



RARE DISEASE DAY 2020

at Vifor Pharma

Rare Disease Day takes place every year on the last day of February to raise awareness about rare diseases and their impact on patients' lives.¹

Our mission at Vifor Pharma is to strive to help patients around the world with severe and chronic diseases lead better, healthier lives. We are committed to delivering innovative treatments to nephrology patients worldwide and to raise awareness of rare conditions such as ANCA-associated vasculitis (AAV).



What happened at the Rare Disease Day Lunch & Learn?



We held a Rare Disease Day Lunch & Learn event at our Zurich offices.

Participants were able to learn more about the science behind AAV from Prof. Dr. Peter Rutherford

Three AAV patients interviewed by Dijana Krafcsik shared their experiences of living with the disease.

Special guest speakers:

- Shanali Perera M.D. Rheumatologist, vasculitis patient & artist shared her experience

of collaborating with Vifor Pharma and creating the artwork for the SEE ME HEAR ME campaign, as well as her vasculitis experience

- Maresa (AAV-GPA) shared her experience and the challenges she faces to lead a normal and successful social and professional life in spite of her condition

- Martina (AAV-MPA) spoke about her diagnosis and the burden of living with this rare, severe autoimmune disease

At the end of the interviews, members of the audience were invited to ask questions to the patients, who provided some valuable insights into the disease. Key topics discussed included: the side effects of standard treatments, the difficulties that affect their quality of life, and adapting to life with AAV.



“At Vifor Pharma we put the patient first.”

The Rare Disease Lunch & Learn was an important opportunity for our employees to hear directly from patients. Conversations with patients allow us to better understand their needs and ultimately improve their quality of life. This is what make us patient-centric”

Barbara Angehrn,
Chief Business Officer

What were the highlights of the event?

A particular highlight for participants was hearing Maresa and Martina share their experience of meeting each other on social media, and using social media as a form of support. To convey this idea, we created the video, 'A Rare Connection: Maresa meets Martina', highlighting how patient exchange through social media can help patients to cope with a rare, severe illness such as AAV.



Watch the video for more details

“Collaborating and co-creating the disease information materials with patient associations, patients and carers throughout Europe is a true “win-win” situation. Maresa and Martina’s success in connecting should inspire other patients to reach out to each other, so no one feels that they are battling their condition alone. Today’s digital world allows us to do this.”



At the end of the event all attendees showed their commitment to rare diseases by making a hand written pledge. As part of our commitment to AAV we will be supporting Vasculitis International with a donation, the first pan-European patient group for the vasculitis community.



What is the SEE ME HEAR ME initiative?

During the session, participants were able to learn more about the **SEE ME HEAR ME** disease awareness initiative co-created by Vifor Pharma with the involvement of patient associations, patients and carers throughout Europe.

The aim of the initiative is to develop materials that will support people with AAV and their carers, by providing clear and comprehensive content to fill information gaps and help them cope with the physical and emotional impact of AAV. The materials also provide links to local patient association groups, so that people who feel isolated can receive in-person support.

“The artwork enabled me to illustrate the disease and what was happening to me, allowing the **patient to be seen as a whole and making the invisible visible.**”

Hopefully this will improve the patient experience and provide new insights to doctors, to create a more holistic approach to treatment in the future.”

Shanali Perera,
Rheumatologist, Vasculitis patient & digital artist



Watch the video for more details

GPA, granulomatosis with polyangiitis; MPA, microscopic polyangiitis

1. Rare Disease Day (2020). What is rare disease day? Available at: <https://www.rarediseaseday.org/article/what-is-rare-disease-day>. Date accessed: March 2020.

Job code: HQ-AVA-2000032 | Date of preparation: March 2020

SEE ME HEAR ME

For patients, relatives and friends affected by ANCA vasculitis

visit myANCAvasculitis.com

What other activities are Vifor Pharma doing internally and externally to raise awareness during Rare Disease Month?



For the second year in a row Vifor Pharma has sponsored the **EURORDIS Black Pearl Awards** and participated in the **EURORDIS Round Table of Companies Workshop** to raise awareness of the impact of AAV among the most influential rare disease policy makers and stakeholders in Europe.

We collaborated with Rare Revolution Magazine taking over their social media accounts for a day, posting interesting content about AAV, to

increase understanding and awareness about the disease.

In Germany we developed an AAV patient experience report with KOL Prof. Dr. Hohenstein, published in the STERN Supplement about Rare Diseases.

Click here
to see the article

