



Stowarzyszenie na rzecz
osób z niedoborami
odporności

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DOWIEDZ
SIĘ WIĘCEJ
O PNO!

**Summary of our activity
in years 2012-2015**

INTRODUCTION

2015 was a crucial year for „Immunoprotect” Association. Not only because, after many years of attempts, the medication program for adults has been finally implemented. Our actions have gained international dimension: the films we produced were translated into foreign languages, we were training the patients associations’ leaders from Central Europe while our president, Mr Adrian Gorecki began his activity as the member of IPOPI executive board.

Our previous executive board’s tenure has finished in November 2015 and the new board has been elected by the General Assembly of Members for the next three years. It’s a good time to summarize our activity in the recent years.

IMMUNOPROTECT: SUMMARY OF OUR ACTIVITY IN YEARS 2012-2015

Full-length film titled 'This could be your story'



We have produced **the first ever** documentary film about PID. We show it to the patients during our meetings but it is also available in the Internet. We have also prepared its shorter version (twenty-five minutes long) which may be displayed during **congresses and conferences** (it has been already displayed at some major

events in 2014 and 2015, like Third General Pediatrics Conference in Wrocław). Moreover, the film is being used as an educational material for **Silesian Medical University and Jagiellonian University's Collegium Medicum** students, subsequently increasing the knowledge of PID among the future doctors. It has been produced in two language versions: **Polish and English**. There is also a Portuguese version prepared for the patients in **Portugal** while the translation to **Slovak** language is in the process.

PID patients stories



Recording the stories of five PID patients stories back in the summer of 2013 in Warsaw, we never dared to dream that this production will be our **flagship educational material**. Its professional realization and interesting content made it immensely popular among the patients and people waiting

to be diagnosed, with almost ten thousand viewings. The stories showed in the films helped many people believe that they are not the only ones struggling with this kind of problems and that it's possible to cope with them. Our project gained **international recognition** too: **eight different language versions** have been produced using the voice over (in English, French, Spanish, Portuguese, Russian, Czech, Arab and Persian) while there is also German version with subtitles. Recently we have been trying to add the Balkan languages versions to the list.

Regional coordinators network



In the beginning of 2012 our Association had approximately thirty members, most of them being rather passive. Today we have more than one hundred members and – what is even more important – **the group of twenty determined volunteers**, mostly being patients themselves, which makes our organization an **unique case worldwide**. Some of our

activists make the network of our regional representatives for different voivodships. They meet frequently to assess current actions and plan the long-term strategies. We organize **trainings** for our regional coordinators improving their competence in the areas of soft skills, communication, public speaking, self-presentation as well as increasing their knowledge about topics like social security or preparing immunoglobulins. These coordinators make **the first contact people for the patients in their region**, being also responsible for **the cooperation with medical staff** and distribution of educational materials.

„Immunoplus” – patients’ magazine



The quarterly magazine for the PID patients has been created anew and is **the first such publication in the world**. The journalists are **mostly patients** and their relatives. We also cooperate with the immunologists, psychologist and other medical staff representatives. Supported by the professional journalists, they write **articles focusing on the PID-related topics**, like patients’ everyday life, psychological issues, medication and its possible threats, availability of different types of treatment and the Association itself. The magazine may be found in **all the hospitals having PID treatment wards** but it’s also available on our website and may be sent to your homes. Its circulation is one thousand copies and it is absolutely free.

PID – the guide for patients and their families

As **the first in the world** we have translated **the complex guide** about PID prepared by American Immune Deficiency Foundation (IDF). It describes all the most common PID-related diseases and many specific hints helping to cope with PID in our everyday lives. One year after the first edition we had to print another five hundred copies to match **the public demand**, making the total number of **copies 1,500**.

Luciano Vassali Award dla Adrian Górecki



As a recognition of his service for PID patients, the President of our Association, **Mr Adrian Gorecki** won Luciano Vassali Award in 2014. This prize is being given every two years to the person **making significant difference improving the standards of PID patients' life in Poland and the whole world**. The voters are the patients' organizations from around the world. In the same year Mr Gorecki has also been voted for his four-years

long tenure in **the executive board of International Patient Organisation for Primary Immunodeficiencies (IPOPI)**.

Medication program for adults

To guarantee the access to the medication for PID patients was in our Association's area of interest since its beginning in 2007. It was our main goal to make the domestic antibodies treatment available for the adult patients. During recent years **we have sent severals letters and petitions**, met with Health Ministry and National Health Fund representatives, recorded the video-petition and collected signatures under the petitions sent to the authorities, we have also drawn the nationwide media attention. Finally, thanks to the entire environment support, **the medication program for adult PID patients has been implemented in 2015**.

Coordination of the Jeffrey Modell Foundation's project in Poland

In years 2011-2014 we coordinated the project of genetic diagnostics development in the University Children's Hospital in Cracow with its result being **more than eighty patients being diagnosed with PID**. We have also **donated 150.000 PLN** to the health center in Cracow, helping it to buy necessary laboratory equipment and reagents.

Ongoing formal and informal support for the patients

Our recent activity focuses on supporting the patients in its broadest meaning. **We help them to find a proper clinic specialized in PID treatment, we direct people looking for a diagnosis, we provide complex information for newly diagnosed patients and their families.** We support the patients who have been let down by their physicians or authorities. In 2013 we intervened when the hospital in Cracow rejected its adult patients plea for subcutaneous therapy. Using local media, we persuaded the hospital's authorities to allow the patients to continue their treatment as the part of children's program continuation. We were also solving problems appearing right after the implementation of a medication program for adults. We have approached the crisis in Lodz where patients were refused the right to therapy for the qualification period (a couple of months). **Sending this information immediately to the media and the cooperation with the patients helped to solve the crisis.** We frequently answer the questions regarding social security issues; we consult the applications and provide necessary information. Several times we were creating appeal letter to the higher instances of Social Insurance Institution. **We are for our patients' disposal every day** – answering their questions by phone, e-mails or community networks. We offer them our knowledge, experience and moral support. **Our offer is available for everyone, not only for our Association members, and it is always absolutely free.**

Meetings with patients



We have arranged **more than thirty meetings with patients** in different parts of Poland. Some of them were co-arranged as the part of the 'Focus on immunity-start with diagnosis' campaign. We visited Warsaw, Cracow, Lublin, Lodz, Szczecin, Gdansk, Bydgoszcz, Bialystok, Wroclaw and many other towns and cities. Our representatives were talking about

social security, psychological issues and our Association's activity, they were also sharing their own experiences. The guests-experts were talking about the PID and PID-related diseases. Between the official parts, we have spent a lot of time answering the unofficial questions asked by the patients and their families.

Preferred types of treatment and the quality of PID patients' and their families' lives – the survey

In the beginning of 2015 we have conducted the unprecedented survey focusing on the PID patients preferred types of treatment and their lives' quality. **It was the first time ever that these people, not only the grown up patients but also the young patients' parents, were asked about the quality of their everyday lives.** 46 adults' questionnaires and 36 filled by the young patients' parents allowed us to determine their needs and preferences. This knowledge will help us to adjust our actions to the expectations, at the same time helping the medical staff to adjust the type of treatment to the patient's needs. **The poster showing results of the survey was presented in autumn 2015 at the International Primary Immunodeficiency Congress (IPIC) in Budapest,** being one of the works selected by the Medical Committee. There are plans to have it published in the scientific magazine. Psychologist Bernadeta Prandzioch was the project's coordinator.

Presence in the media – identity building



We care to keep the PID topic constantly present in the media. In recent three years **we have arranged press conferences and sent press releases to the media.** Our press conference in 2014 summarized the genetic diagnostics support project realized in University Children's Hospital in Cracow. Our representatives were present in

nationwide media like **TVP1, TVP2, TVP Info, TVP Regionalna, Polsat, Polsat News, TVN, TVN24, as well as in Gazeta Wyborcza, Fakt, Dziennik Polski, Gazeta Krakowska and many radio broadcasters.** We were putting emphasis to let the patients present their own point of view, based on their personal experiences. This is why, among the others, we were represented by Adrian Górecki, Wojciech Jałoszyński, Albert Tyłzanowski, Aleksander Żalik, Michał Pietrzak or Zuzanna Kwiatkowska.

IPOPI's educational brochures

We translated almost all of the educational brochures published by IPOPI. Among the topics were issues like everyday life of the PID patients (e.g. 'The guide for schools') or medical problems (e.g. 'PID and intestines disorders'). **In total we published thirteen brochures with 1.000 copies of each of them.** They are available in all the PID treating hospitals in Poland.

Communication with patients – social media, newsletter and AdWords

Providing an education and information for the PID patients is one of our crucial goals. There are different tools we use to achieve it. Beside the traditional way of sending educational materials in their printed version we use **professional newsletters** and Facebook fanpage as well. Our website (www.immunoprotect.pl) has been working for the previous five years while now we are going to refresh it and adjust to the mobile devices. All our educational materials, links to the videos, **the map of PID treating hospitals** and our coordinators' contact details are available there. Our mailing database consists of more than **200 addresses** of patients and their relatives. It is our aim to expand it and include the contact details of all immunologists in Poland. Our Facebook fanpage has got almost **400 likes**, while our website is being viewed several thousands times a month.

We have also conducted **an AdWords campaign** helping people **looking for a diagnosis** (and typing into the Internet search engines keywords related to immune deficiency or **frequent infections**) to find our Association's website. We were also trying to optimize our website for the Internet search.

Medical conferences and expert groups participation



All the primary care physicians meet a PID patient at least once in their careers. This is why **we want to educate pediatricists and internists to help them diagnose PID and direct the patient to the special clinic**. We participated in several pediatricists' and internal medicine specialists' Conferences in Gdansk, Bialystok, Wrocław and many other cities. We were inviting immunologists who were

presenting the PID diagnostics issues while we were also distributing our educational materials.

Our President, Mr Adrian Gorecki is **the member of the expert group devoted to the rare diseases, working by Lazarski School in Warsaw**, seeking for the best solutions available for the patients in Poland. We also participated in the meeting of the Parliamentary Group for the Rare Diseases.

Trainings for other patients' organizations

Experience we have gained allows us to train the other patients' organizations' representatives. Our activities have been presented several times as a part of IPOPI workshops, we were focusing on the issues like patients' rights, fundraising or building an organization's image. In 2015 we were asked by Jeffrey Modell Foundation to conduct a training for Central European patients' organizations' leaders in Budapest. Its topic was communication with patients and cooperation with media.

Psychological support

In 2014 psychologist Bernadeta Prandzioch joined our group of volunteers. She is responsible for explaining psychological issues during the meetings with patients. She also offers consultations by phone and e-mail and regularly contributes writing articles for 'Immunoplus' magazine. She was also coordinating research project about preferred types of treatment and the quality of patients' lives.

Family Day in Kruszwica



In October 2014 we arranged **first nationwide weekend assembly of the PID families**. Its leading topic was sport. The participants listened to the immunologist's and pulmonologist's lectures about physical activity of people with PID. After the lectures we organized the workshops with psychologist. We have also found time for **a football tournament** with the patients' organizations' squad and the

local team taking part in it. In the final part of the meeting we went for a short sightseeing trip around the town.

