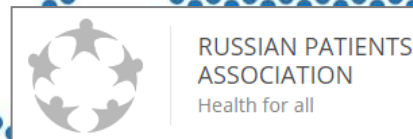
Register



Quick links

[Executive Summary ECRD](#)

EURORDIS partnerships around the world



EURORDIS Members around the world

(Not including members of Rare Diseases International)

Algeria
Argentina
Armenia
Australia
Austria
Belarus
Belgium
Benin
Brazil
Bulgaria
Burkina Faso
Canada
China
Colombia
Croatia
Cyprus
Czech Republic
Denmark
Estonia
Finland
France
Georgia

Germany
Greece
Guatemala
Hong Kong
Hungary
Iceland
India
Iran
Ireland
Italy
Japan
Kazakhstan
Latvia
Lebanon
Lithuania
Luxembourg
Malaysia
Mexico
Morocco
Nepal
Netherlands
New Zealand

Norway
Poland
Portugal
Romania
Russia
Serbia
Singapore
Slovakia
Slovenia
South Africa
Spain
Sweden
Switzerland
Taiwan
The Former Yugoslav Republic of Macedonia
Turkey
Ukraine
UK
USA
Uruguay

