



# STRATEGY AND GOVERNANCE

## How to start your national patient organisation in 10 steps

### BEGINNER

→ CREATING A PATIENT ORGANISATION IS A POWERFUL WAY TO MAKE A DIFFERENCE IN THE LIVES OF INDIVIDUALS WITH PRIMARY IMMUNODEFICIENCIES (PIDS). FOLLOW THIS CLEAR NMO-BUILDING ROADMAP, WITH IPOPI'S SUPPORT.

### OBJECTIVES:

- Build a **community of people who face the same challenges** and can **work together** to overcome them.
- Create an organisation to **raise awareness, provide support**, and **advocate** for the needs of patients with PIDs and their families in your country.



### FIND OTHER MEMBERS

Begin by gathering a **passionate, dedicated team for your patient organisation**. **3-7 members** it's a great foundation to build upon.

To find them, ask your doctor for introductions to other PID patients or their families, and use social media.

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# 2

### WRITE DOWN YOUR VISION AND A LIST OF ACHIEVABLE GOALS

Even if you start small, you can always review your goals later and make them even **bigger!**

# 3

### JOIN IPOPI

**Contact us** and we will help you along your journey.



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## MAKE IT LEGAL! IT'S TIME TO REGISTER YOUR NMO

What are the rules for establishing a patient organisation in your country?

Research and get started! Typically, you'll **need a board of at least 3-4 members** (President, Vice-President, Treasurer, and Secretary) and a written Charter.

Check out how to write a charter [here](#).



## IDENTIFY THE NEEDS OF PID PATIENTS IN YOUR COUNTRY

Contact the **doctors and nurses**, contact as many **patients** as you can. **Talk with them.**

You may want to use the **IPOPI PID Life Index** to understand the situation in other countries.

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## MAKE AN ACTION PLAN AND WRITE A BUDGET

Create a **clear and practical** plan outlining the steps, strategies, and timelines to achieve your goals. Simultaneously, **plan your budget**, considering the financial resources required.



## YOU NEED MONEY FOR YOUR PLANS! START FUNDRAISING!

Explore options like contacting potential sponsors (state funding, plasma industry, or major renowned brands) and combining fundraising with awareness campaigns, such as organising a PID run or walk. [Learn more about fundraising here.](#)

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## 8



### FIND VOLUNTEERS TO HELP

Recruit from friends, patients, family, young doctors, nurses, or university students. Once financially stable, consider hiring staff to manage daily operations.

### START YOUR PROJECTS!

Some ideas for the beginning:

- **Education:** webinars, leaflets, and patient meetings.
- **Awareness:** create your own webpage, social media account, and develop a digital campaign.
- **Advocacy:** learn how to speak with authorities in your country and how to plead for PID patients.

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## 10

### LEARN! LEARN! LEARN!

You can find plenty of resources on the [IPOPI website](https://www.ipopi.org).

Join our NMO webchats, and hard talks, follow us on social media, and apply for travel grants to attend IPOPI's in-person meetings, where you can connect with global peers.