

Multi-Annual Policy Plan 2021-2025

ITP Patient Association Netherlands



Adopted General Members' Meeting
25/06/2022

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1. INTRODUCTION

1.1. Why a multi-annual plan?

A multi-annual plan is a plan determining the direction the association wants to pursue in a given period. It serves as a guideline for the directors of the ITP Patient Association Netherlands. The association will celebrate its 20th anniversary and will become a 'mature' association in 2023. A new policy period and a relatively new board started in 2020. Numerous developments, which are still ongoing, took place in the last five years.

Reflecting on the past period, we can see that a lot has been achieved. Various projects (such as choice assistance and participation tools) have been completed and other projects are well on their way (VBHC). We were involved in the new ITP guideline and are glad that the Netherlands Association for Haematology (NVvH) has approved it.

The communication with the medical specialists is pleasant and allows us to keep track of the developments and, if necessary, explain these to our members.

The policy and the priorities related to these activities will be adopted by the General Members' Meeting every year following proposals by the board. The policy plan 2021 - 2025 contains the general elements of the policy intentions of the board for this period. As a result, it does not only serve as a guideline for the directors of the ITP Patient Association, but also for the other volunteers. It also offers the individual members greater insight into what they may expect from the ITP Patient Association. It provides information about the activities in the years to come and the priorities that will be adopted in particular.

The plan also offers direction for meetings with third parties like the pharmaceutical industry and healthcare providers. Sound cooperation in all fields enhances the position of the ITP patient.

The policy plan must be considered a framework but is not restrictive. The Patient Association will respond to current developments, if desired.

1.2. History

The ITP Patient Association Netherlands was founded in 2003 and passes the threshold of 650 members in 2021. The association has grown into an expert organisation in the field of the rare illness ITP over the years.

The association has the following statutory object:

- promoting the well-being of persons with ITP
- promoting and organising education
- organising peer meetings
- organising and promoting advocacy
- promoting scientific research

In the past years, a lot of work has been performed and a lot has been achieved: the administrative records and financial status are in order, the information desk of the association operates professionally (both with respect to its process and substantively) and guarantees sound services for the members.

Numerous, high-quality educational materials have been developed and are kept up to date, the website has been renewed and works well, and the brand style is recognisable. Peer contact days are professionally organised, visited well, and appreciated, and the forum on the private section of

the website is reasonably popular. Besides the known resources, additional new tools have been deployed in the past years, such as social media and webinars, and support group meetings were introduced.

Important steps in the field of advocacy have been made since the incorporation of a Medical Advisory Council in 2012. This Medical Advisory Council still serves as an important driving factor for increasing the expertise of the ITP Patient Association. In addition, we cooperate at a national level with knowledge centres, the VSOP, and PGOsupport, and contributed to the creation of the ITP expertise network. The UWV is also a regular interlocutory of our association. The ITP Patient Association is also embedded in the international environment with the sister organisations and the International ITP Alliance.

2. GENERAL DESCRIPTION OF THE ASSOCIATION

2.1. What characterises the ITP Patient Association?

The ITP Patient Association is convinced that everyone in society counts, irrespective of any incapacities.

We strive to support people with ITP and their loved ones to ensure that they can participate in society without any restrictions.

We aim to increase the insight into the (consequences of) the illness ITP. In practice, this means that we establish contact between patients to exchange experiences and closely monitor the latest developments in close contact with medical experts.

Where necessary, the association serves as an advocate. Everything takes place in close consultation between the board, volunteers, and members.

2.2. Mission & Vision

The ITP Patient Association has **the vision** that insight into the own illness and support by the association will lead to (greater) active participation of patients with ITP in society and that this is an important condition for the well-being and a meaningful and fully-fledged life for everyone.

It is our **mission** to offer our members and their loved ones this insight by communicating with each other and specialists and encouraging our members to communicate well with their healthcare provider to jointly take a decision about the treatment.

We collect and distribute information and share our experiences. We connect and support. We promote the interests of the members by providing healthcare providers and third parties (the government, benefits agencies, employers, and educational institutions) with information about the disease of ITP.

2.3. Core values

The core values of the ITP Patient Association are:

Equality

Everyone is equal. Patients with ITP experience limitations to a greater or lesser extent, both physically and mentally. However, they remain equal as humans. As a family member, student, member of associations and/or organisations, essentially, as a participant in society.

Connecting and supporting

Shared values lead to a sense of community. We introduce patients/peers to each other to have them experience recognition and support from each other.

Gathering and sharing knowledge

Information is there to be shared – by definition. We look for new insights and methods as extensively as possible and share these with each other. This is the only way to ensure information is valuable.

Cooperation (without limits)

We do our work with others. The board with the members of the association, other volunteers, medical specialists, social organisations, and (internal) sister associations. Together, we make up a large network. We make use of our knowledge, skills, and qualities.

3. ANALYSIS

This chapter consists of various sections, internal analysis, external analysis, and the strengths-weaknesses analysis. Using these sections, this chapter analyses and studies the current situation of our association.

3.1. Internal analysis

We use an internal analysis to attempt to identify the strengths and weaknesses of the association. Once we have identified these, we can determine the potential improvements of the association to handle threats and the strengths to make better use of opportunities.

We look at the following elements:

1. Board and structure
2. Members
3. Volunteers
4. Housing
5. Activities
6. Internal communication
7. External communication
8. Finances
9. IT

1. Board and structure

The association is managed by a board consisting of five members as of 2021. Based on the articles of association, the board must consist of at least three and no more than nine board members. The board, made up exclusively of volunteers, carries out the administrative duties and is supported by a group of volunteers carrying out specific tasks.

There has been an editorial board to prepare the Newsletter since 2020. The complaints committee, an independent body consisting of three members, was founded by the General Members' Meeting in 2020.

Our association has had a Medical Advisory Council since 2012, which consists of various (paediatric) haematologists, who voluntarily meet with a delegation of the board twice per year and are always willing to offer advice. They also often provide substantive presentations on the contact days or in the Webinars.

The board has the following focuses as part of its structure:

- Internal organisation,
- Secretary,
- Finances,
- Internal and external communication, and
- Advocacy

The balance between the number of hours and the numerous activities is inadequate. This can change by introducing priorities and phasing.

Developments in society demand increasing expertise from the board. The Dutch Act on Management and Supervision of Legal Entities (WBTR) took effect on 1 July 2021, for example. We, as an association, comply with many aspects of this act, but we have to take action on others. For example, the articles of association will need to be amended. The WBTR observes a period of five years for this, taking effect on 1 July 2021. We will need to amend it in the course of the policy plan.

It is important to the continuation of the association that the voluntary directors can continue to handle the executive duties. To date, it became clear that friction may arise because not everyone has the same time available and all board members currently suffer from ITP themselves. For this reason, the board introduced a pilot based on which the back office is housed with an external organisation. This back office conducts a number of administrative duties, such as secretarial work, taking minutes, arranging the finances, website management, and help with organising the contact days. This gives the board more time for its executive duties and the substantive management of the association. The pilot will be assessed in mid-2022. Meetings were held to determine how this can be achieved in September 2021. This was also proposed to the General Members' Meeting on 9 October 2021 and we have included it in the budget for 2022. As a patient association, we can apply for a grant from the Ministry of Public Health, Welfare and Sports (VWS) for this goal. This grant has now been requested and granted.

2. Members

The association has almost 680 members in mid-October 2021. A great increase, particularly in 2021. Many new people joined because of the corona pandemic and the related questions about vaccinations. Statistically, approximately 1700 people in the Netherlands suffer from ITP. This means that around a third of these people are a member.

What are the characteristics of our members? Over 65% of our members are female, almost 35% are male, and the sex of a few of our members is unknown. The majority resides in the Netherlands, but we have about 15 Belgian members, as well as members in Germany, France, Cyprus, and Surinam.

The distribution of our members per province, as set out in figure 1, predominantly coincides with the size of the provinces. The provinces of North Holland and Utrecht are slightly overrepresented, while the provinces of Gelderland and Limburg are slightly underrepresented considering their population.

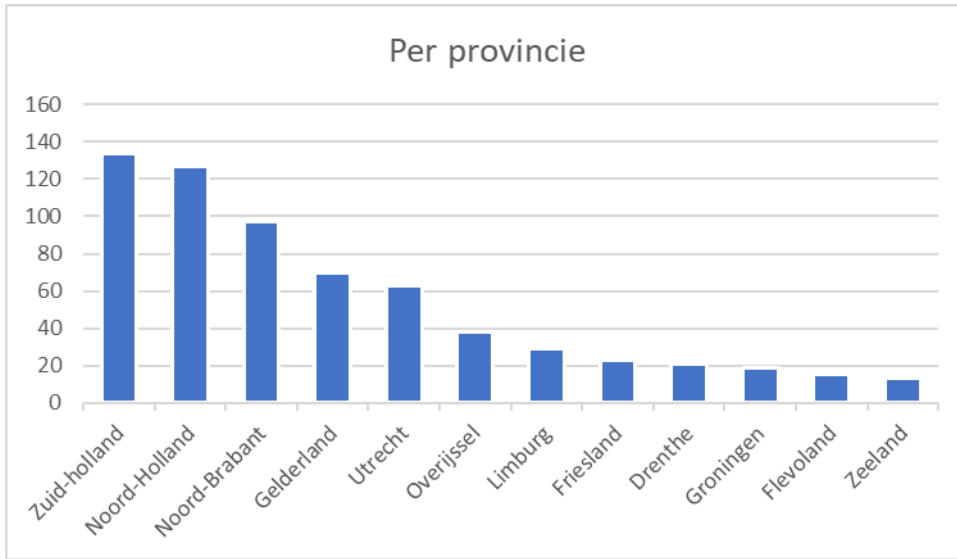


Figure 1. Distribution of the members (649) based on province

Figure 2 shows the distribution of the members based on age with a peak in the category of 51-60 years. This is not surprising, considering the fact that (chronic) ITP is often diagnosed after the age of 50. It is often temporary in children.

Figure 2. Distribution of the members (649) based on age

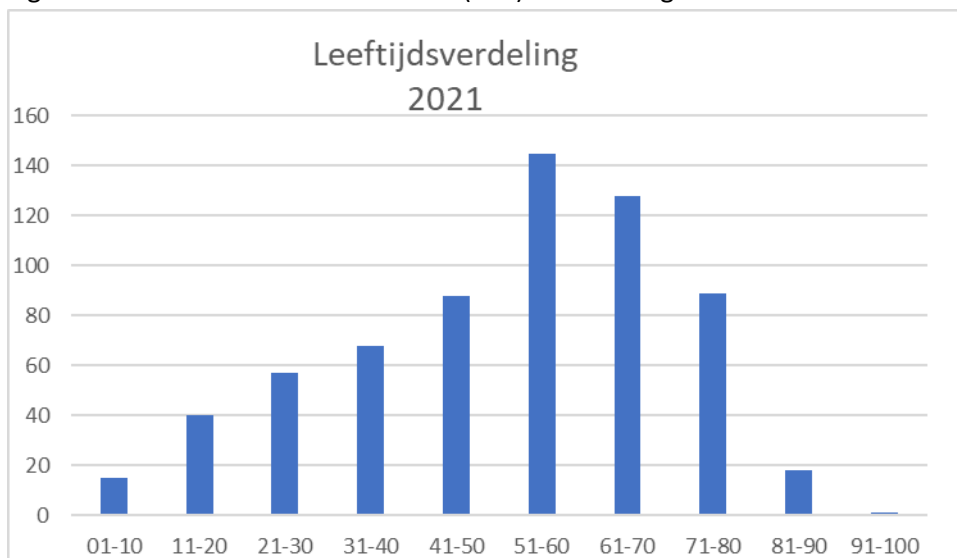


Figure 3 shows when our members joined. The association was founded in 2003; the ITP patients were members of the Haemophilia Association before that. This explains the number of members joining in 2003. The growth in 2021 also stands out. This is predominantly due to the corona pandemic and the concerns related to the vaccinations and the impact on the clotting processes.

Figure 3. Start of membership of current members (668)



Members pay an amount of €25 to join. The patient association is a Public Benefit Organisation (ANBI) and is acknowledged as such by the Dutch Tax and Customs Administration, which means that contributions qualify as tax credits if the threshold is reached. Members can participate in the activities of the association and bring guests in exchange for payment. Relatively a lot of use is made of this option. The contact days with the General Members' Meeting drew a lot of visitors (around 100), and the Webinars introduced in 2020 were also popular. A survey conducted at the start of 2021 showed that the Newsletter is an important source of information. There is currently no membership plan, which we define as a plan which studies and describes the method of maintaining the existing members and the recruitment of potential members. We conduct our membership administration in the online e-Captain membership administration and partner management system. We also use this system to distribute our Newsflashes and other emails sent to the members, as set out in 5 below.

3. Volunteers

Currently, the ITP Patient Association can operate thanks to the efforts of volunteers. Besides the board and committees set out in item **1 Board and structure**, there is a number of other volunteers, internal communication (forum at the private section of website, columns), support groups, advocacy, IT, and updating information brochures. Mid-2021, there are 16 volunteers working for the association. This is a relatively small percentage of our members. There is a desire to increase this share in the future. Volunteers can also be deployed on projects.

The volunteer policy is an area of concern in the years to come. One of the board members will develop the policy and adopt the responsibility of staying connected with the volunteers to increase their commitment to the association.

4. Housing

The patient association does not have its own building or office. This is not needed to date. The board meets at a central location in the country and rents a meeting space, usually at PGOsupport in Utrecht. Administrative work is done from home. The association rents a fitting location for most of our activities, such as the General Members' Meeting and contact days. A space in a hospital is often used for regional information evenings.

We also use digital tools like Webinars or Teams for contact.

Meetings of support groups will possibly take place at the home of one of the members in the future.

The association rents storage space for its brochures and materials.

5. Activities

The association offers separate activities to adults and the group of children and adolescents (up to the age of 20). The activities are varied and aimed at support, networking, gaining knowledge, informing, meeting, and establishing connections. These activities are organised by the board and communicated using the regular channels. For some activities, we ask a minor contribution to the organising costs. Sometimes, we collaborate with external parties to organise an activity, such as the pharmaceutical sector. The ITP Patient Association tries to organise activities throughout the Netherlands as much as possible to ensure all regions are attended. The organisation also organises informal regional meetings throughout the country. The support groups have been organised online to date because of COVID-19.

The members are repeatedly asked to review the activities to enable us to keep the feedback in mind for the next event. At the start of 2021, a large survey was held among the members with questions about wishes and ideas for activities. This led to a good response that also served as input for this policy plan.

6. Internal communication

The members are informed through various channels. The website of the ITP Patient Association is an important element of the association. Besides the provision of information about ITP and potential treatments, there is a page where the members and non-members can be informed of all ongoing activities, projects, and activities of other organisations. There is a member section with a separate login where members can communicate with each other using the forum and where documents can be found that can only be used by members (reports on contact days, videos). A digital members' newsletter is published a number of times per year – the Newsflash, with the latest news about the association, activities organised by the ITP Patient Association, or interesting developments. The Newsletter sent by mail to all members is published three times per year. The Newsletter contains the latest developments, updates from the board, the calendar for the coming period, columns, and stories by patients about their experiences. Each newsletter has a theme.

Social media is also an important element of the internal communication of the ITP Patient Association. The private Facebook page is used frequently for questions of members. The members use this page to communicate with each other. However, not all members are active on Facebook. Sometimes, this is a deliberate choice, but sometimes it is not. We can pay more attention to this.

The members and non-members can always reach the board by email and make frequent use of this option. The association has its own phone number that is answered by the board.

7. External communication

Contact with external parties is especially important to the Patient Association and is maintained properly for this reason. Our website is an important source of information about our association. It is currently available in Dutch. There is also a public Facebook page, a LinkedIn account, and an Instagram account. Our brand style is easily recognisable.

We stay connected with the pharmaceutical industry. The various manufacturers of a number of drugs that play an important role in the new guideline keep in frequent touch with us. Numerous instruction materials are developed in consultation. Our members are often asked about their experiences with the various drugs.

The association attends various conventions to ask for attention for ITP patients. We also attend these conventions to share information. Examples are various national and international haematology conventions. We also collaborate with sister organisations in around twenty countries, all members of the International ITP Alliance.

The external communication expresses the desired mood and culture. External parties rely often on the ITP Patient Association. In order to manage this better, a communication plan and/or content calendar are being developed to enable us to schedule our time more effectively.

8. Finances

The ITP Patient Association is a financially healthy association. We are an association and the members pay a membership fee of €25 per year. The main source of income of the association is the annual subsidy from the Ministry of Public Health, Welfare and Sports.

The current policy framework of the Ministry was amended in 2019. The period from 2019 to 2022 is considered a transitional period. The amendments will be in force until 1 January 2023. After this period, the policy framework will be revised. We will have to handle this in 2022. The direction of the developments is uncertain. The ITP Patient Association has established a risk reserve in the past to address any negative consequences in this respect.

We use e-Captain for our financial administration, as well as for our membership administration. This ensures that various data are connected. An accountant checks the records every year. This accountant also prepares the annual accounts.

9. IT

The ITP Patient Association makes increasing use of IT resources. Laptops have been provided to the board on loan. The Office 365 package on these laptops is used by the board and (partially) by volunteers. This package makes it possible to share documents and, if desired, work on them together, but also to meet online or organise meetings. This has had a positive impact, specifically in the corona period, during which physical contact was not possible.

The e-Captain Internet application is characterised by a modular design. The ITP Patient Association uses various modules to manage our membership file, conduct and register payments, financial records, the website, activities management, and mailings.

3.2. External analysis

The external analysis aims to gain insight into the opportunities and threats of the environment in which we operate. This helps us define the strengths and weaknesses analysis. The external analysis is ultimately also particularly important for determining the strategy of the association.

We look at the following elements:

1. The Patient Association as an organisation
2. Role of the ITP Patient Association in the medical world
3. Role of the ITP Patient Association in relation to the pharmaceutical industry
4. Trends
5. Opportunities and threats

10. The Patient Association as an organisation

The ITP Patient Association can be considered an association with (inter)national relevance. It is the only one of its kind for the rare illness of ITP in the Netherlands. The association has outspoken, self-aware, and well-educated members that raise the bar for the association. The ITP

Patient Association Netherlands performs at the level of other well-operating patient associations, both nationally and internationally.

This means that the association is repeatedly called on to arrange lectures, visit conventions, participate in discussions, or make written contributions.

The patient association is gaining an increasingly important role in patient representation in society as a whole. There is a structure of organisations performing a supporting role around the patient association, such as PGOsupport and the VSOP for rare illnesses. The government also pays attention to this partnership in society and there are various subsidy flows that can be used by patient organisations, as set out in the finances section of the internal analysis. This is addressed by other organisations that offer their services in the field of back-office support using available subsidies.

11. Role of the ITP Patient Association in the medical world

An increasing number of medical centres in the Netherlands want to be considered expertise centres. This is good because this can lead to greater knowledge about the causes, consequences, and treatments of ITP. The ITP Patient Association advises the Ministry of Public Health, Welfare and Sports (VWS) about acknowledging a medical centre as an expertise centre.

The ITP Patient Association has extensive contact with specialists and medical centres (expertise centres). The Patient Association does not only serve as a “retriever”, but also as a “bringer” and “motivator”. Of course, the Patient Association retrieves information and insights but also encourages the medical world to conduct research or exchanges (international) knowledge. Knowledge about ITP is not always perfect or up to date at the level of first-line care (including general practitioners). Haematologists, too, are not always aware of the state of affairs related to, for example, the new guideline.

The role of the ITP Patient Association is not only limited to that of an advocate, but we actively contribute to tools and projects, such as the labour participation tool, the Value-Based Healthcare project, and the ITP expertise network.

12. Role of the ITP Patient Association in relation to the pharmaceutical industry

Pharmaceutical companies like to call on the ITP Patient Association. For example, to conduct surveys among the members or to develop brochures or interactive (video) platforms.

Where relevant, pharmaceutical companies sponsor patient associations.

Our association does not have any principal objections to sponsoring, but always wants to preserve its independence. Influence over the association by pharmaceutical companies is undesirable.

However, it is important to share information and experiences needed by the pharmaceutical industry for the development of new medications. On the other hand, we require the pharmaceutical companies to share the knowledge accrued in this manner with us to give patients insight into their illness.

13. Trends

The healthcare sector is in the spotlight, particularly due to the corona crisis. The share of the healthcare sector in the national economy is around 12%. Almost 16% of the labour force works in the healthcare sector. Rabobank and ING regularly publish economic updates about the healthcare sector. Because of corona, there remains great pressure on the curative care sector. Work pressure in long-term care is also increasing and the situation has not yet normalised. ING argues that it is important to make investments on two sides in the coming period. Both in prevention to reduce the increase in chronic ailments and to improve the mental and physical resilience of people, and in healthcare itself: by investing in healthcare professionals, informal caregivers, volunteers, and digital resources that make it easier for people to make use of care while reducing the pressure on the healthcare sector. The Rabobank also points out similar developments and

emphasises digitisation and medical technology. “The healthcare sector wants to move 10 to 15% of the care from the waiting room to the living room in the coming five years”, states Rabobank. This requires sufficient healthcare and technical staff, adequate financing, and the right medical technology. Refer to the bottom of this policy plan for a link to the various websites.

However, the patient receives little attention in these sketched developments. “Diagnosis 2025” is the name of the contribution by the Zorgmarketing platform which points out the trends in the healthcare sector. These trends were set out in 2010 but were updated in 2021. Also refer to the website references at the bottom of the policy plan. The following trends are relevant to the ITP Patient Association:

- Greater differentiation in healthcare consumers: more customisation, targeted, more customer-oriented approaches. The right care at the right place at the right moment.
- More DIY care: the client increasingly becomes a market party. This means that there will be more providers of healthcare products, based on which clients will have more options.
- Higher expectations with respect to healthcare quality and experience: more attention paid to quality.
- Greater uncertainty due to sense of insecurity and complexity: taking into account feelings of insecurity.
- A longer, healthy life: the most important healthcare customers are the elderly.
- Everyone is a patient: more chronic illnesses and regular occurrence of several ailments.
- Health is a choice: greater attention is paid to lifestyle.
- Digitisation of the consumer–healthcare interaction: a shift from physical to digital. Digital will become the new normal (eHealth).
- A more targeted approach using medical technology: more tailored healthcare using technologies.

Another visible or developing trend is positive health. This is a way to take a broader look at health. For a long time, we considered health the absence of illnesses and limitations. This is no longer the principle, instead, health is the ability to adapt as a person, to be in control. Is the client adequately self-sufficient, for example? Does he or she feel happy or lonely? Or is there medical care or support needed from the environment? It is important that all people feel healthy and energetic in the manner that suits them. This more dynamic approach does justice to people and what is meaningful to them. In addition, positive health is a method: using six dimensions, the so-called spider web, people can identify their own health status and use it as a guideline for discussing health and well-being.

14. Opportunities and threats

The trends set out above lead to a number of opportunities and threats. More attention paid to the role of the patient, the client, interaction with healthcare providers, and digitisation can be considered opportunities. Digitisation, in particular, takes place in an increasingly pressurised labour market. At the same time, digitisation is occurring in a variety of fields and can also be considered a threat. Digital care leads to questions about the collection of data. Who may do something with these data? And what happens then? A balance between more efficient care and the interests of the (healthcare) user requires continuous attention. Digitisation in the healthcare sector can also exclude people with limited digital skills. Particularly the elderly, people with a migration background, poor families, and the mentally incapacitated have difficulties keeping up with digitisation. The risk of increasing digitisation is that human contact and the human factor move to the background. This also happens in other sectors, but this personal, human contact is essential in the healthcare sector.

Attention paid to positive health can be considered an opportunity. This is a different role of a person as a healthcare consumer, and it prepares the client better for the appointment with the physician. At the same time, the change from patient to healthcare consumer can be considered a threat. The consumer wants to receive immediate service.

3.3. Strengths-weaknesses analysis (SWOT)

The internal and external analyses jointly lead to the strengths-weaknesses analysis of the ITP Patient Association. The internal analysis leads to the strengths and weaknesses. The opportunities and threats mainly arise from the external analysis but are also based on the internal analysis.

Strengths	Opportunities
Professional association <ul style="list-style-type: none"> • Expertise • Advocacy • Medical Advisory Council • Organisation in order • Finances in order Unique Stable number of members Commitment of volunteers Provision of information and activities offered to members	External support (back-office) Digital highway, eHealth Exposure thanks to 20th anniversary <ul style="list-style-type: none"> • Growth in the number of members • Awareness of ITP Attention for 'Positive health' Increasing interaction between physician/patient (deciding together) Paediatricians on Medical Advisory Council International relationships
Weaknesses	Threats
Harder to reach children and adolescents Work pressure on volunteers <ul style="list-style-type: none"> • Level of professionalism can scare away potential volunteers (board members) -> bar is (too) high • Embedding expertise • Small core of volunteers outside of the board • Relationship with the board 	'Consumerism' Generating and maintaining attention for this rare illness Digital developments are impossible to keep up with for a number of members External pressure (increase in external questions) Development of subsidy channels as of 2023

4. DESIRED SITUATION OF THE ITP PATIENT ASSOCIATION

Based on the paragraphs above, we can define a common thread for the future:

The ITP Patient Association will continue its current direction and activities to maintain and optimise the quality of its work and the advocacy for its members.

This is why we define the following important aspects for the years to come:

1. **Balanced internal organisation**

Why: because the (high) ambition level may not demand too much from the organisation. The association has a relatively small group of volunteers. This makes us vulnerable.

This leads to the following important topics for the following years:

- Expanding the pool of volunteers;
- Sticking to the defined goals as set out in the annual plan.

2. **Consolidating the current association in terms of content and organisation.**

Why: because we believe that we are heading in the right direction with our extensive and high-quality range of activities for the members, the sound relationships with external contacts such as the pharmaceutical sector and our sister organisations, our presentation using the new website, both in Dutch and English. But also because we are a professional association with its organisation and finances in order.

This leads to the following important topics for the coming years:

- continuing to organise the contact days, regional meetings, and webinars,
- (continuing to) participate in meetings of sister organisations and national and international haematology conventions,
- Contributing to requests by the pharmaceutical industry,
- Paying attention to going concern, membership administration, finances, IT, and organisation, including using a back-office,
- and paying attention to new developments, such as the Dutch Act on Management and Supervision of Legal Entities (WBTR).

3. **Enhancing “recruitment of members” and “maintaining” existing members and volunteers.**

Why: because it is unfortunate that we cannot assist and reach more ITP patients with our activities and efforts, particularly adolescents and children. In order to do so, we will focus both on support from a back-office organisation and on increasing our pool of volunteers, as part of which we will need to determine how we can activate our members.

This leads to the following important topics for the coming years:

- Regularly supplementing and updating our website, both in Dutch and English,
- Continuing with existing internal communication tools (Newsletter, Newsflashes, Forum),
- Updating brochures, developing new brochures where necessary,
- Developing videos of adolescents in cooperation with third parties,
- Developing social media campaign to increase our online visibility,
- Increasing the awareness about ITP through the 20th anniversary of the ITP Patient Association in 2023,
- Defining and expanding volunteer policy,
- Creating a closer relationship with existing volunteers, including by means of volunteer days.

4. Advocacy through the relationship with the healthcare sector and the patients.

Why: ITP is a rare illness and relatively unknown, including among healthcare providers and diagnosed patients. A stronger relationship with the healthcare sector and the patients enables us to provide more information and generate awareness. The physicians of the Medical Advisory Council can serve as a starting point for this aspect.

This leads to the following important topics for the coming years:

- Regular contact with the (members of the) Medical Advisory Council,
- Regular contact with the Expertise Centres,
- Regular contact with the UWV,
- Generating awareness about ITP through the anniversary in 2023.

5. Attention paid to Positive health

Why: People with a positive mindset are happier and feel healthier. This is why the Patient Association always works using positive energy. What is possible? The specialists are focused mainly on treating the ill, dysfunctional part of the person based on their profession. Positive Health is based on what is possible, the things that are important to the person himself/herself. This demands a different role from the healthcare sector and the patient. Positive Health is a relatively new concept and we want to increase the awareness of this concept in our role as a patient association.

This leads to the following important topics for the coming years:

- Organising instructions through lectures and webinars,
- Organising workshops,
- Talking with the Medical Advisory Council.

6. Transfer of knowledge about ITP

Why: general practitioners, the education sector, the UWV, and others generally have insufficient knowledge about (the rare illness) ITP. Patients often need to tell others what they are suffering from after the diagnosis. The ITP Patient Association is studying what it can do in this respect. Digital developments (like eHealth) may contribute to this.

This leads to the following important topics for the coming years:

- Initiating research in consultation with the expertise centres,
- Contributing to Cyberpoli.nl,
- Continuing our contributions to the Expertise Network,
- Visiting (inter)national conventions and symposiums,
- Keeping existing information platforms up to date with the pharmaceutical industry.

5. IMPLEMENTATION

The board presented the general elements of this multi-annual plan at the GMM in October 2021. The mission, vision, core values, and strengths-weaknesses analysis were discussed. The prioritisation of the activities for 2022 was also presented. The policy plan will be presented to the members for adoption in the GMM of spring 2022.

Ambitions and actions will be copied to and developed in detail in an annual plan which will always be presented in the GMM taking place in the latter half of the year in the form of an activities plan. The board must ensure that the policy goals are communicated and pursued.

Regular evaluations will take place to determine whether we are still on the right track or whether changes need to be made.

We expect to be able to present the ITP Patient Association as the leading party for ITP patients, medical professionals, the pharmaceutical industry, and healthcare providers by means of this policy plan and the mentioned ambitions. We anticipate the future, increase the reputation of the association, and, of course, want to offer the greatest possible assistance and support to our members.

This policy plan will be updated four years after this date (2025).

6. ANNUAL PLAN FOR 2022

1. Balanced internal organisation		
Policy field	Going Concern	New
Board		- Evaluating annual plan
2. Consolidating the current association in terms of content and organisation		
Board	<ul style="list-style-type: none"> - Daily management - Membership administration - Financial records - Medical Advisory Council 	<ul style="list-style-type: none"> - Finishing and adopting policy plan - Outsourcing back-office activities - Recruiting board members - Starting anniversary preparations - WBTR
Activities	<ul style="list-style-type: none"> - Contact days 	<ul style="list-style-type: none"> - Focus on contact day for children and adolescents
Finances	<ul style="list-style-type: none"> - Consolidation 	<ul style="list-style-type: none"> - Policy framework Ministry of VWS
IT/schedule	<ul style="list-style-type: none"> - Consolidation 	<ul style="list-style-type: none"> - Annual schedule tool
External communication	<ul style="list-style-type: none"> - Participating in conventions - Meeting with pharmaceutical section 	
3. Enhancing “recruitment of members” and “maintaining” existing members and volunteers		
Support for members	<ul style="list-style-type: none"> - Information desk 	<ul style="list-style-type: none"> - Start writing a member plan
Volunteers	<ul style="list-style-type: none"> - Volunteer day 	<ul style="list-style-type: none"> - Volunteer policy
Internal communication	<ul style="list-style-type: none"> - Supplementing and updating website - Newsletter, Newsflash, Forum - Social media - Brochure materials 	<ul style="list-style-type: none"> - English translation of website - Dentist brochure
External communication	<ul style="list-style-type: none"> - Participating in projects 	<ul style="list-style-type: none"> - Social media campaign - Videos for adolescents
4. Advocacy through the relationship with the healthcare sector and the patients		
Advocacy	<ul style="list-style-type: none"> - Consultation with expertise centres - Medical Advisory Council - UWV 	<ul style="list-style-type: none"> - Newly appointed expertise centres
5. Attention paid to Positive health		
Activities		<ul style="list-style-type: none"> - Organising lectures
6. Transfer of knowledge about ITP		
External communication	<ul style="list-style-type: none"> - Contact with expertise centres - Continuing our contributions to the expertise network - Participating in conventions - Continuing contributions to existing platforms 	<ul style="list-style-type: none"> - Contacting newly appointed expertise centres - Contributing to Cyberpoli.nl - Knowledge transfer

Glossary

PGOsupport	: an independent knowledge and advice organisation for patient participation.
SWOT analysis:	Strengths, Weaknesses, Opportunities, and Threats
Strengths/Weaknesses analysis	: Strengths, Weaknesses, Opportunities, and Threats
VSOP	: Patient association for rare and genetic ailments
VHBC	: Value-Based Health Care
WBTR	: Dutch Act on Management and Supervision of Legal Entities

References to websites

(end of 2021, possibly limited validity)

ITP expertise network : <https://itp-expertise.net/>

<https://www.ing.nl/zakelijk/kennis-over-de-economie/uw-sector/gezondheidszorg/Impact-Corona-op-de-zorgsector.html>

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<https://www.zorgmarketingplatform.nl/kennis/diagnose-2025-17-trends-gezondheidszorg/>.

<https://www.zorgmarketingplatform.nl/kennis/9-mega-marketing-trends-in-de-zorg-voor-2021/>

<https://www.iph.nl/kennisbank/wat-is-positieve-gezondheid/>