



Ms Otilia Stanga

Before her present involvement with patient rights and advocacy, she was a graduate of Political Science and Communication from the West University of Timisoara and she had a marketing manager position in a local company. In 2012, her daughter Maia (now 14 years old) was diagnosed with a primary immune deficiency. Since then, she started reading a lot about PIDs, found out about the existence of IPOPI and ARPID and got more and more involved with the Romanian patient organization. After a series of life altering events- finding out about her daughter's illness and the death of her partner in 2013- learning as much as she could about her daughter's condition and about the possibilities for treatment and a life as close as possible to normal for her daughter became her main focus. She studied to become a medical nurse. She researched legal aspects related to access to treatment and to different means of social support for patients and their caretakers, trying to find ways of communication to institutions and decision makers, trying to find the best strategies adapted to the local situations in Romania.

In 2015, she started volunteering for ARPID, offering legal advice for patients, fundraising for projects, being a patient advocate in different meetings, translating patient information leaflets. In 2017, she became the vice-chair of ARPID and after the elections in 2019, she became the chair of the organization. She managed and developed the projects that the organization was already in the course of implementing, continuing to fundraise for these projects and to plan and implement their different activities. She organized editions of the PID children summer camp. She represented the organization in relation with various stakeholders, doing advocacy for patients' rights to treatment and health. In 2018, she conceptualized and put into practice the first patients' conference.

After a very serious immunoglobulin crisis in 2017- 2018, the organization was deeply involved in lobbying for a solution to the crisis and for finding ways of insuring access to this treatment for all the patients who need it. As a result of these struggles, SCIG treatment was introduced for the first time in Romania. In the last years, she was intensely involved in a campaign for creating the legislative and practical infrastructure for plasma collection in Romania, campaign that it is still ongoing.

Despite all the difficulties and challenges this new life brought, after many years of corporate work, she feels like now she has finally found her true self as being one of the voices for the Romanian PIDs patients. She sees her work at ARPID as being intensely personal, in relation to her own family situation but also in relation to all the PIDs patients and all the parents of PIDs kids that she is in constant contact with. Also, she sees her work as being part of the broader frame of the importance of access to health care for all patients as an essential human right.

