

ANNUAL REPORT FOR 2021

ITP Patient Association Netherlands



Patiëntenvereniging
Nederland

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Board report

Introduction

The year 2021 revolved around the corona pandemic, the vaccinations, and the corresponding uncertainty for many ITP patients again. The information desk of the association received more questions than ever before and many patients decided to join our association. This led to a great increase of almost 100 members in 2021. This year required the board to improvise extensively, meet remotely, and organise webinars, including about ITP and COVID-19 vaccines. However, we were able to organise our first national contact day in Artis, which made the board and the attending members, based on their responses, incredibly happy.

The year 2021 was the first year of the new ITP guideline, which development we contributed to in 2020. The new guideline offers a better substantiation for the determination of auto-antibodies against thrombocytes. The treatment order also changed compared to 2013; splenectomy will only be recommended if TPO agonists or Rituximab are not effective and at least 12 months have passed following the diagnosis. As of August 2021, a new TPO agonist, Avatrombopag, was introduced on the Dutch market.

This report will first discuss our activities conducted in 2021. It will subsequently discuss the association and the composition of the board and the pillars of the policy. This will be followed by notes to the financial situation of the association and conclude with a brief look ahead.

Looking back on the activities

In 2021, we conducted numerous activities now that we knew that we needed to keep the uncertainties related to the corona pandemic into account. We faced a lockdown immediately in January. This is why we chose to organise webinars during spring and a 'normal' national contact day in autumn. This was possible because of the great efforts of board members and other volunteers. The association consists of volunteers and does not employ staff. For this reason, support from high-quality volunteers is needed greatly to be able to continue to conduct all existing activities and introduce new activities.

Peer contact:

- The peer contact day in spring was cancelled. Instead, we organised a webinar on 7 April with Dr Vera Novotny and Dr Hans Zaaier about COVID-19 and vaccination.
- On 17 April, a webinar was organised for children and adolescents with paediatricians Drs Monique Suijker and Drs Elise Huisman.
- In autumn, we organised our contact day in Artis on 9 October with the General Members' Meeting and a presentation by physicians Drs Sufia Amini and Dr Gerard Janzen.
- Unfortunately, the volunteer afternoon could not take place in 2021 at the last moment. Instead, a gift was sent to the active volunteers by mail.
- Support groups are small-scale regional meetings for peer contact. These revolve around exchanging experiences. Because of corona, the meetings took place digitally using Teams on 10 March and 8 July in 2021. Volunteers Karin de Boer and Martine Deinum lead the support groups. Ultimately, these groups should be organised regionally by members in the region.
- The private forum on our website, moderated by volunteer Thea Metz, is for all members, who are given access using their password once they have logged in.
- Social media, managed by the board.

- Facebook (since 2012). Last year, we received a great number of “likes” and exchanged numerous messages, including using Messenger and on the private Members Page. Refer to the Facebook overviews below.
- Instagram, which we slowly start using more.
- LinkedIn, to also reach professionals.

Social media overview:

Facebook overview:	01/01/2021	31/12/2021	Entirety of 2021
Private section			
Number of members:	78	84	
Number of visits:			2767
Number of messages			41
Number of comments			143
Number of responses			227

Messages on Facebook and Instagram are posted by the board. An overview of the results in 2021:

Message reach:	Facebook	Instagram
Number of messages posted	52	37
Persons reached	65057	311
Number of likes	1228	209
Number of clicks on links	8874	
Number of comments	567	11
Number of shares	229	

Reach of LinkedIn in the period from 1/4/2021 to 31/12/2021:

LinkedIn reach	
Number of new followers	52
Number of views	4773
Number of unique views	2995
Number of clicks	255
Number of responses	156
Number of comments	2
Times shared	9

Education

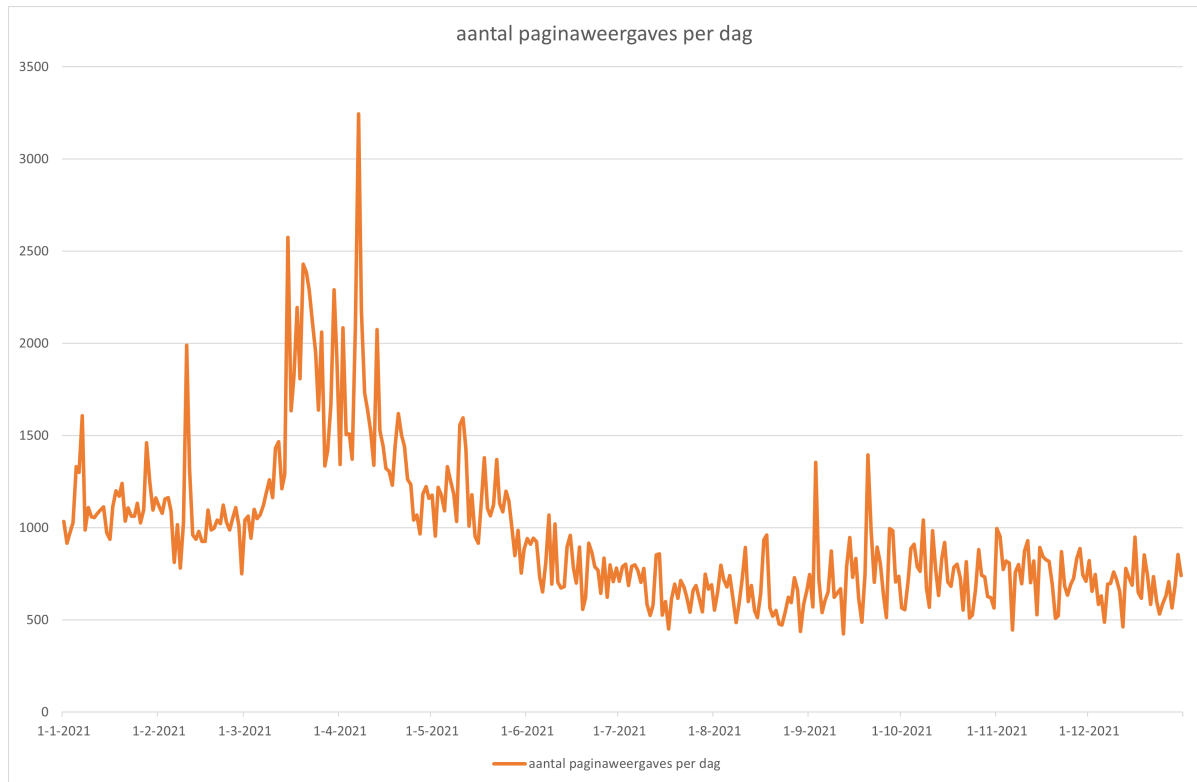
All scheduled activities took place in 2021.

- Three newsletters were created and sent by mail, supplemented with 3 Newsflashes sent to all members by email.
- We provide information about ITP during the webinars and contact days (also refer to the peer contact section). A webinar about ITP and COVID-19 vaccines on 7 April. Dr Vera Novotny discussed the new guidelines introduced at the end of 2020 and the risks of corona for ITP patients at this webinar. Dr Hans Zaaijer addressed the alleged dangers of the COVID-19 vaccines and debunked them, but also pointed out that side effects are unavoidable. On 17

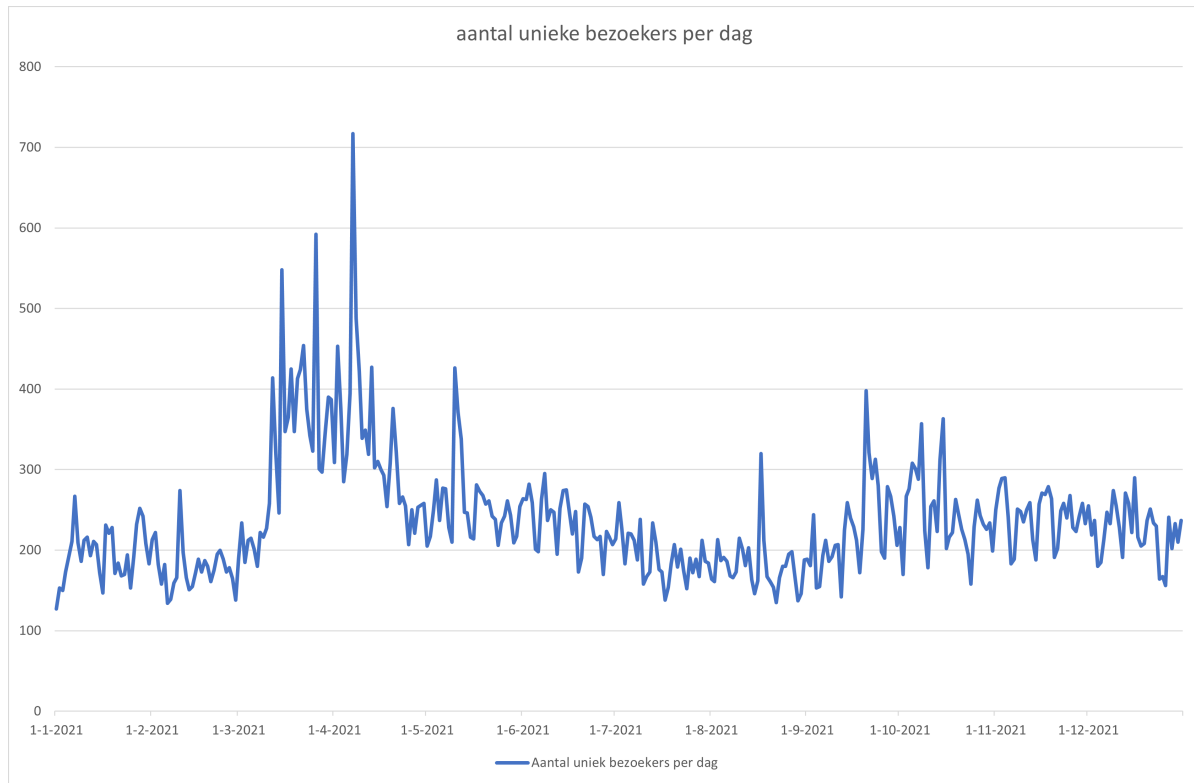
April, at the webinar for children and adolescents with paediatricians Drs Monique Suijker and Drs Elise Huisman, the group was given a general instruction before dividing into a section for children and a section for adolescents, followed by a section specifically on ITP and menstruation. On 9 October, Drs Sufia Amini presented a summary of the new revised Dutch guideline for ITP. Dr Gerard Jansen presented his studies on COVID-19 and ITP.

- The year 2021 marks the first full year of our website, which was launched in late 2020. The two graphs show the page views and the number of unique visitors per day in 2021.

The page views of our website per day in 2021 have been set out below:



The unique visitors per day in 2021:



The peak in March/April stands out in the 2 graphs above. This coincides with the expansion of the corona vaccination programme.

- In 2021, we started to translate our website into English, which will launch in 2022. This is possible thanks to the sponsoring by pharmaceutical company SOBI.
- The adolescents' brochure was revised in 2021. A new brochure was published called 'Visiting the dentist or oral surgeon with ITP'. This brochure was created in cooperation with Dr Wobke van Dijk, who will obtain his doctorate on this topic, among others, at the Van Creveldkliniek of Utrecht University in 2022. The brochures are also available as PDFs on our website and can be downloaded. We hand these brochures out to new members. Hospitals also order brochures to give to new ITP patients.
- In September, special attention was asked for the IT Awareness Month (September) and Awareness Week using the Awareness poster and actions on the website, LinkedIn, Instagram, and Facebook.
- New members receive a confirmation letter with an information kit once they sign up.
- In 2021, our phone line received many more calls than in previous years. Patients, members, and non-members can contact us for general information. Usually, we are mainly called by newly diagnosed patients, but we now received numerous questions about ITP, corona, and vaccinations.

Advocacy

- The association contributes to keeping the Expertise Network up to date. Specialists at various (university) hospitals cooperate in the Immune Thrombocytopenia (ITP) (being incorporated) expertise network. They are familiar with the latest insights into ITP, can diagnose or confirm ITP, and can render an expert opinion to other healthcare providers. Ongoing ITP research is also listed on the website.
- In 2021, we contacted the UWV to be able to pay more attention to the incapacity assessment in the context of the Dutch Work and Income Act.
- We have 2 volunteers that can offer support to members:

- Martine Deinum is a Hands-on Expert who can help ITP patients, including non-members, deal with ITP. She is also a stress and burnout coach.
- Yordi Bresser, who contributed to the Study Tool as a young patient, can advise pupils and students as hands-on expert.

Network

- We again had frequent contact with, among others, physicians, specialists at hospitals, universities, and the pharmaceutical industry in 2021. The association is increasingly being considered an important interlocutor. Examples are the Benigne working group NVvH (Dutch Haematology Association) and PGO Support, but the pharmaceutical industry, too, was able to find us in 2021.
- The 'people with ITP and their loved ones' brochure was created in cooperation with Amgen (Romiplostim) and published in 2021. Together with Novartis (Eltrombopag), we worked on the HearMe Platform, which was launched in 2021. This explains the increase of the second peak in the image of the number of visits and number of page views of our website around September, as set out above. We cooperated with SOBI (Avatrombopag) for refresher training for physicians at the start of 2021. We also sent out a survey with SOBI about patient needs and preferences related to ITP, the TRAPeZe study, in the latter half of the year. We gave information about the ITP patient journey to employees of ArgenX (Efgartigimod). At the start of December, we participated in an advisory board of the Sanofi pharmaceutical company (Rilzabrutinib, a product in development).
- More and more individual requests for aid related to work, healthcare, income, and the like are submitted by our members. The association has a front desk role in this respect and can refer individual requests for aid to professionals in its network, such as a lawyer.

Medical Advisory Council and Expertise Centres

- Our Medical Advisory Council, founded in 2012, consists of:
 - Dr Leendert Porcelijn, Sanquin
 - Dr Martin Schipperus, internist-haematologist at UMCG (Groningen)
 - Prof Dr Roger Schutgens, professor in thrombosis and haemostasis, internist-haematologist UMC (Utrecht)
 - Drs Monique Suijker, paediatrician-haematologist at UMCU (Utrecht)
 - Prof Dr Jaap Jan Zwaginga, professor in Clinical Transfusion medicine, internist-haematologist LUMC (Leiden)
 - Dr Gerard Jansen, internist haematologist at Erasmus MC (Rotterdam)
 - Drs Elise Huisman., paediatrician-haematologist at Erasmus MC Sophia Kinderziekenhuis (Rotterdam)

This is an important body in the field of collective and individual medical advocacy. This was particularly important, particularly in 2021, because it had the most up-to-date information about ITP and corona.

- The members are consulted regularly for specific patient questions and they present lectures on studies, research projects, and developments related to knowledge about ITP, its occurrence and cause, as well as medication on contact days.
- We met with the Medical Advisory Council once in 2021.
- There have been Expertise Centres for ITP appointed by the Minister of Public Health, Welfare and Sports since 2015. In 2021, the ITP patient association contributed to a new assessment round for expertise centres. In this context, input from members being treated at these centres was requested. Besides the Van Creveld Kliniek (VCK-UMC), University Medical Centre Groningen (UMCG) has also been appointed as an expertise centre. The University Medical Centre Leiden (UMCL) was rejected but objected to this in 2021. They were appointed as an expertise centre in 2022.
- In 2022, we will continue to intensify the cooperation with the already existing VCK expertise centre and establish partnerships with the UMCG and UMCL. We will make plans for greater support for our activities and participation in various studies.

National and international fairs & symposiums

The goal of these meetings is to learn about new developments, exchange experiences, talk to each other about practical matters we encounter, and discuss how we can help each other in this respect.

Because ITP is a rare illness, we want to gain information at a European and global level. All IP patient associations, through the International ITP Alliance, ask for global attention and awareness, as part of which we gather, exchange, and provide the knowledge present to patients and family members in the Netherlands. We also want to do this in countries where there are no ITP patient associations or only a few active persons. This knowledge is distributed using international and national websites, seminars, and Facebook, among other things. If possible, we want to gradually support international cooperation and expand international contacts.

The meetings took place digitally in 2021. The main events have been set out below. We did not participate in all of them.

- NL Hematologie Congres in Papendal, an annually recurring convention at the end of January.
- The European Haematology Congress in June 2021.
- The Platelet Disease Support Association (PDSA) organised a very professional digital convention for the second year in a row. It took place in the last weekend of July/early August 2021. Several board members and volunteers took part.
- In 2021, two meetings of the International ITP Alliance were held with members from the whole world. One took place on 22 April 2021. The other digital International Alliance meeting took place on 6 November, which we attended.
- The ITP Support Association of the United Kingdom also organised a digital conference on 8 and 9 June 2021, which was attended by several board members.

Professionalisation

Various board members and volunteers completed courses at PGOsupport and e-Captain to learn about and prepare for the work at the patient association.

Continuity

These activities aim to operate and ensure the continuity of the association. We have generally followed the schedule using the budget available.

The Association

Legal form

The association was incorporated on 13 May 2003 and is registered in the Commercial Register of the Chamber of Commerce and Factories in 's-Hertogenbosch with number 17156005. The association has had its registered offices in Nieuwegein since 2018.

Object

The (statutory) object of the association is:

- a. promoting the well-being of persons with thrombocytopenia in the broadest sense of the word (hereinafter referred to as ITP) in general and that of its members in particular;
- b. promoting and organising information for patients, their partners, physicians, and related professions, and increasing public education;
- c. promoting and organising peer contact for patients and their partners;
- d. promoting and organising advocacy, both individually and collectively;
- e. promoting scientific research into thrombocytopenia and everything related to it.

Composition of the board

Mieke Budel	duo chairperson as of 31 October 2020, in office since 9 June 2018 and resigning in June 2024, second period of 3 years.
Ineke Steetskamp,	duo chairperson as of 31 October 2020, resigning in October 2023, first period of 3 years.
Jenny Willemse,	secretary, in office since May 2016, resigning in May 2022, second period of 3 years.
Marjan Pronk-Ligthart,	treasurer, in office since 18 May 2019, resigning in May 2022, first period of 3 years.
Jo Bisscheroux,	board member, in office since 31 October 2020, resigning in October 2023, first period of 3 years.

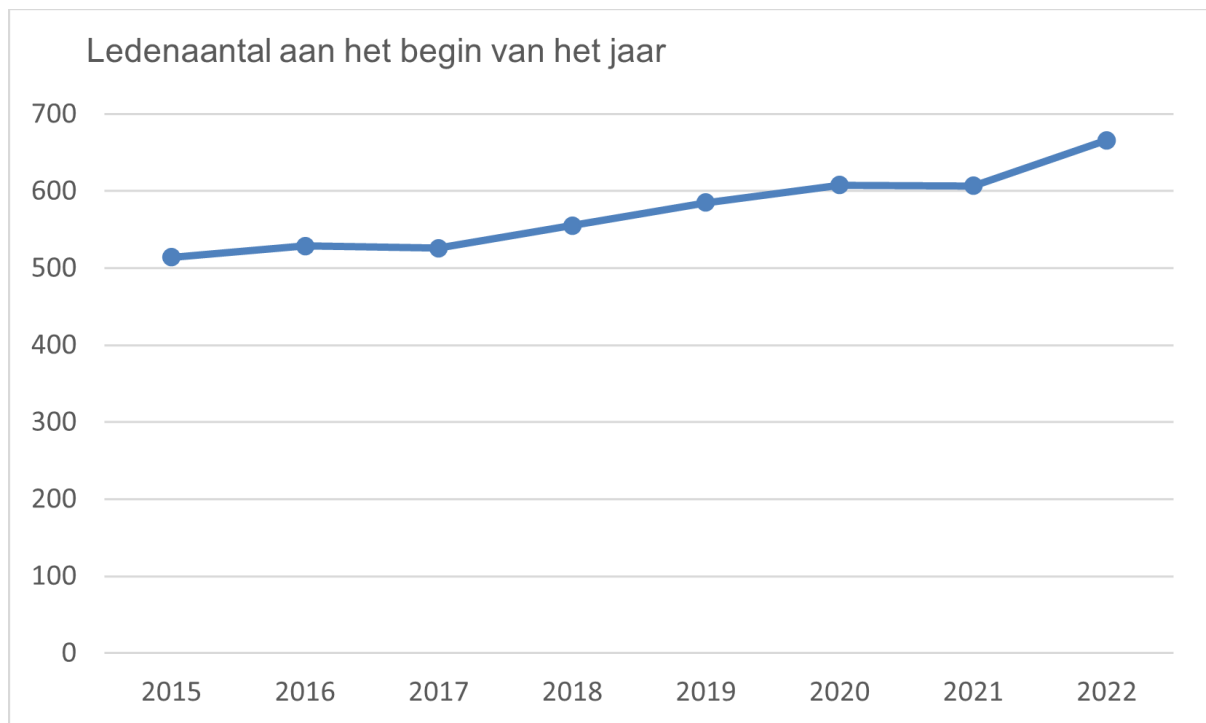
General Members' Meeting

Usually, we organise a General Members' Meeting twice per year. The GMM is the highest body of the association. Because of organisational reasons, this GMM is usually linked to a peer contact day. This year, we chose to only organise a GMM during the national contact day in October because of corona. The agenda of the GMM includes the adoption of the budget (October/November), the adoption of the annual accounts (May/June), and potential board elections. With respect to the annual accounts, the board is granted discharge once the GMM has approved the annual report and annual accounts. This year, all these actions took place on 9 October 2021.

Members:

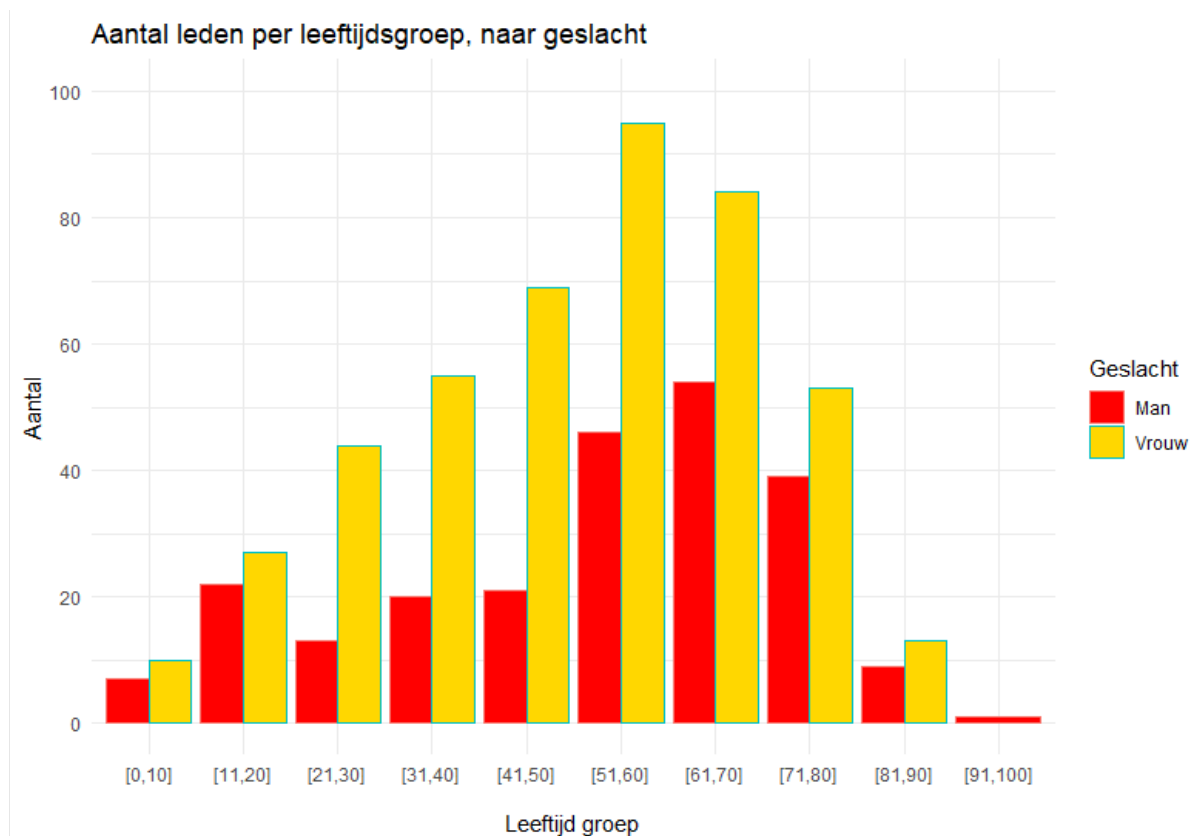
We keep our membership administration in the online membership administration and relationship management system called e-Captain. We also use this system to distribute our Newsflashes and other emails sent to the members.

The information below provides information about the number of members of the patient association.



We can see the number of members increase because we received many members due to the uncertainty related to ITP, COVID-19, and vaccination in 2021, and many ITP patients decided to become a member.

The 'number of members per age group, based on sex' figure shows the composition of our members. This corresponds to the way ITP manifests, as it is often diagnosed after the age of 50.



Pillars of the policy

Operations/ensuring continuity

ITP PV has become a strong association in terms of its administration and organisation with sound financial housekeeping. A concern is the persistent quantitative and qualitative composition of the board and other volunteers. The board has been working in its current form for over 1.5 years now and the distribution of duties has become self-evident. On the contact day in October, the current volunteers were introduced to each other and the members. The scheduled volunteer day at the end of November should have been the starting sign for closer cooperation with all volunteers. Unfortunately, but justifiably, it had to be cancelled. We will have a new opportunity in May 2022. The subsidy policy of the government is also important, as it will be revised in 2022 for the period starting in 2023. Refer to the 'finances' section below for more information.

Policy plan 2021-2025

At the start of 2021, the board conducted a survey among the members. Almost one-third of the members responded. This offered the board extensive input for activities to be scheduled and we will use this material to revise the policy plan of the association. The current policy plan 2015-2020 ended in 2020. Because of corona and the new board members that had to be trained in 2020, a start was made with preparing the new policy plan 2021-2025 in 2021. We were supported by a professional of PGO support. A policy plan sets out the mission, vision, objects, and the corresponding policy. Essentially, it is important to create a plan for what we want to have achieved with the association in 2025. The outlines of this plan were shared with the members in the GMM on 9 October and the policy plan will be presented to the members in the GMM of June 2022.

Internal regulations

The Internal Regulations (IR) of the patient association were also amended and expanded in 2021. They were adopted by the General Members' Meeting on 9 October. The IR is a version of the articles of association and sets out how we have arranged the matters internally. The amendment was necessary because of the many changes in the last few years, such as privacy legislation and digitisation. The position of the members and the board has been clarified.

Finances

Reporting

We use e-Captain for our financial administration, as well as for our membership administration. This ensures that various data are connected. The books for 2021 were audited by accountancy firm Koeleman in Hilversum. This accountant also prepares the annual accounts.

Guidelines for preparing the annual accounts

The Ministry of Public Health, Welfare and Sports and DUS-I issued guidelines for the provision of subsidies in the context of the patients and disability policy (PGO Subsidy Scheme) and the preparation of the annual accounts for 2021.

This provision of subsidies is subject to various laws and regulations that are all based on the OCW, SZW, and VWS Subsidies Framework Scheme, available at <https://wetten.overheid.nl/BWBR0037603/2021-10-01>:

Subsidy by Ministry of VWS

There are four subsidy flows. Subsidy flow 2 is relevant to ITP PV. Subsidy flow 2 is intended for peer contact and the provision of information, but may also be used for advocacy on behalf of patients with a specific ailment. The policy framework for the provision of subsidies to patient and disability organisations includes the opportunity to apply for an institutional subsidy for peer contact of up to €45,000. We also apply for this subsidy.

A report must be submitted to DUS-I for subsidies greater than €25,000.

An accountability file must have been submitted for 2021 no later than 03/06/2022. The adoption period is limited to 22 weeks.

We must comply with the following conditions:

- Organisations that apply for a subsidy of €25,000 or more must not only submit an activities plan, but also a budget.
- The organisation must provide an 'actual costs declaration' with the accountability report.

We will also start making use of subsidy flow 1 for the year 2022 to apply for a €10,000 subsidy to outsource a large part of the back-office activities. Our association has entered into a partnership agreement with Qs10 for the year 2022, as set out in the Outlook section.

Policy framework

The current policy framework was amended in 2019, as set out in 'the Decree of the Minister of Medical Care of 11 July 2019, reference 1553192-193083-PZO, entailing an amendment to the Decree on the Adoption of the Policy Framework for the Provision of Subsidies to Patient and Disability Organisations 2019–2022 concerning a number of changes". 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. This will be relevant to us in 2022.

Result 2021

It was again a financial challenge to keep the monetary flows, budgeted and actual, within the budget in 2021. The subsidy to be received is based on a budget approved by the ministry in advance with associated plans that have been set out in detail, such as the total number of members present. Fortunately, the national contact day in the latter half of the year could take place in 2021. Besides the member contact days, we stayed connected with our members and incurred expenses by organising a number of Webinars with various speakers in the medical field. The total income and expenditure led to a positive result in 2021, as set out in the annual accounts later in this document. The majority of the sponsored funds received will be spent in 2022. This explains a large part of the positive result in 2021.

For the year 2021, the board again decided to keep a risk reserve of €70,000 because it is not clear what the new subsidy schemes will mean to the association in the coming years.

Donations

The association receives increasingly less external support for all key activities: internationalisation, professionalisation, peer contact, information, advocacy, and continuity. Donations/sponsoring can be provided by the printer of the newsletter, an accountant, another service provider, a hospital, or the pharmaceutical industry.

These are incidental donations, not structural, and are called targeted donations. The donation in question will be used for the specific goal. For example, we received sponsorship from the SOBI pharmaceutical company to have our website translated into English in 2021.

ANBI Status

The association has been categorised as a Public Benefit Organisation as of 2009. This makes the association a Public Benefit Organisation based on the criteria of the Dutch Tax and Customs Administration. This is communicated on the site of the association and the website of the Dutch Tax and Customs Association lists the institutions that are categorised as Public Benefit Organisations. We can see that increasing use is being made of the fiscal benefits offered by this Public Benefit Organisation status. In the future, we will pay more attention to this in the communication plan.

Member contributions

Members contribute to the additional income of the association. Some of the members pay more than the minimum €25 fee, which additional payments are considered a gift.

There are still members who pay based on an invoice, which is additional administrative work. We appreciate it greatly when members decide to sign a direct debit order. This saves €3 in additional costs.

Outlook

The start of 2022 again revolved around corona, but the developments show that a lot becomes possible again in the spring and summer of 2022. We will schedule our contact days on location again. The first one will be in Openlucht Museum Arnhem on 25 June, and the second one will take place in the latter half of the year. A number of priorities have been defined in the policy plan 2021-2025 that will be presented to the members for approval in 2022. These were presented at the GMM in October 2021. We want to pay more attention to children and adolescents. A contact day for children has been scheduled for late May 2022, and we want to organise a day for adolescents in late September. A social media campaign should generate more attention for ITP. We will start preparing for our 20th anniversary which will take place in 2023. The postponed volunteer day to further enhance the relationship with our volunteers is scheduled for May 2022. In organisational terms, we will need to pay attention to the Dutch Act on Management and Supervision of Legal Entities (WBTR), which took effect on 1 July 2021.

The plan to engage external support (back-office) for the association was presented to the members at the GMM in October 2021. A subsidy can be applied for and was granted for this external support. We have been working with Qs10 since the start of 2022, which supports us with a variety of matters (such as taking minutes at meetings, looking for and scheduling locations for contact days, and the like). This gives the board more time for the actual executive duties. We will assess the partnership halfway through 2022 and make changes if necessary. We will continue doing everything that we are doing as an association: maintaining extensive contact with the expertise centres and with the pharmaceutical industry in the Netherlands and abroad.

Mieke Budel, duo chairperson
Ineke Steetskamp, duo chairperson
Jenny Willemse, secretary
Marjan Pronk-Ligthart, treasurer
Jo Bisscheroux, board member

Nieuwegein, 25 June 2022