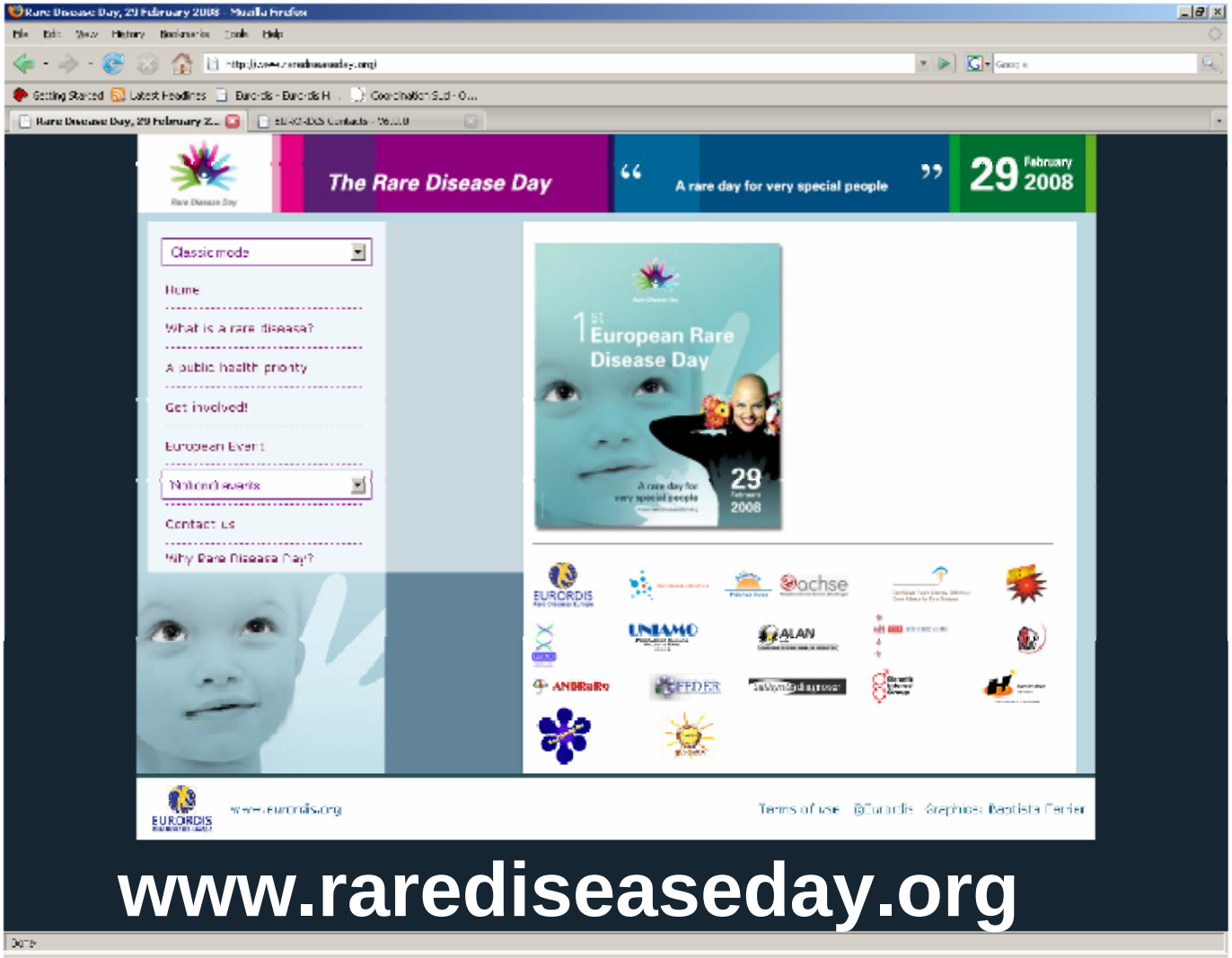
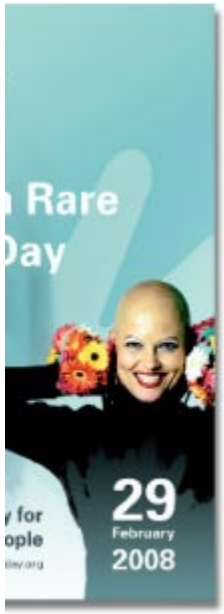
Rare Disease Day 2008



Rare Diseases Organisation Belgium

RaDiOrg.Be is the Belgian Rare Disease Alliances recognized by EURORDIS Rare Diseases Europe

Member of EURORDIS Rare Diseases Europe



Contact NL :
Ortolans 62
1170 Brussel
info@radiorg.be
Tel : 0498/70 15 03 (Lut De Baere)

- Persmap 'Zeldzame Ziekten Dag 29/02/2008'
- Radiorg.be, Kort
- Radiorg.be, Logo-duiding
- Enkele gegevens van Radiorg.be
- Wat is een zeldzame ziekte?
- Organisaties voor zeldzame ziekten in België
- RaDiOrg.Be in de pers

Contact FR :
Ortolans 62
1170 Bruxelles
info@radiorg.be
Tel : 0495/68 23 48 (Yvonne Jousten)

- Dossier presse 'Journée des Maladies Rares' 29/02/2008
- Radiorg.be, En bref
- Radiorg.be, Explication du logo
- Quelques données de Radiorg.be
- Qu'est-ce qu'une maladie rare?
- Des organisations pour des maladies rares en Belgique
- RadiOrg.be dans la presse

ELIOTT'S EVENT

Deze website kwam mede tot stand dankzij de steun van Eliott's Event
Ce site Web a pu être réalisé grâce au parrainage de l'asbl Eliott's Event

Rare Disease Day

In Canada

- **8-page national newspaper insert** (circulation of 1.7 million) devoted to rare disorders and the Canadian Organization for Rare Disorders. **12 stories** profiling various diseases, individuals, researchers, clinicians, and research companies.

- **Press conference** at National Press Gallery to start day on 28 February with several Members of Parliament and other distinguished guests in attendance. Keynote from our **Member of Parliament who lost a grandson to rare disorders** and is our **champion.**

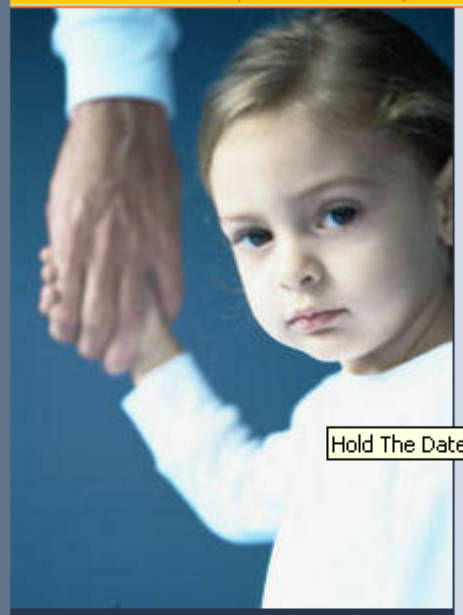
- **Day of Action on Parliament Hill** with over **30 volunteers having individual meetings with 65 Members of both Senate and House of Commons**. We received very positive response for our **proposal to create a national "Chance for Life Fund" for rare disorders**. Many of the MPs will follow up with letters to the Health Minister and government.

- A **motion** for Parliament to consider establishing a rare disorders program was raised in the House of Commons. There should be a vote on moving forward with investigation in the next week or two. This is a tremendous step forward since Canada has no official definition of rare disorders or diseases.

- There have been nearly 1,000 responses to our **appeal** for the public to write to their Members of Parliament to establish the **Chance for Life Fund**.

- 5 out of 10 provinces issued an official **Royal Proclamation** of February 29th as Rare Disease Day

- A **one-hour show** on Rare Disorders featured CORD's treasurer, together with a patient and a parent on **national TV**. This, and local TV and radio interviews in various cities generated numerous phone calls and visits to CORD's website.



Welcome to CORD

1st International Rare Disease Day - February 29, 2008

" A Rare Day for Very Special People"

Make Feb 29, 2008, 1st International Rare Disease Day, the start to a "Chance for Life" for Canadians with Rare Disorders.

Ask your Member of Parliament to support the Chance for Life Fund.

Patients, family members, and friends are travelling to Ottawa to present a proposal for a "Chance for Life" fund. This fund will support treatment for Canadians with severe and life-threatening rare disorders. Please urge your Member of Parliament to support this very important initiative.

Please join us in Ottawa on Thursday February 28th for a "Day of Action."

To send a letter or email to your local MP, please click here.

"A Chance for Life Fund"

Canada is one of the only developed countries in the world that does not have an orphan drug policy. Not only does Canada not support research and development into treatments for rare and neglected disorders, Canadian patients with rare disorders often do not have the same access to life-saving therapies as patients in other countries. CORD requests immediate action on the following proposals.

· Establish a national (federal/provincial/territorial) "Chance for Life Fund" equivalent to 2% of the total annual public drug expenditure to be designated for therapies for rare disorders.

· Establish a multi-stakeholder Advisory Body, including treaters (medical caregivers) and patients, to recommend treatment access for life-threatening or serious rare disorders based on scientific standards and social values (humanitarian, ethical and compassionate criteria).

· Establish Centers of Reference for specific rare disorders, comprised of national and international experts, who will develop criteria for treating patients based on scientific evidence and patient impact and provide on-going surveillance into the real-world safety and effectiveness of these treatments on individual and group basis.

· Provide incentives through Orphan Drug Regulation and policy equivalent to those in the

SHARE YOUR PHOTO!
SHARE YOUR STORY!
For more information, please click here.

CLICK HERE TO READ *The LINK* 2007 NEWSLETTER

Mission Statement

Through an educational and information support network, CORD is committed to the enhancement of the lives of all persons affected by rare

Rare Disease Day

In Denmark

- A **film** with two Danish children suffering from rare diseases and the Crown princess Mary was produced. The film was shown on **prime time** on one of the two leading Danish TV-channels. One and a half hour before the film was shown there was an **interview** with one of the families in the "early evening show" on the same channel.

- On the other leading Danish TV channel, Rare Disorders Denmark was "advertising“ a **trailer**, during two weeks twice a day every day, educating about the problems rare disease patients face and referring them to Rare Disorders Denmark. You can see this trailer on the Internet http://www.dr.dk/dr1/obs.

- Rare Diseases is the theme in the February issue of “**Health” magasine,** which is distributed in all **Danish pharmacies**.

- Two-page article in one of the **leading Danish newspapers** and in several local newspapers and the General Director of the national alliance was interviewed by four journalists.

- The **conference** on the 29th was completely sold out!

- There were over 1000 people at the **march**. There was media and press coverage.

www.29februar.dk - Mozilla Firefox

File Edit View History Bookmarks Tools Help

http://www.29februar.dk/

Getting Started Latest Headlines Eurordis - Eurordis H... Coordination Sud - O...

Rare Disease Day, 29 February 2008 | EURORDIS Contacts - V6.0.0 | www.29februar.dk

29februar.dk

- Nyheder
- Om Sjældne Diagnoser
- Det mener vi
- Medlemsforeninger
- Fokusområder
- Værd at vide
- Udgivelser
- Interne sider
- Links

Søg

Velkommen til Sjældne-dagens kampagnesite.

Formålet med Sjældne-dagen er at sætte fokus på de sjældne sygdoms- og handicapgrupper på den sjældneste dag.

Program for Sjældne-dagen:
Kl. 9:00 - 16:00 Konference "Et sjældent godt liv" Program (pdf)
Kl. 16:00 - 17:00 Sjældne-march, hvor du kan "gå-penge-hjem" til en forening Læs mere
Kl. 17:00 Kronprinsesse Mary overrækker Sjældne-prisen Læs mere

Detaljeret program: klik her

Støt sjældne-sagen på Sjældne-dagen

Tirsdag den 26. februar 2008 viste TV2 filmen **Mads, Marie og Kronprinsessen** i anledningen af Sjældne-dagen. Læs mere og se billeder fra filmen

Sjældne Diagnosers OBS-indslag på DR1

Hovedsponsorer:

SWEDISH ORPHAN genzyme

Fortæl din sjældne historie og læs andres - klik her

Få en Sjældne-pakke - klik her

Øvrige sponsorer - **klik her**

Samarbejdspartner: **Center for Små Handicapgrupper**

Sjældne Diagnoser | Frederiksholms Kanal 2, 3. | 1220 København K | Tlf: 33 14 00 10 | E-mail: mail@sjaeldnediagnoser.dk

Done

Rare Disease Day

In France

- At the **Press Conference**, which took place on Feb 27th at the Groupama for Health Foundation in Paris, the following topics were discussed:

- European Rare Disease Policy –Ségolene Ayme Rare Disease Task Force

- The French dynamic on Rare Diseases and its impact on other European countries' Rare Disease policies – Christel Nourissier, Secretary General of Eurordis

- An example of European Rare Disease Network (Porphyria)

- Rare Diseases in France, spokesperson for the French RD Alliance

Children’s drawing competition for RD Day

Alliance Maladies Rares

- Accès Membres & conseillers nationaux
- Questions/Réponses
- Liens Utiles
- Partenariats
- Newsletter

Votre e-mail ok

s'abonner
se désabonner

À la Une

vendredi 29 février 2008

Rare Disease Day

6 000 maladies rares
30 millions d'européens concernés
Un enjeu majeur de santé publique

Un jour rare entièrement consacré aux maladies rares ? C'est enfin une réalité !

Le **29 février 2008**, l'Alliance Maladies Rares, collectif français de 181 associations, sous l'égide d'EURORDIS, fédération regroupant 34 pays, organise la **1ère Journée européenne des maladies rares**.

Lire la suite

Actualités

1ère Journée européenne des maladies rares

Date de parution: 7 février 2008

Ni Pauvre Ni Soumis

Date de parution: 18 février 2008

Consultation publique sur une action européenne dans le domaine des maladies rares

Date de parution: 8 janvier 2008

Plus d'actualités

Coups de cœur

15/02/2008 : Appel à projet de la Fondation Roche

25/10/2007 : Premier forum maladies rares à Marseille

08/11/2007 : Premier forum maladies rares à Nice

Plus de coups de coeur

Agenda

21/02/2008 : Colloque « Lutte contre le cancer : état des lieux et perspectives »

28/01/2008 : Colloque sur la certification des sites santé

Plus de dates

Pour écouter, informer et orienter malades, proches de malades et professionnels de santé :
Maladies Rares Info Services
0 810 63 19 20 (numéro Azur, prix d'un appel local) est disponible du lundi au vendredi, de 9h à 18h

AFM

L'Alliance Maladies Rares bénéficie du soutien de l'Association Française contre les Myopathies

Rare Disease Day

In Germany

In an official celebration, the first **“Eva Luise Köhler Research Award for Rare Diseases”** was granted by Eva Luise Köhler, the wife of the President of Germany and patroness of the ACHSE, the German Alliance for Rare Diseases.

The **price** is granted by the “Eva Luise and Horst Köhler Foundation for Rare Diseases”

At the awarding ceremony Stephen Groft of the NIH (Office of Rare Diseases - USA) was a special guest and part of a discussion
on the importance of research.

Eva-Luise Köhler (l) mit
Prof. Dr. rer. nat. H.-J. Galla (M)
und Prof. Dr. med. Volkmar Gieselmann (r)

Classic mode

ome

/hat is a rare disease?

public health priority

et involved!

uropean Event

National events

ontact us

/hy Rare Disease Day?

achse
Allianz Chronischer Seltener Erkrankungen

Germany - ACHSE Allianz Chronischer seltener Erkrankungen

Erster europäischer Tag der Seltenen Erkrankungen

Ein seltener Tag für außergewöhnliche Menschen

SUPPORT MESSAGE OF EVA LUISE KÖHLER

Patroness of ACHSE - The German Alliance for Rare Disease

People living with a rare disease need our support. A proper diagnosis within a reasonable time frame, the best possible treatment and adequate medication is not self-evident for many of them. Our society should take on the challenge of changing this: by improving the knowledge on rare diseases, by furthering research for better and different treatment, by improving the standards of care and by understanding the specific needs of those affected.
As patroness of ACHSE and as Head of the Board of the Eva-Luise-and-Horst-Köhler-Foundation for Rare Diseases I bit you to join this cause and to support those living with one of these many diseases. They need help from friends and family, from politicians, doctors, scientists, insurers and so on, from neighbours and passers-by, from you and me. If we join forces we can contribute to a better life for many.
I therefore fully support the Eurordis' initiative of celebrating a European Rare Disease Day on the 29th of February and hope that it will lead to more awareness of the difficulties people living with a rare disease are confronted with.
Eva Luise Köhler

Activity Highlights:

In an official celebration the first “Eva Luise Köhler Research Award for Rare Diseases” will be granted by Eva Luise Köhler, the wife of the President of Germany and patroness of the ACHSE, the German Alliance for Rare Diseases. The price is granted by the “Eva Luise and Horst Köhler Foundation for Rare Diseases” At the awarding ceremony Stephen Groft of the NIH (Office of Rare Diseases - USA) will be a special guest and part of a discussion on the importance of research. The celebration will be followed by a speech of Dr. Stephen Groft on "Research Perspectives for Rare Diseases in the USA as part of a global approach" and debate.

The first school project on rare diseases will start in Berlin. In the Private-Kant-Schule the children will be addressing the problems and needs of people living with a rare disease. The idea of the project is also to gather

Rare Disease Day

In Greece

- **Press Conference** in the press-room of the Ministry of Health and Social affairs about NPRD.
- **TV spot** appeared on 10 national TV channels and a **radio spot** with the voice of a very well-known Greek actress that played in all radio stations for 20 days
- **Information material**, leaflet, dossier, poster
- Presentation to specific social-interest **TV programs**
- Awareness event in a central place in Athens
- Announcement of the winners of a **Writing competition** at schools (ages 12-17) all over Greece running on January 2008, with the subject "rare diseases"
- A **reception** was held by H.E. The President of the Hellenic Republic Dr Karolos Papoulias and Mrs May Papoulia in honor of the members of the Greek Alliance of Rare Diseases (PESPA) at the Presidential Mansion on Friday 29th February 2008.
- Extensive **press coverage**


Ημέρα των Σπανίων Παθήσεων
1η
Ευρωπαϊκή Ημέρα
Σπανίων Παθήσεων
Μια σπάνια ημέρα
για ξεχωριστούς ανθρώπους
www.rarediseaseday.org
29
Φεβρουαρίου
2008
EURORDIS
achse
UNIAMC
ALAN
ANBHalle
FEDER
Υπό την αγίδα του
Υπουργείου Υγείας και Κοινωνικής Αλληλεγγύης
Η αφίσα εκδίδεται με την ευγενική χορηγία της
ACTELION

Marianna Lambrou, President of the Greek Alliance of Rare Diseases (PESPA) with
the President of the Hellenic Republic Dr Karolos Papoulias and Mrs May Papoulia at the Presidential Mansion

Rare Disease Day

In Hungary:

1. Information booklet on rare diseases and three other flyers about Rare Disease Day, HUFERDIS, and planned Habilitation Centre for Rare Diseases. All of them were distributed to decision makers and the media.

2. Appointment to meet with Ágnes Horváth, the Minister for Health of the Republic of Hungary, followed by a series of consultations with decision makers and experts.

3. Letter writing and email campaign sent to more than 10000 addresses.

4. Starting of an exclusive Hungarian home page for the Rare Disease Day containing all the programmes and presentations.

5. Interviews to specific radio and TV channels expressing social-interest: 4 long (30-60 minutes) interviews to 3 radio channels (including the national radio), one short report in TV2 which one of the two leading Commercial Hungarian TV-channel.

6. Conference and Exhibition on rare diseases on 02.27 in the beautiful building of National Health Insurance Fund: nearly 300 participants!

7. Expert conference in the Hungarian Academy of Sciences on 02.29 on rare diseases. 87 participants of the research and health care sites from all over the country.

8, Conference organised on Reference Centres of Rare Diseases in the Hungarian Parliament on 03.19.


Rare Disease Day
A Ritka Betegségek
Első Európai Napja
2008
február
29
Egy ritka nap a
nagyon különleges
emberekért.
www.rarediseaseday.org

Rare Disease Day

In Italy

- Official Opening of the campaign " Rare Diseases "at the **Town Hall of Rome** with the **press conference.**
- A **Press Kit**, including a CD with special EURORDIS UNIAMO label, with all the documents, was handed over to all the participa as well as forwarded to all the journalists previously contacted. 12 journalists attended.
- UNIAMO's President introduced the First European Rare Disease Day " A Public Health Priority" and reported on the European Commission Communications process.
- 40 people attended. **Mrs Galluppi was interviewed by the main national TV Network** (RAI 1) and two regional networks
- A **cartoons video clip** on Rare Diseases, especially created for the event to reach children as well as a **8-minutes film** about real life experiences of three families with children affected by rare diseases were shown.
- Press conference organised by DEBRA at the **European Parliament in Rome**
- **Workshop** in Rome organised by SIP (Italian Paediatric Society) and SIMGePeD (Genetic Paediatric Disabilities): Priority of training, updating and research in the field of the rare diseases in the age of development. 80 participants.
- A **concert** with an Italian famous singer at the Auditorium in Rome. Presentation of the First European Rare Disease Day made by UNIAMO President, Mrs Galluppi. The cartoons video clip and the movie " Special Lives " were shown again to the **1500 participants** among them politicians, health professionals, pharmaceutical industry representatives and patient representatives.
- The list of **regional events** is available on UNIAMO web site page www.uniamo.org

3. Prima Giornata Europea delle Malattie Rare

iornata europea delle malattie rare, in Europa e oltre.

ne organizzazioni di pazienti di diversi Paesi in rappresentanza di una gran varietà di
in grande scala per una grande campagna in favore delle malattie rare.

aesi europei ed in Canada si terranno conferenze stampa, forum di discussione, marce
li, tutto in funzione di migliorare la conoscenza dei bisogni delle persone colpite da

venute nei vari Paesi saranno presentanti il 4 marzo al Parlamento Europeo a Brusselles
one Pubblica sulle malattie rare.

sito europeo www.rarediseaseday.org

IAMO, titolare per Eurordis dell'organizzazione della giornata nel nostro Paese, coordina
di piazza, il cui elenco è in continuo aggiornamento, e che vedrà protagoniste
are federate e non federate.

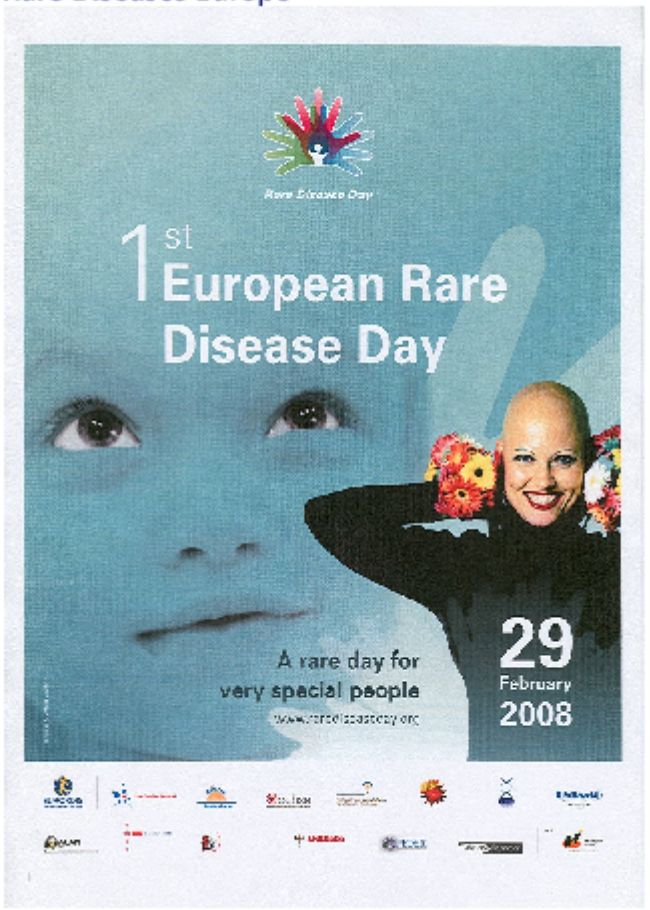
amma di UNIAMO per la giornata europea si compirà il 28 febbraio con un concerto
i nell'auditorium della Conciliazione a Roma. Il concerto, che è realizzato in
INDUSTRIA, inizierà alle ore 21.00. L'ingresso è ad inviti. Per ulteriori informazioni
associazione locale o alla segreteria UNIAMO.

pa nazionale di UNIAMO per la Giornata Europea delle

iovedì 21 febbraio si svolgerà a Roma presso la "Sala del Carroccio" nel Palazzo del
ampidoglio la conferenza stampa nazionale di presentazione della Prima Giornata
uropea delle Malattie Rare.

Member of EURORDIS
Rare Diseases Europe

UNIAMO FIMR onlus
Italiana Malattie rare
San Marco 4781, 30
Tel/Fax (+39) 04124
C.F. 92067090495
info@uniamo.org



Rare D

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MALATTIE RARE
ONLUS

C.F. 9206


A.N.I.Ma.S.S.
Onlus
Associazione Italiana Malati
Sindrome di Sjögren
(malattia rara degenerativa curabile ma non guaribile/
provoca secchezza degli occhi, bocca, aggredisce
pancreas, fegato, cuore, stomaco, articolazioni, ossa
e può associarsi a malattie autoimmuni
reumatoide, les, vasculiti,
rare in linfoma eccetera.)
AL TUO MEDICO
SAPERNE... DI PIÙ
Per chi è affetto da questa grave malattia e si sente solo
e abbandonato chiami questo numero:
333 83 86 993
oppure invii una e-mail a:
si colleghi a: www.csgalileo.com/animass
per tesseramento e donazioni
A.N.I.Ma.S.S.
Onlus
Associazione Nazionale Italiana
Malati Sindrome di Sjögren
presenta
Progetto Salute:
Arte Teatroterapia
in Via S. Chiara, 6 - Verona
A.N.I.Ma.S.S.
Onlus
Associazione Nazionale Italiana
Malati Sindrome di Sjögren
presenta
Progetto Salute:
Arte Teatroterapia
in Via S. Chiara, 6 - Verona

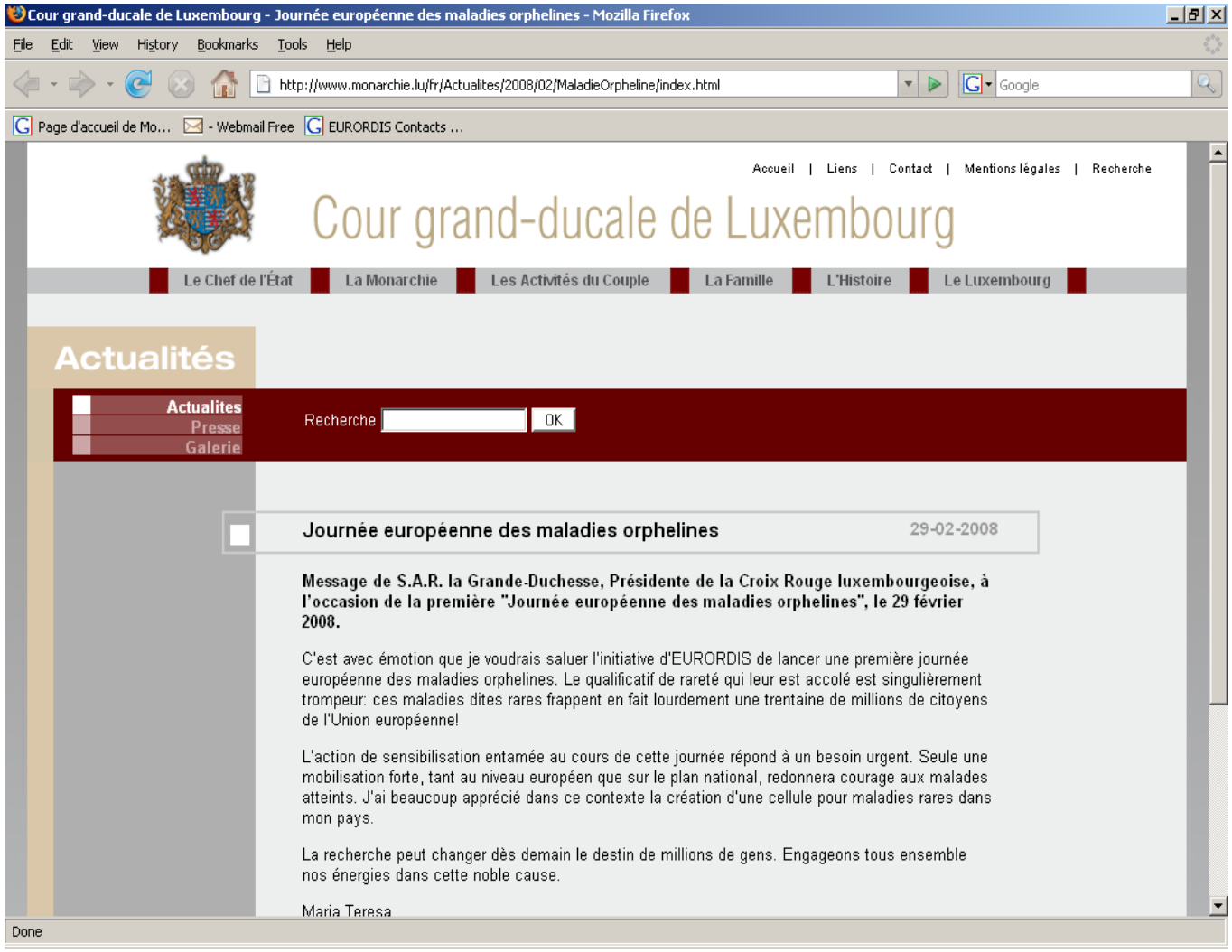
Rare Disease Day

In Ireland

- The celebrations started early on Friday morning when a patient affected by **Fabry Disease**, Dr Colin O'Reilly appeared on the **only Irish breakfast television programme** – Ireland AM (TV3) to tell his story. Appearing with him was Ms. Eibhlin Mulroe who is CEO of the Irish Platform for Patients Organization Science and Industry (**IPPPOSI)** to highlight the **statistics** and the current position on rare disorders in this country.
- At 11am a group of 100 patients and scientific representatives **released balloons** at a **photo shoot** which was followed by a **formal meeting** on rare disorders at the **Lord Mayor of Dublin's residence** – The Mansion House. The meeting was hosted by GRDO and was attended by 100 specially invited representatives from patient groups, the scientific community, industry and government bodies to discuss the acute needs of patients affected by rare disorders in Ireland and the **development of a national plan for rare disorders.**
- The meeting was chaired by Mrs. Judy Windle of GRDO and was addressed by Professor Andrew Green, Director of the National Centre for Medical Genetics in Crumlin, representing the scientific and medical community. The diversity in patients needs from diagnosis to access to treatment was represented by Dr. Colin O'Reilly (Fabry Patient) and Mr. Hubert McCormack (Spinal Muscular Atrophy). Ms Eibhlin Mulroe the Chief Executive of IPPOSI spoke about the current situation in Ireland with regard to **Orphan Drug Regulation.**
- **Extensive media coverage** was secured in both national and regional press and the story was carried in three Evening News programmes on RTE One and TV3.

Rare Disease Day

In Luxemburg



- **Press Conference**
- **Evening TV program on Rare Disease**
- **Articles in all major newspapers**

ALAN asbl

LIEWESFREED SICHEN AN FANNEN, DAT ASS ONST ZIL!

3.3.2008

- News&événements
- L'association
- Services
- Maladies neuromusculaires
- Maladies rares
- Partenaires&Sponsors
- Presse&TV
- Téléchargements
- Devenez membre
- Contactez-nous
- Groupes d'entraide
- Don
- Jobs
- Rare Disease Day

Général:

- Page de démarrage
- Sitemap
- Impressum

ALAN a.s.b.l.

Bienvenue sur alan.lu

L'**A**ssociation **L**uxembourgeoise d'aide pour les personnes **A**tteintes de maladies **N**euromusculaires et de maladies rares – ALAN a.s.b.l. soutient les personnes atteintes de maladies neuromusculaires et, depuis janvier 2005, aussi les personnes atteintes de maladies rares.

Créée en 1998 par des personnes atteintes de maladies neuromusculaires et leur famille, l'ALAN a.s.b.l. a pour objectif premier d'améliorer la vie quotidienne des personnes concernées. L'association est reconnue d'utilité publique par l'arrêté grand-ducal du 29 avril 2000.

Vous trouvez sur notre site des informations sur les différentes maladies, ainsi que les moyens que nous mettons en œuvre pour venir en aide aux familles et personnes concernées. Notre forum a été spécialement créé pour faciliter l'échange de renseignements et d'expériences.
N'hésitez pas à nous contacter pour tous commentaires et suggestions.

Bonne visite !

Don

Pourquoi donner ?
Grâce aux dons collectés, l'ALAN aide au quotidien les familles et personnes atteintes de maladies neuromusculaires et de maladies rares. Faire un don à l'ALAN, c'est lui offrir les moyens de poursuivre son action.

Comment donner ?
Il suffit de faire un virement avec la mention don ALAN a.s.b.l. sur l'"un de nos comptes bancaires suivants :

INVITATION À LA CONFÉRENCE DE PRESSE 29.02.2008

Alan reportage um Radio 100.7 den 28.02.2008

RareDiseaseDay

Agenda

Poste

poste pour un(e) technicien(ne)

Rare Disease Day

In Romania

Bucharest Feb. 29

- **Roundtable** “Rare Diseases – a public health priority In the EU” at the Ministry of Public Health. At the meeting **the Minister signed a partnership agreement on the National Plan for Rare Diseases** and informed the media about the objectives and activities that will be Developed in the Plan. **Press conference** that was organised the same day attracted 5 national TV channels and all national newspapers.

- Presentation of the NPRD at the **National Forum of Family Doctors**, attended by 300 family doctors.

- Dorica Dan, President of the Romanian National Alliance was **interviewed on the BBC** and national TVR2 (45 min report)

In Romania

- **Scientific Seminar** on Rare Diseases organised by the University of Medicine and Pharmacy
- **Information materials** (12 000 leaflets, 500 stickers, 500 journals, 400 posters) have been delivered in the streets, hospitals, medical institutions and NGOs by PeaceCorps and student volunteers in 20 cities.
- **3 billboards** have been placed in central places in Bucharest, Iasi and Cluj for the entire month of February;
- **Official opening** of the campaign on Feb. 25 at **Zalau's City Hall**. 200 people attended. There was a press conference and interviews from two local TV stations.
- Presentation of the **film** "Rare People and Rare Diseases"
- A musical **concert**
- Special courses on **inclusive education** in schools all month of February
- **Art contest** "A rare day for very special people" - 18 winners received awards from the County Council.
- A **workshop** on management of RD in Romania and in Europe, in **Targy Mures**
- A **seminar** about RD diagnosis and treatment possibilities in Romania, in Bucharest
- A **workshop** on the impact of rare diseases in neonatology, in **Iasi**
- A **seminar** entitled "The First European Rare Disease Day" in **Oradea**
- A **seminar** entitled "Together for Rare Diseases", 400 participants in **Timisoara**
- One week campaign, **tent** with exhibit and information materials. Organised by the University of Medicine of Timisoara and NGO "Save the Children".

rima Zi Europeană a Bolilor Rare
29 februarie 2008

Campanie națională organizată de
lianța Națională pentru Boli Rare România
la inițiativa ***EURORDIS***

ZIUA BOLILOR RARE

Sumar campanie:

Lansare campanie – Zalău, 25 februarie
Seminarii boli rare: Cluj, Bucureşti, Oradea, Iaşi, Timişoara, Tg. Mureş, 26-29 februarie
Întâlnire Ministerul Sănătății – 29 februarie
Distribuire materiale informative în 20 de oraşe

„O zi rară pentru oameni foarte speciali"
Bolile rare: o prioritate de sănătate publică"

APWR

Material realizat cu sprijin financiar genzyme

De ce este nevoie de campanie?

- **Pentru că este nevoie în mod constant să creştem nive conştientizare asupra bolilor rare** în rândul factorilor de dec profesioniştilor din sănătate şi al publicului general.
- **Pentru că acționând simultan în întreaga Europă, vocea paci cu boli rare va fi cu siguranță auzită de mai mulți oameni.**
- **Pentru că bolile rare sunt o prioritate** azi în Uniunea Europe
- **Pentru că o zi concentrată pe boli rare poate aduce sper informație** persoanelor afectate de boli rare, aparținătorilo familiilor lor.
- **Pentru că Europa este punctul focus al majorității acț noastre azi;** sperăm ca în viitor această Zi Europeană a Bolilor devină o Zi Internațională a Bolilor Rare. Concentrându-ne pe este un prim pas.
- **Pentru că dorim egalitate de acces la îngrijire şi tratament** pacienții cu boli rare din Europa.
- **Pentru că avem nevoie de o acțiune care să unească toți f implicați în comunitatea bolilor rare,** având același scop.
- **Pentru că avem nevoie de mai multe fonduri** pentru cerc îngrijire, şi de **mai multă cercetare** şi mai multe eforturi direc către bolile rare.
- **Pentru că trebuie să continuăm să militäm** pentru pacienții rare.

Rare Disease Day

In Spain

- 15 media attended FEDER's **Press Conference**, three of them National Press Agencies, one local TV. Even though the media attention was focused on the debate between the two candidates for the Spanish Government Presidency. The **press pack** was entitled "Inequalities in care for RD patients" and included a report on RD at European level and a focus on the situation in Spain

- Many **regional awareness-raising activities** took place in Cataluña, Andalucia, Extremadura, and other regions

- A **ceremony** took place in the Spanish College of Pharmacists, chaired by the president of the College and the President of FEDER, together with Prof. Josep Torrent and a patient, representative of the Neuromuscular Association.

- A great deal of **media** called all day long. FEDER's President, Rosa Sanchez de Vega, gave an interview, in English, for an English radio station in the Mediterranean for English speaking people who live there.

FEDER

Federación Española de Enfermedades Raras

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scador de ER

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¡Danos tu firma!

Manifiesto en el Día Europeo de las Enfermedades Raras

¡¡¡¡Por fin llego el día!!!! Toda España unida en la lucha por los derechos de los más de tres millones de afectados por patologías de baja prevalencia

Más de 25 millones de europeos padecen una patología de baja prevalencia

A casi un 30% de los pacientes les resulta difícil o imposible acceder a las consultas de los especialistas sanitarios. Cuando lo consiguen, en un 40% de los casos el diagnóstico suele ser erróneo

Servicio de Información y Orientació

Formulario de Consulta

Qué es el SIO

El SIO en cifras

Grupo de Pacientes

sio

Tel: 902 18 17 25

Agenda FEDER

Marzo

L	M	X	J	V	S	D
					1	2
	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30

Rare Disease Day

In Sweden

Her Majesty, the Swedish Crown Princess Victoria,
attended the RDDay and handed the ‘David Lega’ Award to an exemplary young person living with a cranofacial disability

RD Day was celebrated along with **10th anniversary** of the Swedish National Alliance at the *Nalen* ‘dancing’ Palace in downtown Stockholm.
A **seminar**, focusing on the need for **national centres of reference** for rare diseases, was inaugurated by the State Secretary at the Ministry of Health and was attended by other distinguished lecturers from the medical profession, patient representatives and from the government (National Board of Health & Welfare and County Councils). The seminar was attended by **200 people representing 25 rare diseases.**
An **evening dinner** for members and guests/VIPs, followed.

Extensive **media coverage.** One of the largest daily newspapers in Sweden, Svenska Dagbladet, distributed a special edition concerning rare diseases on February 29. The President of the Swedish National Alliance, Elisabeth Wallenius was interviewed in a radio programme broadcasted from the local radio of Stockholm on February 28. The Day was also mentioned in a nationwide radio channel, P1, in the programme “Scientific news”.


Sällsynta dagen - Windows Internet Explorer
http://www.sallsyntadagen.nu/
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Sällsynta dagen
SÄLLSYNTA DAGEN
Hem
Om sällsynta dagen
Stöd sällsynta dagen
Budkavlen
Sponsorer
Du kan hjälpa!
Skriv under vår namn-insamling!
Namninsamling
2337 personer har redan skrivit på.
Gör det du också!
En sällsynt dag,
för sällsynta diagnoser,
då sällsynt blir vanlig.
Välkommen att här ta del av information om den Sällsynta dagen. En dag som skapats för att uppmärksamma att det finns människor som har sällsynta diagnoser och därför lever med särskilda svårigheter.
Dagen har inrättats för att upplysa allmänhet, politiker och vårdgivare om att det finns sällsynta diagnoser och att det är många olika diagnoser. Det är inte ovanligt att ha en sällsynt diagnos. Men de som har en hamnar ändå en ovanlig situation.
Riksförbundet Sällsynta diagnoser är initiativtagare till dagen som genomförs i flera europeiska länder. Det är vi som anordnar Sällsynta dagen i Sverige.
Riksförbundet Sällsynta diagnoser är en handikapporganisation för människor med sällsynta diagnoser som leder till omfattande och livslånga funktionshinder. Förbundet har ca 7 500 medlemmar och representerar ca 50 olika sällsynta diagnoser.
Det är vår förhoppning att öka medvetandet i samhället om sällsynta diagnoser. Stöd oss och sprid ordet vidare!
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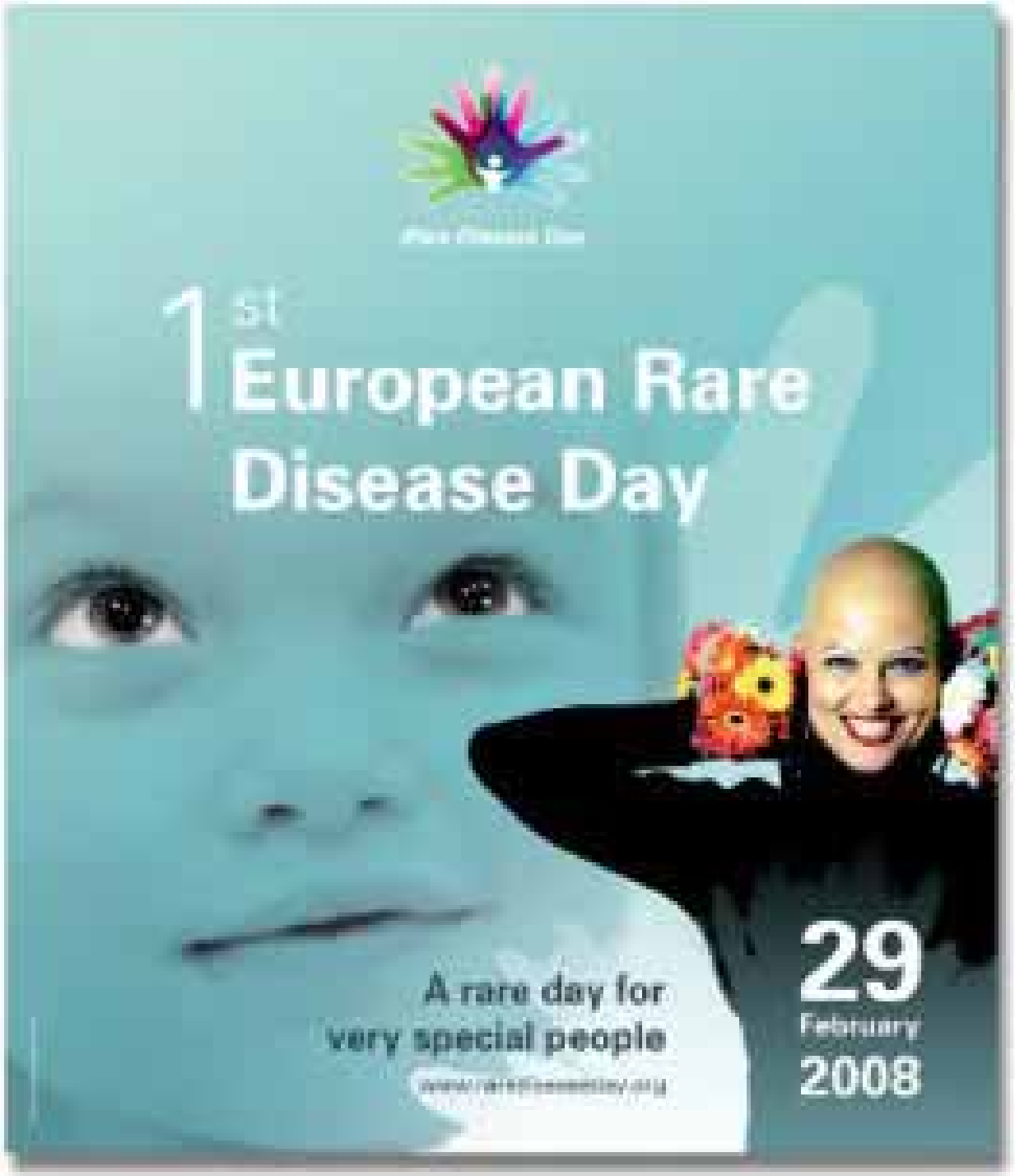
Rare Disease Day

In the UK

To mark Europe's first Rare Disease Day 29th February 2008 over **150 patients** from across the country traveled to **Westminster to meet parliamentarians face to face** to raise the awareness of the needs of patients with rare diseases and to discuss policy developments at a UK and European level.

Dr Evan Harris MP hosted GIG's Rare Disease Day event on 26th Feb at the House of Commons. Over 200 people attended.


Rare Disease Day



Member of EURORDIS Rare Diseases Europe

"Neurohereditary Diseases" Charity Association

Conference is devoted to 1st European Rare Disease Day

(27.02.2008 Yerevan, Armenia) 2 - University clinical hospital

Problems of Rare Disease in Armenia

A.Matevosyan MD,PhD

Head of the Republic Center of Medical Genetic

Rare Disease Day

In Russia

- **Press Conference** in St Petersburg on February 26th, gathered doctors, government officials, patients, patients' relatives, patient organisations and mass media.
- Presentation of the Russian Patient Organisations National Alliance
  « Genetics »
- Distribution of **flyers**
- Exhibit of **drawings** made by children suffering from rare diseases and their photos
- **Information meetings** at first-level medical centres from Feb. 26-28

Rare Disease Day

In Ukraine

- Press conference in the Kharkiv's Press Room on February 29th. The Regional Public Health Affair took part in it.
- Production of an social TV program, devoted to SMA and other rare diseases, and a short film describing the daily lives of children with rare diseases. This was shown on national television and via satellite TV on February 28th.
- Billboards in several locations in Kiev
- Press releases were sent to Ukrainian media throughout the country before the RD Day. Interviews on specific TV channels expressing social-interest.
- Letter writing and email campaign to the Ministry of Public Health, Regional Health Affairs and institutions.
- Fund raising campaign.


Один из 6000 народжених дітей хворий на СМА;
50% дітей, що діагностовані зі СМА, не зустрінуть свій другий День народження;
Кожен з 40 людей носій гена, що призводить до СМА;
СМА вражає, незважаючи на вік, стать або національність.
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Rare Disease Day 2008

Over 12,000 visits to the RDDay website

Awareness-raising activities across the EU and all the way in:

- Canada
- Norway
- Croatia
- Russia
- Ukraine
- and… Armenia!