February 29th (Wednesday)

Rare Disease Day 2012 will be particularly special this year.

2012 is a leap year, so the day will fall on February 29 - a rare day for rare diseases.

For the 5th year running, hundreds of Patient Organisations from more than 40 countries worldwide, including the Malta Health Network, are organising awareness-raising activities converging around the slogan “Rare but strong together!!”

A disease or disorder is defined as rare in Europe when it affects fewer than 1 in 2000.
A disease or disorder is defined as rare in the USA when it affects fewer than 200,000 Americans at any given time.

One rare disease may affect only a handful of patients in the European Union, and another may touch as many as 245,000.

In the EU, as many as 30 million people alone may be affected by one of the existing 6,000 to 8,000 rare diseases, having an impact on patients’ lives.

- 80% of rare diseases have identified genetic origins whilst others are the result of infections (bacterial or viral), allergies and environmental causes, or are degenerative (progressive) and proliferative (multiplying).
- 50% of rare diseases touch children.
- The focus of this year’s event is the importance of Solidarity in the field of rare diseases, to focus on the need for collaboration and mutual support amongst diseases, stakeholders and across countries.
- Patients are rare and expertise is scarce.

• Rare diseases are few and far between, but collectively they are many and people living with them all face similar challenges - so they will be stronger if they join forces.

Rare Disease Day is coordinated by EURORDIS and organised with rare disease national alliances in more than 25 EU countries.

EURORDIS (The European Organisation for Rare Diseases) is a non-governmental patient-driven alliance of patient organisations representing more than 502 rare diseases’ patient organisations in over 46 countries, covering more than 1,000 rare diseases.
EURORDIS aims at building a strong pan-European community of patient organisations and people living with rare diseases, to be their voice at the European level, and - directly or indirectly - to fight for the right of rare disease patients to benefit from timely diagnosis, quality healthcare and treatments, and social integration in an equitable way across the various European countries.
http://www.eurordis.org/publication/what-rare-disease

The Malta Health Network (MHN) gives patients a voice on health related issues and represents in Malta, in the European Union and internationally, the interests of patients and health of the community, developing better coordination, collaboration, and capacity building through exchange of best practice among Health NGOs and Patient representation groups. MHN influences health related policies and practices for the welfare of the community. http://www.maltahealthnetwork.org

MHN is approaching printed media and audio/visual outlets, Radio & TV Stations, to create more awareness about rare disease issues and to publicly express its solidarity with persons affected by a Rare Disease. Through encounters with the MEDIA, contact person: Philip M Chircop- Vice President – Malta Health Network (MHN): 99207043; 21447304; phchircop@gmail.com
On 29 Feb at 12:00 noon GMT: (13.00 local time) “Rare but strong together”

Join and raise your hands to show your Solidarity with rare disease patients around the world!

Whether you are 10 people in an office or Classroom, 50 people at a conference or 100 people at a public area; let’s show the world that we are all mobilised for people living with rare diseases and driven by the same objectives.

Show the world we are "Rare but strong together"!!

- 75% of rare diseases touch children.
- 30% of rare disease patients die before the age of 5.
- 80% of rare diseases have identified genetic origins.
- Rare diseases may affect 30 million European Union citizens.
- No existing effective cure

Here are a few examples of diseases considered as RARE:

Alkaptonuria (AKU): a rare autosomal recessive disease, affecting tyrosine metabolism.

Alternating Hemiplegia: a rare neurological disorder

Atypical Hemolytic Uremic Syndrome: an ultra-rare autoimmune disorder.

Behçet's Syndrome: chronic, rare condition caused by disturbances in the body’s immune system

CAPS: a group of auto-inflammatory rare diseases

CDG Syndrome: a group of very rare inherited metabolic disorders

Cystinosis: characterised by abnormal accumulation of the amino acid cystine.

Epidermolysis Bullosa: a group of rare inherited disorders that affects skin and mucous membranes.


Glut1 DS: a genetic disorder that impairs brain metabolism, resulting in insufficient cellular energy to permit normal brain growth and function.

Hereditary Spastic Paraplegia: a group of rare inherited neurological disorders. Primary symptoms are progressive spasticity and weakness of the leg and hip muscles, characterized by insidiously progressive lower extremity weakness and spasticity.

Waldenstrom macroglobulinemia: a rare form of blood cancer.

Multiple Myeloma: is a type of cancer arising from plasma cells which are found in the bone marrow

Von Hippel-Lindau: a rare genetic cancer syndrome, an alteration in the VHL-tumor-suppressor gene, which puts the individual at increased risk of developing tumors in various organs throughout life.

Interstitial Cystitis Patients

Rett Syndrome: a neurodevelopmental disorder of the grey matter of the brain that almost exclusively affects females. Repetitive hand movements, such as wringing and/or repeatedly putting hands into the mouth, are also noted. People with Rett syndrome are prone to gastrointestinal disorders and up to 80% have seizures. They typically have no verbal skills, and about 50% of individuals affected are not ambulatory. Scoliosis, growth failure, and constipation are very common and problematic.

Retina International

Allergy and Airways Diseases

Patients with Haemochromatosis

Wilson's Disease

Retinitis Pigmentosa Society International Association of Autoimmune Pathologies

contact person: Philip M Chircop- Vice President – Malta Health Network (MHN): 99207043; 21447304; phchircop@gmail.com