

# SEE ME HEAR ME

#myANCAvasculitis

## **SEE ME, HEAR ME and Understand AAV**

### ***INCREASED AWARENESS FOR ANCA VASCULITIS***

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**One of the key issues that we have to deal with as vasculitis patients is that the disease is still so little known. This is true for the general public and recently diagnosed patients, but also for many physicians outside the centres of expertise. Together with a number of patient organisations, the Vifor pharmaceutical company is currently putting together a campaign to address this issue. At least for ANCA associated vasculitides such as GPA, MPA and EGPA. The Dutch Vasculitis Foundation, among others, is playing an important role in this process.**

This story began early in 2012. We heard about the development of a product with the codename CCX-168. It would presumably have the potential to drastically reduce the prednisolon dose for AAV or even make it unnecessary. We asked PhD student Arda Göçeroğlu to write a brief article about it, which then appeared in the December 2012 Vasculitis (still named WegenerWijzer at that time). We continued following that product and in December 2017, together with Dr. van Daele of the Erasmus MC, we published an article about the Advocate study, in which the product—which in the meantime had been given the name Avacopan—was tested on a large cohort of patients. This study is now nearing completion and the initial results are expected by the time you read this.

### **CAMPAIGN**

In the meantime, the product supplier has not been sitting idly by. They apparently have a lot of confidence in the results of the study. This is evident from their intention to increase awareness of vasculitis among both doctors and patients by launching a campaign to this end. And of course that is where our interests run completely parallel. We too want more general public awareness and we want all doctors and patients to be well informed about what vasculitis is and the best way to deal with it.

In October 2018, Vifor invited *Vasculitis Stichting* [the Dutch Vasculitis Foundation], along with three other patient organisations from France, Germany and the United Kingdom, to discuss and exchange views on patient input for the campaign. Well, generally speaking, we are rather cautious in our contacts with the pharmaceutical sector, but we would have much to gain from this, so we were happy to take up the invitation.

\*This document is a translation of an existing Vasculitis Stichting newsletter



## OBJECTIVE

In the opening meeting, Vifor defined their own objective as follows:

*Gain better insight into the experiences of patients with AVV and their caregivers, from diagnosis to treatment and with the common objective raising awareness of AVV.*

*This initiative aims to complement the invaluable work already being done on a daily basis by patient organisations across Europe to support people affected by AAV.*

The patient representatives agreed with this objective and that led to regular consultations under the banner “European AAV Patient Ambassadors”.

## ART

Then Vifor began with the creation of two key websites. One for doctors and the other for patients. They are now online and you can find the one for doctors at [www.understandAAV.com](http://www.understandAAV.com) and the one for patients at [www.myANCAvasculitis.com](http://www.myANCAvasculitis.com) . Patients' organisations were greatly involved in the creation of content for these websites. Three initiatives stand out: the models for the 'patient journey' introduced by the *Vasculitis Stichting*, the German initiative for filming 'a day in the life of an AAV patient' and, above all, the UK initiative to involve the artist Shanali Perera.

Shanali trained as rheumatologist, but became a vasculitis patient and so was forced into a different career, which turned out to be art. Her story and artistic talents made a big impression on the people at Vifor and that was the start of a close collaboration regarding the campaign.

The idea is that patients, dressed entirely in black, are professionally photographed and Shanali projects an artistic image of the organ involved in the particular case. The attached photo shows what that looks like.

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## **MATERIAL**

The photos will also be used in brochures to be created and in addition to this type of still images, interviews with patients and their caregivers will be recorded, which will lead to short films. All the material made will also be available free of charge to the *Vasculitis Stichting* and the other patient organisations. So, a tremendous benefit for us.

They started with several photo shoots and interviews in the UK and on 6 November, a complete group of professionals travelled to the Netherlands to do the same with a number of Dutch patients. It was an impressive day that was greatly enjoyed by the patients involved. Besides the Vifor team, an entire team from a professional agency, including a make-up artist, photographer, audio-visual technicians, etc. was also present in Utrecht.

## **CONTRIBUTION**

The participants were not only photographed and interviewed, but they spent an entire morning together reviewing all sorts of designs for brochures together with the communication agency and giving their opinion on the layout and artistic design of the website. An interesting and dynamic process in which it became clear that our input is not only actually taken into account but in fact is also guiding.

We had a great example of this at a previous meeting in Brussels attended by our volunteers Merinke Kuiper and Thom Leicht. The intended slogan for the patient campaign was *Be Seen, Be Heard*. However, a better and more action-conveying suggestion from Thom was selected: *See Me, Hear Me*. So that is now the slogan of the website and the entire campaign. Thanks Thom!

## **FINALLY, TWO IMPORTANT THINGS ABOUT THIS CAMPAIGN**

We do not just consider the material for patients important, but also that for doctors. In this area too, we are working on material that we could only dream of until now. That is why we have strongly urged that, in addition to the usual translations into languages such as Spanish, French and German, Dutch is included, however small we may be. We received permission and, if all goes well, that translation will be completed and implemented on the website by the time you read this.

Secondly, we are well aware that this is all about AAV. At the moment that is nearly 1100 of our 1400 patients, so we must not miss that opportunity. Rest assured however, that we shall continue to make this kind of effort when it comes to the interests of all our other patient groups, as well.