

CYPRUS ALLIANCE FOR
RARE DISORDERS

THE "FOLIA" CENTRE

Information, Support &
Education for Patients with
Rare Diseases



| φωλιά |

κέντρο ενημέρωσης,
υποστήριξης και εκπαίδευσης
ατόμων με σπάνιες παθήσεις



Bank of Cyprus



ΔΙΚΤΥΟ ΕΘΕΛΟΝΤΩΝ
ΦΙΛΩΝ ΣΠΑΝΙΩΝ
ΑΣΘΕΝΩΝ

ΑΝΩΝΥΜΟΙ
ΔΩΡΗΤΕΣ



Initiative of the Cyprus Alliance for Rare Disorders

Member of the European Organisation for Rare Diseases
(EURORDIS)

Our goal is to serve patients

SERVICES 2017-2019

1. Rare Diseases: What are they?

The term refers to 6.000-8.000 different diseases that affect 6-8% of the population. It is estimated that Rare Diseases (RDs) affect 27-36 million EU citizens and up to 60.000 people in Cyprus.

2. What is the Folia Centre about?

In collaboration with the Bank of Cyprus and the support of the Cyprus Ministry of Health, the Cyprus Alliance for Rare Disorders (CARD) established the Folia” Centre with the aim to provide service and assistance to patients with RDs and their families.

3. Who can benefit from the services offered at the Folia Centre?

The Folia Centre primarily addresses its services to Associations of Patients with Rare Diseases and individual patients who, precisely because of the “rareness” of their condition, cannot form an organised association.

4. What type of services does the Centre provide?

The services of the “Folia” Centre focus on the 3 pillars of **information**, **support** and **education** and operate under the supervision of a multidisciplinary panel of experts. The Centre **does not** provide medical service or healthcare. The patients can refer to the Centre for the following services:

Information

The “Folia” Centre provides information about bills and legislations that are currently in vigour, bills that have been updated or bills that are currently being created, as well as laws, directives and recommendations of direct interest to patients (and citizens – potential patients). The patient can access this information via monthly electronic bulletins, newscasts, print and website publications, and via Social Media channels (Facebook, Twitter, and YouTube).

Preparation of studies

The Centre investigates problems, as well as general or specific issues concerning a particular disease or individual patients themselves, and prepares studies to help patients to efficiently convey their demands and suggestions to the responsible bodies.

Support

Pancyprian Patient Support Line

In collaboration with a social worker, a psychologist and other specialists, the “Folia” Centre provides telephone support to patients at 22203762 (Monday-Friday, 09:00-17:00), regarding: (i) benefits offered by the State and other provisions; (ii) existing health and healthcare services in Cyprus; and (iii) reference centres abroad; (iv) networking opportunities with patients suffering from the same disease.

Also, the Centre offers:

Secretarial Support: Redaction, writing, documentation/validation of letters and demands; Sending and monitoring outcome.

Support to Patient Associations: Logistics and legal counselling; Preparation, writing, submission and monitoring of outcome with the aim to pursue funding at national, European and international level.

Intervention/ Suggestions: Preparation of position papers or suggestions to the executive and legislative bodies at national level, as well as decision-making bodies at national, European and international level.

Patient Representation: Provide support to patients in securing representation and participating in decision-making committees at national, European and international level.

Alternative uses of the Centre: The Centre offers office space to Patient Associations to use for their own purposes and meetings, as well as other forms of facilitation (e.g., overnight stay, child entertainment).

Education

The “Folia” Centre creates material and co-organises activities such as educational conferences, workshops, information days, lectures, meetings; creates material and co-organises activities in support of educational programmes organised by member associations.

*Patient Educational Centre (PEC)

The “Folia” Centre collaborates with specialist CARD collaborators to advance a Patient Training Centre in the following areas:

- Patient rights as they derive from national, European or international conventions, recommendations, directives etc.
- Reinforcement of Patient Associations’ function and capacity building.
- Current legislations, directives, recommendations concerning RDs, and those that are under development.
- Regulations, studies, programmes, strategies and actions of the relevant national committees that operate under the:
 - Ministry of Health
 - Ministry of Education and Culture
 - Ministry of Labour, Welfare and Social Insurance.

Educational Tools:

- Online platform
- Educational booklets
- Smartphone applications
- Seminars, workshops, lectures
- Collaborations with academic and research organisations
- Constitution of counselling committees and expert committees

How can I support the Centre?

- By registering as a member of CARD
- By making a donation
- By making a gift relevant to our needs

- By participating in the Network of Friend Volunteers of Rare Patients (DEFISA)

CYPRUS ALLIANCE FOR RARE DISORDERS

Since 2010, the Cyprus Alliance for Rare Disorders (CARD) has been working side by side with the patients to offer them a unified voice and to support their daily struggle for a decent life, welfare and full social integration. Together with its 15 member associations and over 100 individual patients, CARD actively participated in the development of a National Strategy for Rare Diseases, and remains vigilant to ensure that the national strategy is fully implemented on the basis of its 5 pillars. To effectively do so, CARD maintains an active participation in the National Committee for Rare Diseases and the Committees of other national, European and international patient associations. In parallel, CARD works for the promotion of the demands of the rare patients residing in Cyprus.

CARD is an umbrella association, bringing together the voices of 15 patient associations:

1. Thalassaemia International Federation (TIF)
2. Muscular Dystrophy Association Cyprus (MDA Cyprus)
3. Adult Congenital Heart Defect Association Cyprus (ACHDAC)
4. PANCYPRIAN THALASSAEMIA ASSOCIATION (PTA)
5. Myasthenia Gravis Association (MGA)

6. Cyprus Primary Immunodeficiencies Association and Friends
7. Association for Inherited Metabolic Diseases “Aspida Zois” Cyprus
8. Cyprus Association of Familial Amyloid Polyneuropathy Patients and Friends
9. Cyprus Association for Huntington Disease
10. Children with Liver diseases – Giorgos Psaras Round Table
11. “PROMITHEAS” - Association of Patients with Liver Diseases and Friends Cyprus
12. “Anemoni” - Centre for Cerebral Palsied Children
13. Cyprus Brain Tumour Association
14. Association “One Dream, One Wish” – For Children with Cancer and Related Diseases
15. Association for Cystic Fibrosis Cyprus

Last update: March 2018



| φωλιά |

κέντρο ενημέρωσης,
υποστήριξης και εκπαίδευσης
ατόμων με σπάνιες παθήσεις

