



TWINNING

A proposal for IPOPI NMOs

It is envisaged that an IPOPI twinning programme could become a service that improves the care of patients with PID throughout the world. ESID and other regional organisations for doctors are already engaged in sharing programmes for doctors and nurses and the IPOPI proposal is to have similar sharing available to national member organisations.

Twinning could play a critical role in a country. Regular support and coaching through twinning helps a patient organisation become a driving force for change and progress. It has been shown that national patient organisations effectively promote access to PID care. National member organisations (NMOs) are a powerful voice representing the interests of patients. The challenges grow and we must all grow with them.

The IPOPI Skills Manual is a starting point for developing strong and effective NMOs. But the advantage of twinning is that you become involved with people who have past experience to share with you. By developing partnerships between emerging or vulnerable NMOs with well-established, knowledgeable and experienced NMOs there will be an increase in both experience and expertise. And it is not only the new, emerging or struggling NMO that will benefit: the experienced and well-established will learn new things as well!

Our newer NMOs must develop national policies and goals, understand the realities of their regions and appreciate the global reality for people with primary immunodeficiencies. Our community is global and we must work together to achieve mutual goals.

WHAT IS TWINNING?

Twinning is a FORMAL, TWO-WAY COLLABORATION or PARTNERSHIP between two IPOPI NMOs.

Twinning is FORMAL because the NMOs must arrange a verbal or, preferably, written agreement about the twinning agreement or project. Twinning is NOT one organisation giving to another. It is TWO-WAY because the twinned NMOs work together, share information and are both better off as a result. Twinning fosters this collaboration and partnership.

BOTH partners must gain for twinning to be a success. Partnerships where the established organisation views itself as the 'giver' are at risk of being unbalanced.

WHY IPOPI TWINNING?

If established, twinning will enable/facilitate a network of co-operation between national PID organisations around the world. Established NMOs have knowledge, experience and resources. Transfer of those can be used to help emerging NMOs reach a level of performance that directly benefits people with PIDs.

THE OBJECTIVE

The objective is to strengthen NMOs who are emerging or struggling so that there is an improvement of PID diagnosis and management in their country. The direct association with IPOPI enhances the transfer of skills and knowledge between established and emerging NMOs. The skills that are transferred may relate to patient advocacy, management, fundraising and public relations. Through co-operation and partnership, PID patient organisations are strengthened.

TYPES OF TWINNING ACTIVITIES

Twinning activities can be based on something twins have in common, such as shared language or culture. Activities can also be chosen based on the strength of one twin or the needs of another.

Some of the main types of potential twinning activities are outlined here:

- **VISITING** your twin to meet them, collect information and assess a situation is called an assessment visit. Assessment visits are a way to exchange information and ideas. Training itself does not take place on assessment visits.
- **TRAINING** is a way to pass on knowledge, values and skills. Training can be formal or it can be an informal exchange of knowledge about fundraising, membership, volunteer and board development, government relations, publications, policy making or strategic planning. Training can be held on-site or via exchange visits. On-site training is when staff, board members or volunteers from one twin train others at the site of their partner. Exchange visits are when both twins sent people to visit the other so both partners become familiar with each other's situation.
- **EXCHANGING INFORMATION** – such as publications or materials for doctors and/or patients. You could also share information by telephone, fax or e-mail. Sharing information should happen regularly and should be two-way.
- **NETWORKING** through something like a friendship exchange scheme or a pen-pal link between two NMOs
- **SUPPLYING IMMUNOGLOBULINS** is **not** a priority activity as it is not a sustainable activity. *Working with a twin so that a regular national supply of Ig is available is the sustainable solution.*
- **WORKING TOGETHER ON SPECIAL PROJECTS** such as summer camps, workshops, awareness campaigns or national conferences is a great way to achieve success.

THE BENEFITS OF TWINNING

Some of the benefits are outlined below:

- Capacity building: this is about transferring skills and knowledge. This leads to more capable organisations that are better able to provide PID services. *Strong patient organisations are a driving force for change and progress.*
- Sharing of best practices: 'Best practices' are methods and strategies that have been used by others and were found to be effective. Twinning is a way to share techniques and interventions that have been shown to work well in other areas. Learning about these best practice approaches can save groups valuable time and effort.
- Encourages collaboration: Collaboration is about working together. Twinning allows organisations to work together on a project that interests them both.
- Builds relationships: Twinning helps to build strong relationships among PID organisations. These relationships become important when an organisation has a need. People from one organisation can turn to their twin for help or they can work together on a specific issue.
- Offers new challenges: Twinning offers new challenges to established NMOs. A new challenge can energise an organisation and offer a chance to increase experience and expertise.
- Promotes solidarity: Twinning helps to create a feeling of belonging to a larger community – a global family. It is also a way to be inspired by others. Inspiration empowers people to work for rights and services for the PID community.
- Broadens horizons: Twinning helps you to reach out to others, break down barriers and learn about other cultures. It broadens your horizons to see how PID affects people in other parts of the world.
- Builds a global movement: Twinning is a way to build a successful global PID network that includes everyone. This is important because PID affects people from all over the world. Global events influence PID healthcare policy, funding and development