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## BUSINESS MODEL & VALUE PROPOSITION

### 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 in order 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 'under represented countries').

In nearly all cases the existing local groups are staffed by volunteers only and have limited resources.

Given the situation above 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

There is currently no such global network and while in some continents VPAGs already work together this is not yet the case in Europe. We will therefore have a strong focus on creating a European network first.

### The model

To further explain our business model, we will use the business model canvas. This model will clarify what are value proposition is, what audience it will serve, how we are going to realize this 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?

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## 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.

### *Gains:*

Collaborating VPAG's can create more awareness; both for vasculitis 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 money

### *Pains:*

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

### *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 will develop:

- A library of commonly shared vasculitis publications, video's and other information sources (knowledge database) to help other VPAG's spread 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 more traffic and awareness of the disease;
- 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
- A manual on how to create and maintain a professional VPAG.

## Key Resources

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

*Staffing:* Up until now VI is run by volunteers only. Our initial funding allows us to buy additional resources related to the start-up, if and when needed. There is specific expertise available in some of the VPAGs already connected like for example Public Relations and Translation skills in Italy and web development skills in The Netherlands.

### *Tools:*

Communication will mainly be done using online tools like ZOOM, Basecamp, and E-mail. This requires access to a computer and the internet which might be a challenge in creating new VPAG's in underrepresented countries.

### *Funding:*

We were able to start VI using initial funding from three parties: Vasculitis NL (Vasculitis Stichting), Vasculitis UK and Vifor. The former two are VPAG's, the latter one is a pharmaceutical company.

## 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.
- Vifor Pharma Management Ltd.; Vifor supported us financially allowing us to set up this organisation.

## 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 rheumatology.
2. Not (yet) registered
3. Non-European VPAG's
4. Non existing VPAG's

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

## Key relationships

What relationship has to 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 founding 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 individual representing it. The relationship will very likely be characterised by VI supporting the group rather than the other way around. Within VI this group will be classified as **Affiliate Members** rather than full members.

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**Non-European VPAG's (segment 3)**

It is important to build a relationship with these group based upon mutual trust and respect for each other's domain and activities. In particular during the first 3-5 years of VI the focus will 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 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 particular 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 particular country.

**Annex:**

List of VI current member organisations.

## ANNEX

### National VPAG

United Kingdom: Vasculitis UK

**The Netherlands:** Vasculitis Stichting

**Ireland:** VIA: Vasculitis Ireland Awareness

**France:** Association France Vasculites (main group), L' Association Behçet France (Behcet), Association Takayasu France (takayasu)

Finland: Suomen Vaskuliittiyhdistys ry

No national VPAG, but other variations of PAG's

**Greece:** Hellenic League Against Rheumatism (ELEANA), has a Vasculitis group within ELEANA.

**Italy:** has no main group, but does have two PAG's: Behçet (PAG: SIMBA) and EGPA (PAG: APACS)

No national VPAG, but other variations of PAG's/No (V)PAG yet

**Germany:** Vasculitis patient groups in Germany are organized by region (kreis) through patient support groups for which the Germans use the word Selbsthilfegruppe (self-help groups). The first one to join Vasculitis Europe was the Selbsthilfegruppe from Mainz. There is also a Vasculitis Support Group operating from Bad Bramstedt

SVI needs to explore other countries and their possible (V)PAG.

Other types of customer segments are well represented countries and underrepresented countries. Officially registered and not officially registered.

### Customer Relationships

Customers will mainly be contacted via Basecamp, ZOOM-calls and E-mail because of the international nature our contact. Sometimes members see each other via meetings in person (conferences and seminars). Other possible ways are newsletters and LinkedIn. Other possible ways to find more members are hospitals, google, websites and via other VPAG's.

### Channels

To acquire our customers, we will use various techniques. First of all, we will improve our own website to inform our possible customers what we do and where our customers can sign up for our service. While this might not be discovered by the right people really fast (VPAG's with a low affinity with online marketing), we will also be using google, our growing network of VPAG's and experts working in hospitals in European countries.

### Cost Structure

Since VI is still in its start-up phase the main costs in our business model now exist out of developing our own website and corporate identity. Furthermore, we have bought some software to be able to collaborate and communicate (Basecamp 3 – Zoom – Formstack)

The organisation is still fully run by volunteers and nobody is on the payroll. We also do not have a rented or acquired office.

As soon as we start to develop our products and services this might change depending on our level of activity, revenue stream and success.

## Revenue stream

For the start-up VI was funded by the Dutch Vasculitis Foundation (Vasculitis Stichting), Vasculitis UK and a European pharmaceutical company called Vifor. Starting capital was 25.000 euro.

Future funding should come from:

- our well-funded and/or financially healthy members
- Research project where we will participate while being financially rewarded for our input.

Our first project was FAIRVASC in which our members from the UK, Ireland and The Netherlands participated and got a 50k grant from INSERM.

The same three VPAG's also joined forces in a proposal called VALIDITY for which a 100k fee is foreseen for our input.

- European and/or local grants for the development of our products and services.
- Contributions from the pharmaceutical industry.

This will be done according to all the rules and keeping the right balance between this and other funding.