

Romanian Association for Patient with Primary Immunodeficiency's “ARPID”



arpid



Romanian Association of Patients with Primary Immunodeficiency's ARPID, was established in October 2010, after a meeting in Berlin, organized by IPOPI (International Patients Organization with Primary Immunodeficiency's for eastern countries). It was first time when we discover that we are not alone fighting with PID disease, with the Romanian Health System, with ourselves

As you know, IPOPI was established in 1992 and works as the global advocate for PID patient community in cooperation with its National Member Organizations-NMO, and key PID stakeholders.

Now, a number of 47 countries are in the International team and new members are still coming.

For ARPID, first steps were difficult starting with 15 members, no resources, no help from authorities.
We created a small website and become to work together

In September 2011, after a meeting in Belgrade, organized also by IPOPI, our way was radically changed. With IPOPI support we realized a new, modern, interactive website. This website is easy to be access, to contact us, to ask questions about PID's. We also have a Facebook address:

www.facebook.com/ImunodeficientePrimare

www.arpid.ro

Publications

Imunodeficiențele primare

Mentine-te sanatos!
Un ghid pentru pacienti
si familiile acestora



Imunodeficiențele primare

**Un ghid
pentru scoli**



Imunodeficiențele primare

**Tratamentul imunodeficiențelor
primare: un ghid pentru pacienti
si familiile acestora**



We started the translation in Romanian language for 3 booklets and published 2 months later. This booklets go to patients, parents of patients, doctors, nurses, in kindergartens. Other publication, with the signs of PID's in children and adults, was also spread in medical world.



World PI Week

22 - 29. April 2013

Primary Immunodeficiency:
Turning Hope into Action!

TEST!

DIAGNOSE!

TREAT!



In 2013, together with “Jeffrey Modell Foundation-Romania” we organized the “Immunodeficiency Week” including 2 big manifestation:

- Green for a better immune system
- Dance of the immune system

“Green for a better immune system”

- We planted 2500 trees near Timisoara for a better live in town, for a healthy one

“Dance of the immune system”

- Organized also in Timisoara, bring together a lot of children, teachers, doctors, patients. They dance for hope, harmony and peace, for respect and understanding of patients with PID's.





In this time, our team was growing until aprox. 50 members. We appreciate around 350 people with PID's in Romania, but the number is under the global statistics, because our patients are under diagnose.

In Romania we have few centers for patients with PID's:

- Hospital "Louis Turcanu" in Timisoara for children, also Jeffrey Modell Foundation is there.
- University Hospital in Cluj for adults
- Pediatric University Hospital in Bucharest
- Few small centers in Sibiu, Targu Mures, Iasi.

Last year, with the help of doctors involved in PID's we obtain the recognition of adult patients, which were included in the National Programme of Rare Diseases, first step for the adults treatments.

What we still have to do ?



Working together with doctors involved in PID's for realize the National Register of all Romanian patients, adults and children.

Working with the authorities, doctors for strong qualified medical centers in Romania for PID's.

ARPID objectives include also:

- To support patients with PID's for integrating in professional and social life;
- To assure the expense for some investigations, some drugs, or medical article;
- To facilitate the communications and psychological support for patients with PID's;



Our next steps:

- To continue the battle in order to obtain IVIG for all patients;
- To initiate approaches in order to obtain other drugs – antifungal drugs, G-CSF, subcutaneous immunoglobulin;
- To continue our collaboration with physicians working with PID's patients;
- To continue working with the International Team and IPOPI.