

Immunoglobulin crisis in Romania

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www.arpid.ro

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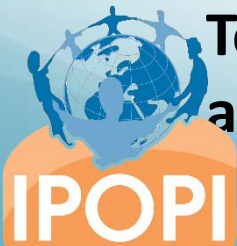
ARPID was established in October 2010 by one doctor and a small group of patients.

Main objectives:

- **Advocacy in behalf of PID patients**
- **Raising awareness about PIDs**
- **Increase the level of understanding about PIDs among patients through informative leaflets, conferences, annual meetings and summercamps**

At the beginning we were around 15 patients

Today the organization has 100 patients, children and adults, who benefit from the support of very few doctors and medical centers in Romania.



Situation of patients with PIDs in Romania

Diagnosis

- **Delayed diagnosis:** lack of PID knowledge and limited access to specific laboratory tests
- **Diagnosis mostly possible or probable:**
 - Until recently genetic diagnosis was performed in collaboration with other european centers.
 - We started the molecular genetic diagnosis in Timisoara center
- **No SCID screening program for newborns.**
- **No national register for PIDs.**



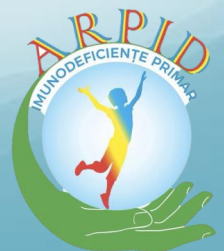
Situation of patients with PIDs in Romania

Acces to treatment

- Since 2016 temporary dysfunctions in access to Ig
- Serious gaps in supplying with Ig, starting July 2017, with only 1 distributor left on the market
- Ig quantity delivered was far bellow real needs, which lead to massive underdosing or treatment interruption

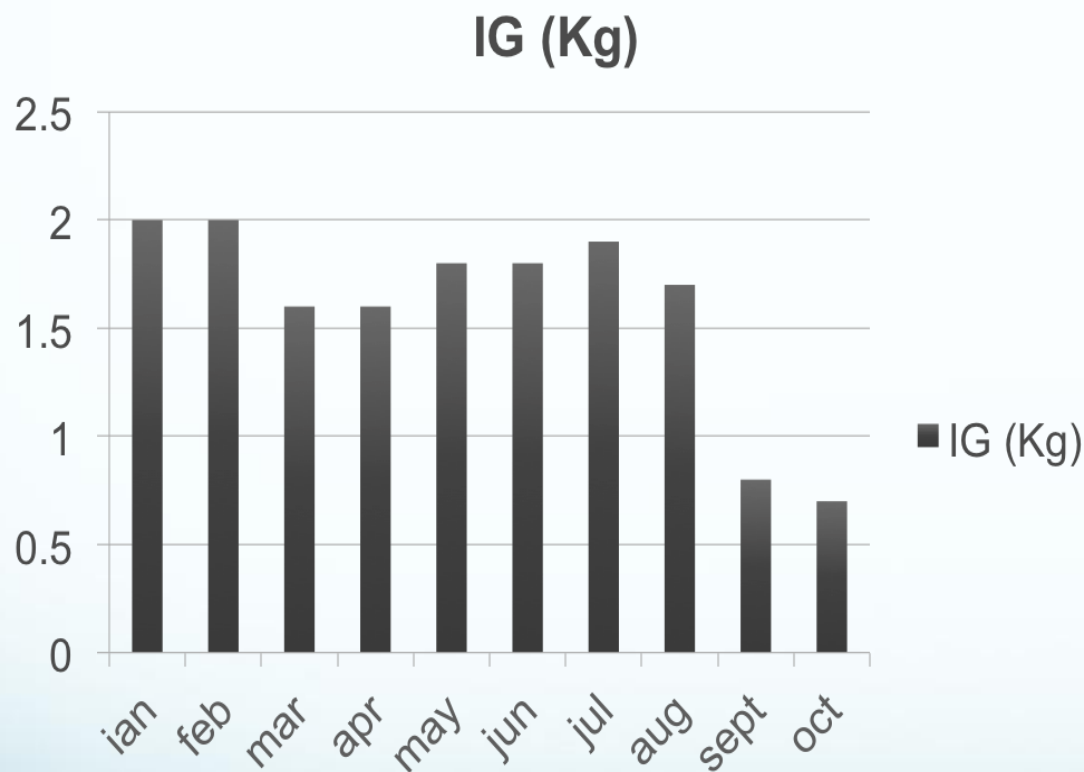
Consequences:

- Poor quality of life – many children were isolated at home
- Complications
- One declared death, conected to the lack of Ig



Situation of patients with PIDs in Romania

PID IG use 2017



Consumption:

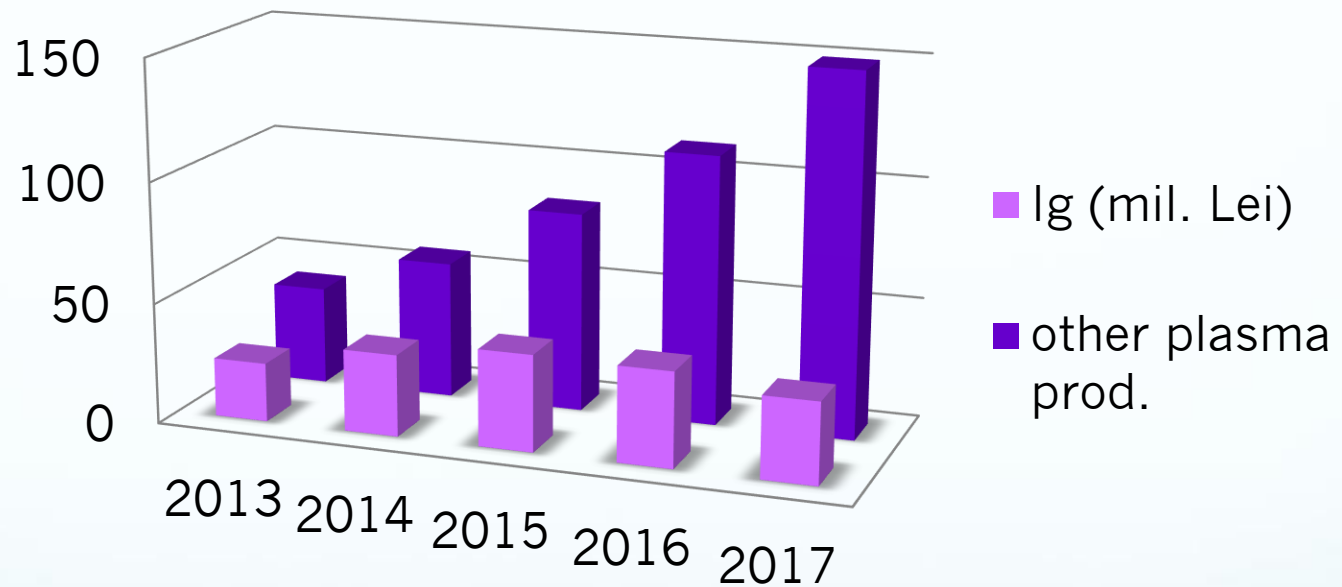
2016 – 170 kg (35 kg for PID)

2017 – 67 kg (16 kg for PID)

**Real Ig needs are of
956 kg/year (150 kg for PID)**



Romanian Ig and other plasma products consumption



ARPID achievements in 2017-2018

Several meetings with romanian authorities led to:

- **Suspension of the claw-back tax for 2 years for all plasma products**
- **Activation of EU Civil Protection Mechanism**
- **Admission of SCIG on the Rare Disease National Programme**

Other actions:

- **We formed alliances with other NGOs in order to make our voices heard**
- **Protest in front of the Ministry of Health**
- **Huge media coverage**



