Strategic Plan 2025 –2027

“Good policy is a framework for action, not a substitute for it.”

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introduction

This Strategic Plan has been prepared primarily for internal use.
Because Vasculitis International (VI) is a Dutch non-profit institution registered as an Institution for General Benefit (ANBI), the plan has been drawn up in such a way that it is visible that the organization complies with the requirements of this ANBI-status. Moreover, Vasculitis International wants to be a transparent organization whose actions and resource management can withstand any test of criticism. This plan therefore not only shows an overview of our objectives, activities and working methods but also provides some insight into the recruitment, management and expenditure of funds.

Summary

Starting VI from scratch was initially a slow process but in 2024 things really took off. We organized – in co-production with the US Vasculitis Foundation - a patient day linked to the International Vasculitis scientific conference in Barcelona, held a AAV Patient Summit in Amersfoort NL and started the development of a website for Germany called vaskulitispatienten.de

This strategic plan focuses on 2025, 2026 and 2027

Since we are a relatively young and unknown organization, we deliberately choose to spend a serious part of the text here on our profile and impact model.

Our Goals and Objectives for the next 3 years are presented in 4 groups: ENCOURAGE - EXPAND – DEVELOP - and INTERNAL.

Encouraging patient groups to collaborate is an ongoing activity and we will do by showing them products, services and tools already in use by others. We also bring patient representatives together in digital meetings and where financially possible in face-to-face meetings. We will therefore organize a digital get-together in 2025 and try to find the funding for the next Summit to be held in 2026.

We will try to *expand* our network with countries like Portugal, Denmark, Sweden, Norway and the Baltic states. We will also try to get more hospitals to formally join us.

As for *developing* products and services, one of the important goals for this period is to transform our current website into a full-blown source of information including a library with documentation and tools to support the local patient groups.

We will develop a website for German speaking countries and already started this process using the URL *vaskulitispatienten.de*. This site will serve as a tool to unify German groups and as a template for a similar site for the Czech Republic.

It is crucial to realize that we want to be agile and try to respond to developments, initiatives and needs popping up, as much as we can.

Internally we will continue to work with volunteers during the duration of this plan and use as much sophisticated tools as possible to operate cost-effectively and create maximum output towards our goals and objectives. For funding we will still be highly dependent on the pharmaceutical industry during this period, but we will work hard to turn that around by trying to attract funding form other resources.

profile

Mission statement

Vasculitis International (VI) is a not-for-profit organization aiming to encourage and support international collaboration between Vasculitis Patient Advocacy Groups (VPAG's).

Raison d'être and strategy

The vasculitis patient's voice can best be heard by bundling patient expertise. This is important to achieve the best possible cure and care and to influence the research agenda. Patient Advocacy Groups play an important role in bundling this expertise. They do exist in some countries, but they do not yet exist in others (usually referred to as 'underrepresented countries'). In nearly all cases the existing local groups are staffed by volunteers only and have limited resources.

Given this situation, our mission-driven impact model encompasses a strategy in which we want to establish and maintain a network of VPAG's, bundling expert knowledge in patient experience, including the personal, clinical, pharmaceutical and research aspects of it.

In order to do so we want to:
encourage existing national VPAGs to collaborate internationally
support them to be able to do so
develop initiatives to create VPAGs in those countries currently missing such organisation

Impact model

To further explain our impact model, we will use the "business model canvas" as a guide. This model will clarify what our value proposition is, what audience it will serve, how we are going to realize our goals and how we will capture the value we create.

The model contains the following key elements:

Value Proposition:	What do we offer; why would a VPAG join VI?
Key activities:	What key activities are required to deliver our value proposition?
Key resources:	What resources do we need to deliver the value proposition
Key partners:	What partners are key in achieving our goals?
Key segments:	How can we segment the audience we are aiming for?
Key relationships:	What type of relationship has to be established/maintained for each segment?
Key Channels:	What communication channels are needed to reach our audience?

VALUE PROPOSITION

What is it we offer and why should a VPAG join us?

By collaborating in an organised fashion, VPAG's will maximize their gains and minimize their pains and workload.

Maximizing Gains:

Collaborating VPAG's can create more awareness; both for VI and for their own VPAG.
Collaborating VPAG's have a bigger internal and external network to make that happen.
Collaborating gives VPAG's more resources, contacts, exposure and power.
Collaborating will not only bring VPAG's more awareness but also more members, influence and resources.

Minimizing Pains:

Collaborating will help VPAG's to overcome problems with lack of resources, money, knowledge and experience.

Minimizing Workload:

Collaborating can provide VPAG's with tools, products and services already developed by others or jointly developed from within VI.
Collaborating will give VPAG's extra resources and expertise to organising events, write and publish information, build presentations etc.

Key activities

In order to serve both existing VPAG's and VPAG's to be created VI strives to develop:

- A library of commonly shared vasculitis publications, video's and other information sources (knowledge database) to educate VPAG 's and help them to increase vasculitis awareness;
- A template website which gives those VPAG's who currently do not have such a site, a unique place on the web, leading to well informed patients and increased vasculitis awareness;
- A network and database with clinical, pharmaceutical, research and other relevant stakeholders, to help with subsidiary questions, funding, medical questions and so on.
- A helpdesk to link VPAG's to each other and to other relevant players

Key Resources

Our value proposition requires several key resources like staffing, tools and funding.

Staffing:

Up until now VI is run by volunteers only. There is some specific expertise available in some of the VPAGs already connected, which we will use as much as we can. Our initial, current and expected future funding allows us to buy additional external resources if and when needed, in order to keep VI going during the timeframe of this 2025-2028 Plan.

Tools:

We acquired Microsoft365 for Non-Profit organizations and Internal communication will mainly be done using online tools like ZOOM, TEAMS, BASECAMP, and E-mail. We will also use modern technology tools as much as we can to avoid unnecessary travel and external consultancy. Think about tools like Translated Captions for Zoom, Cognito for the creation of digital forms, AI tools like ChatGPT etc.

Funding:

Revenue Generation
Initial funding was provided by Vasculitis Netherlands, Vasculitis UK, Vasculitis Ireland Awareness (VIA) and Vifor Pharma. To allow us to execute our goals and objectives both Novartis and CSL Vifor provided us with some unrestricted funding in 2024 while both have the intention to do so again in 2025.
All in all, this gives us good starting position for this 2025-2028 plan, ensures our continuity for at least the 2025-2028 timeframe of this strategic plan.
Financial Stewartship
A serious part of our funding stems from the pharmaceutical industry as unrestricted grants. We do realize that this happens under the assumption that we carefully manage these funds to achieve our goals and objectives. We will therefore operate along these lines of our responsibility, use an external bureau for our accounting and instruct them to prepare the Financial Statement according to the official RJ650/RJK C2 guidelines. We will publish these Financial Statements on our website according to the ANBI guidelines.
Utilization of funds
We are a relatively young organization and can only handle small projects. For bigger sized projects we will try to find additional funding from sources like the European Union, Funding Agencies, Pharma etc.

Key Partners

- There are a few key partners that we need to successfully execute our idea:
- International medical experts within the field of vasculitis; including organisations like EUVAS, EULAR, ERN-RITA.
- EURORDIS: non-governmental patient-driven alliance of patient organisations representing 929 rare disease patient organisations in 72 countries, located in France, Brussels and Spain.
- ERN RITA / RIPAG: European Reference Network for immune mediated diseases and its patient arm RIPAG (RITA Patient Advocacy Group
- VPAG's from non-European countries like the Vasculitis Foundation in the US or the Vasculitis Foundation Canada.
- Pharmaceutical companies to help us building a financial structure ensuring continuity and achieving our goals.
- Some of the relationships above have not been formally established in the first years of our existence but will be established within the timeframe of this plan.

Key segments

Our VPAG segments are:

1. Existing European VPAG's
    1.1. Officially registered in their country as a VPAG
    1.2. Officially registered in their country as part of a wider organisation like thpose for rheumatology or Rare Diseases.
2. Not (yet) registered VPAG's
3. Non-European VPAG's
4. Non existing VPAG's

Every VPAG who wants to join VI must be capable of proving that they really represent patients with vasculitis and express their willingness to share information and resources

Key relationships

What relationship must be established for each of the segments?

Existing Registered European VPAG's (segments 1.1. and 1.2)

The relationship with these groups should be based upon frequent communication and active collaboration. Preferably not only within VI but also within ERN RITA and its patient representation group called RIPAG. The type of relationship should also help us in establishing new VPAG's in underrepresented countries.

Existing NOT registered European VPAG's (segment 2)

The relationship with these groups is very likely to be less informal and depends heavily on the size of the group and type of individuals representing it. The relationship will very likely be characterised by VI supporting the group rather than the other way around. Within VI this group can be classified as **Affiliate Members** rather than full members.

Non-European VPAG's (segment 3)

It is important to build a relationship with these groups based upon mutual trust and respect for each other's domain and activities. Like in the first years of our existence VI's focus for 2025-2028 will again be on Europe so the relationship has to be solid but will very likely be more 'low-key' than those with the European segment.

Non existing VPAG's

This will be the type of relationship where we are in the lead and pro-active. Since this segment does not exist as a group, the relationships will be based upon individual contacts with doctors, patients and other local stakeholders. The relationship will be characterised by a supporting attitude from the side of VI, emphasising that our goal is nothing more or less than to strengthen the voice of vasculitis patients in that country.

Key Channels

How do we reach our audience and communicate with them?

First of all we will use all modern communication channels like our own website, those of our members and partners and social media.

For segment 1 (European VPAG's) communication channels will always be used in close cooperation with that VPAG.
For segment 2 (non-European countries) communication channels will always be used in close cooperation with our VPAG partners in that particular area.
For segment 3 (non existing VPAG's) we will mainly use communication channels in their local language. Where possible we will use the input and resources from doctors and their hospitals in that country.

GOALS AND OBJECTIVES for 2025 - 2027

We defined our core activities in four main categories:

ENCOURAGE patientgroups to collaborate
EXPAND our network with other patient groups
DEVELOP products and services to support patient groups
INTERNAL activities to ensure sustainability and future proofing

Encourage

Encouraging patient groups to collaborate is difficult for several reasons. They are usually made up of volunteers with very limited resources, do not always speak English and their primary focus is their national community.

Encouraging them to collaborate is therefore an ongoing activity and we will do by showing them products, services and tools already in use by others. Where useful and possible we will translate things for them and connect them to people who can help them.
A nice example in 2024 was the AAV summit in Amersfoort NL where doctors, nurses and patients from 10 different countries discussed the position of specialized nurses in vasculitis. It resulted in motivated members who continued to collaborate after the meeting.
So also in the next 3 years we will tempt them to collaborate by giving them real live examples, contacts and tools to do so.

Another way of encouraging them is to bring them together in digital meetings and where financially possible in face-to-face meetings. We will therefore organize a digital get-together in 2025 and try to find the funding for the next Summit to be held in 2026.

Expand

We have a serious group of patient groups collaborating already, but we are still missing a number of countries and in some countries the organization is weak, very small or the participation level is not as high as we would like it to be. Spain for example is weakened in 2024 due to the serious illness of its president. Takayasu France is very small, the president does not speak English and some extra support is needed, Greece is officially still on the list but participation level is low and we will try to increase that.

In this coming period, we should include countries like Portugal, Switzerland, Denmark, Norway, Sweden and the Baltic states. In summary our objective is to increase the number of collaborating patient groups from 10 to 16 during the timespan of this strategic plan.

We will also try to convince hospitals to get more actively involved in our network.

Develop

One of the important goals for this strategic period is to transform our current website into a full-blown source of information including a library with documentation and tools to support the local patient groups.

A second one is to try to unify the German user groups and encourage them to collaborate.
For this we started to develop a website called *vaskulitispatienten.de* which contains patient information but also a section where the different small groups can present themselves and post info on their upcoming events. We will try to get at least 3 key opinion leaders on board supporting the initiative.

A third project will be to use our experience with Germany and the German website to create a patient group and website for the Czech Republic. We will do so in close collaboration with dr. Zdenka Hrušková.

We will also work with dr. Hrušková to establish a patient group in the Czech Republic.

In the meantime we will be open for suggestions from our ‘members’ to develop tools, products and services that can be used in multiple countries.

Internal

For the period of this strategic plan, we will continue to mainly work with volunteers and try to maximize the use of a clever selection of software- and other tools to maximize our output an minimize our operational cost and overhead.

Maarssen, The Netherlands, January 2025