Zrzut strony: http://www.eurordis.org/ <--kliknij na adresie

Living with a Rare Disease

New e-learning module on statistics for clinical research

Participate in EURORDIS' survey on registries

Clinical Added Value of Orphan Medicinal Products (CAVOMP)

Who we are

EURORDIS is a non-governmental patient-driven alliance of patient organisations representing 537 rare disease patient organisations in 49 countries.

Read our mission statement

What are you looking for:

Social Networks

EURORDIS - European Rare D

Like

3,137 people like EURORDIS - European Rare Dis

Katia, Maria Fernai, Fonny, Alexander, Leticia

Tweets

Rare Diseases Europe
@eurordis
Today is IPPOSI's Information Day: Patients' On
Expand

NORD
@RareDiseases
Patient orgs are sharing their stories at a press
Retweeted by Rare Diseases Europe

Tweet to @eurordis

Featured patient organisation

CDG: Two stories, one shared hope

Liliana and MP were born 27 years apart. Their stories show us the progress and development achieved in nearly 30 years.

read more...

Featured Events

ESGCT and SFTCG Collaborative Congress 2012

October 26-29, Versailles, France, esgct.eu

read more...

Members' Corner

Rett Syndrome Europe General Assembly 2012

Rett Syndrome Europe General Assembly 2012, London, novemnber 17, 2012
www.rettsyndrome.eu/rse-general-assembly-2012/

rse General Assembly November 17, LONDON

read more...

RareConnect

A social network of Rare Disease Communities led by NORD and EURORDIS in partnership with leading disease-specific patient groups. List of Rare Disease Communities:

- Alkaptonuria (AKU)
- Alström Syndrome
- Alternating Hemiplegia
- Atypical Hemolytic Uremic Syndrome
- Behçet's Syndrome
- CAPS
- CDG
- Cystinosis
- Dravet Syndrome
- DysNet, Dysmelia - Limb Differences
- Ehlers-Danlos Syndrome
- Epidermolysis Bullosa
- Evans Syndrome
- Familial Mediterranean Fever
- Fibromuscular dysplasia
- Glut1 DS
- Hereditary Spastic Paraplegia
- Lipoprotein Lipase Deficiency
- Mastocytosis and Mast Cell Activation Disorders community
- Waldenstrom macroglobulinemia
- Multiple Myeloma
- Multiple system atrophy
- Moebius Syndrome
- Narcolepsy
- Neuroacanthocytosis
- Paraneoplastic Neurological Syndromes
- Pulmonary Hypertension
- Trimethylaminuria
- Von Hippel-Lindau
- Waldenstrom macroglobulinemia

eNews

Find out the latest news from the rare disease community!

Email:

Subscribe to our eNews

Now available in Russian!

Rare Disease Blog

Sept 21, 2012: EURORDIS intervention at Dutch Healthcare Insurance Board public hearing Mon, 01 Oct 2012 - Amsterdam – 21 September 2012: Intervention of Yann Le Cam on behalf of EURORDIS at the...

Argument of the Academic Medical Center in response to the preliminary advice from the Dutch Healthcare Insurance Board (CVZ) to stop reimbursement of Fabrazyme and Replagal Mon, 24 Sep 2012 - Public meeting of the advisory committee at the office of the Dutch Healthcare Insurance...

Sept 21, 2012: Update (Part IV, conclusion) to the ongoing Pompe and Fabry situation in the Netherlands Mon, 24 Sep 2012 - Friday September 21, 2012 the Appraisal Committee (Adviescommissie Pakket, ACP) of the...

Access to Medicine: A Campaign for Rare Disease Patients to access treatments Wed, 19 Sep 2012 - On Wednesday the 12th, we attended a panel debate regarding the lack of drug development...

WE ARE GRATEFUL FOR THE FINANCIAL SUPPORT OF THE EURORDIS WEBSITE BY :

AFM TELETHON
Executive Agency for Health and Consumers
leem Fondation