Why start your own national association?

guide for patients, caregivers and advocates who want to bring IgG4-RD tient representation to their own country.

ublication of the European Federation of IgG4-RD Patients · Established September 2025 · Based in Brussels

Our purpose

The recently established (September 2025) European Federation of IgG4-RD Patients has, as one of its primary goals, the objective to support patients with IgG4-RD who want to set up their national association. The aim is to help patients meet other patients, to represent them at a national level, to increase awareness of the disease, and to promote improved diagnosis and treatment in centres of excellence in their own country.

We strongly believe that all European countries need patient representation at a national level to improve the quality-of-life outlook for what has been, to this day, a lonely road for most of us.

The hurdles — and why you don't need to face them alone

There are many hurdles to overcome when setting up an association: the legal process and cost, opening a bank account (harder than you think), finding patients despite the GDPR rules, establishing good governance, linking up with other stakeholders such as specialist doctors, sponsors and subsidy providers. We have been through all of this at an international level, and the Federation is here to support you on every level.

What the Federation offers

Stature and a European voice

- Membership gives you immediate stature: a Federative Medical Board with some of Europe's most respected IgG4-RD specialists, close ties to the European specialist network, a legal entity based in Brussels, an established board and bank account.
- Voting rights at European level — jointly decide policies and objectives, learn from each other, build momentum together.

Practical, financial and legal support

- Initial financial support for the legal setup of your association, subject to a simple agreement.
- Draft statutes and other foundation documents (e.g. for setting up a national Medical Board).
- Guidance throughout the registration process in your country.

A ready-to-go website and content

- An empty country website (yourcountry.igg4.eu), free of development cost, ready for you to fill in: contact details, board, objectives, events, country-specific medical information.
- Authoritative, pre-approved medical content on the disease, diagnosis, available treatments and outlook — so we speak with a single, reputable voice.
- Multilingual CRM, freedom to add appropriate redirect domains, and your own colour accents alongside the Federation brand.

Brand, marketing and visibility

- A complete marketing toolkit including your unique country logo and a library of illustrations of real patients and doctors.
- A subscription to Canva, pre-loaded with your logo and the Federation brand components, to make social media posts effortless.
- Templates for presentations, banners, posters, leaflets and more — all in the joint brand with your own country logo.

Real patients, real photography

- Free-of-rights access to a database of real IgG4-RD patient and doctor photography — we stay away from AI-generated or stock illustrations because we are about real people.
- Funding for new photography of real IgG4-RD patients in your country, on the condition the rights are shared between the model, the association and the Federation.

Sponsorship and partnerships

- Assistance in obtaining sponsorship from pharmaceutical companies and navigating the often-complex approval procedures.

> **The single voice, single look principle.** All medical publications are aligned with the Federation's medical board, while country-specific topics (insurance, national specialist centres) remain yours. The single look means strict use of the brand book guidelines, with your own logo — uniformity across associations strengthens awareness and recognition for all of us.

The initial requirements

- There is no IgG4-RD patient association in your country already affiliated with the Federation.
- A minimum of three IgG4-RD patients (“The Group”) willing to take on roles in the first national board (typically chair, secretary, treasurer).
- Only IgG4-RD patient members hold voting rights in the association (carers and others may join as members).
- The Group does not adopt statutes detrimental to IgG4-RD patients or to other federative associations.
- The Group becomes a member of the Federation and adheres to the “single voice and single look” principles.