

THALASSAEMIA INTERNATIONAL FEDERATION TAKES THE LEAD IN THE CREATION OF A NATIONAL RARE DISORDERS ALLIANCE

For the first time in Cyprus, patients with rare disorders unite their energies and voices to establish the Cyprus Alliance for Rare Disorders.

Owing to the close collaboration and initiative of the Cypriot organizations listed below which represent patients with rare disorders, and after almost two years of intensive actions and deliberations, the alliance of organizations representing patients with rare disorders was founded by the following:

1. Thalassaemia International Federation (TIF)
2. Muscular Dystrophy Association Cyprus (MDA Cyprus)
3. Adult Congenital Heart Defects Association Cyprus (ACHDAC)
4. Pancyprian Anti-anaemia Association (PAA)
5. Cyprus Myasthenia Gravis Association
6. Cyprus Primary Association and Friends - Immunodeficiency
7. Cyprus Society for the protection of spastic and handicapped children (ELEPAP)
8. Parents Society of the centre for the protection of spastic and handicapped children.

Principal goals of the Alliance:

- To lend support to the national rare disorders programme announced recently by the Ministry of Health, which falls within the European Union's health programme and especially the prioritised promotion of rare disorders.
- To lend support to the efforts of rare disorders patients for improvement of prevention, medical treatment, as well as social and other services related to each of the rare disorders (when known and diagnosed). Ultimate goal is the betterment of health and quality of life for every patient with rare disorders.
- To provide support and continuous education to the patients and their families concerning the latest developments in medicine and research.
- To raise awareness regarding rare disorders in the Cypriot society.

The activities of the alliance will benefit from a national scientific advisory committee to be established in the near future and the Alliance will be represented in the advisory committee which is in the process of being organized by the Cyprus Ministry of Health.

For the occasion of founding the Alliance, a press conference has been organized by its members for 23 September 2010 with the following guests:

Representatives of the Ministry of Health
The president of the European Organization of Rare Diseases (Eurordis)

Representative of the European Community
Representatives of the Cypriot Medical Community

For more information please contact the secretary's office:
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For the organizing committee
Dr. Androulla Eleftheriou, Executive Director of TIF

RARE DISORDERS IN EUROPE

Approximately six thousand rare disorders have so far been identified and these affect 36 million Europeans.

According to the European definition, rare disorders are those with a prevalence of one or less per 2,000 inhabitants. The European Union has focused great attention and numerous multifaceted activities on promoting awareness of rare disorders, and has supported the founding and strengthening of national organizations for patients with rare disorders. The European Organization of Rare Diseases (Eurordis), an umbrella organization covering almost all national patients associations from more than 20 European countries, has accomplished an enormous task. Eurordis works in close and constructive collaboration with the European community and other scientific services and health organizations with the aim of development and continuous improvement of the policies regarding health and quality of life for rare disorder patients in Europe.

Problems faced by patients with rare disorders are particular to each disorder, although many apply to all diseases. Common problems produced by these chronic, serious and often incurable diseases are:

- Commonly delayed diagnosis
- Lack of diagnostic means, only found in a few specialized care units
- Lack of medical research, because funding is used up for more common diseases which affect public health 'more'.
- Accuracy of medical treatment regarding drugs, as well as the need for a multidisciplinary approach. The lack of development of new drugs from the pharmacy industries is a consequence of the relatively small market and constitutes a significant problem for the patients.
- Need for expert health care centres
- Need for psychological support