SEE ME. HEAR ME.

SUPPORT FOR ANYONE LIVING WITH, OR AFFECTED BY, ANCA-ASSOCIATED VASCULITIS (AAV)

Peter Verhoeven* 1;2, Julie Power 1;3, John Mills 1;4, Dijana Krafcsik 5, Peter Rutherford 5, Dieter Götte 5

Vasculitis International 1, Vasculitis Stitching 2, Vasculitis Ireland Awareness 3, Vasculitis UK 4

and Vifor Fresenius Medical Care Renal Pharma Ltd. 5



BACKGROUND / INTRODUCTION

ANCA-associated Vasculitis (AAV) is a rare, severe small vessel vasculitis that affects multiple organs such as kidneys, lungs, nervous system, gastrointestinal system, skin, eyes and heart with a high acute mortality risk.

As every patient presents differently, diagnosis is often delayed. From initial diagnosis onwards, patients suffer from an impaired quality of life.

Patients express a need for more recognition of their views and more information about the disease and its treatment. This collaboration and cocreation initiative amongst PAN-European Patient Associations as well as the Pharma Industry aims to increase the awareness about AAV.

METHODS

This initiative gathered extensive research into patients' needs including

- (1) Qualitative Research with thematic analysis to gather insights into the patient journey
- (2) Exchange with and provision of educational material from patient association heads across Europe, patient members of these associations and carers of patients with AAV
- (3) Specific Patient Expert Shanali Perera (MD), a Rheumatologist specialising in Vasculitis, who has been living with Vasculitis and is a digital artist.

Based on a series of workshops information needed was identified and was created to provide comprehensive content that helps individuals to better cope with the physical and emotional impact of AAV.

Figure 1 – The AAV Patient Journey identified in Qualitative thematic Research - 32 AAV patients across 4 EU countries.

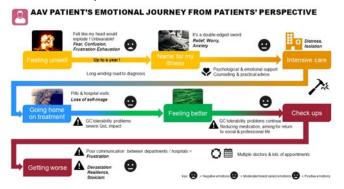


Figure 2 – Different creative concepts developed in collaboration with patient expert Shanali Perera. Making the invisible organ damage visible, the creative title Be Seen Be Heard was selected as the best option by PAN EU Patient Associations, highlighting that Patients and Cares can represent AAV best. This served as basis for further development of the creative initiative but patients changed this to SEE ME. HEAR ME.



Figure 3 – Incorporating cross European input and feedback in the development of the final creative by Shanali Perera creating digital art. Materials were validated by PAN-EU Patient Associations.



RESULTS

The co-creation of relevant information for patients led to the development of the SEE ME.HEAR ME initiative presented online on www.myancavasculitis.com.

The content intends to be multinational and multilingual and covers the following key areas:

- (1) an awareness programme making the invisible, visible,
- (2) a series of first-hand patient and carer stories,
- (3) extensive written content designed to fill information gaps including AAV disease details, the diagnosis, follow up and treatment and self-care.
- (4) Links to patient association groups are provided. It is continually evolving to further enhance people's experiences of living with and coping with AAV.

Result 1 – People with and effected by AAV support the collaboration and co-creation initiative. In every individual patient visual and story, the affected organ has been highlighted as art pieces drawn by Shanali Perera and adjusted to the individual patient image.



Result 2 – Patient Experience is shared in the form of video and patient case stories which show how every AAV patient presents differently. Carers share their experience to support other carers.



SUMMARY / CONCLUSIONS

People with or effected by ANCA-associated Vasculitis need support throughout life. The online patient platform myancavasculitis.com aims to generate awareness around AAV, provide information and materials to enhance people's experiences of living with the disease and to allow the patient to have a deeper dialogue with their own clinical team.

Moreover, it provides support for carers and gives valuable insights about living with AAV such as patient experience reports and video interviews from patients across Europe. The website is offered in different languages, allowing people effected by this disease to benefit from the content beyond national borders.

People effected by AAV are SEEN and HEARD throughout this pan-European initiative. Not every disease is visible from the outside. Creating awareness for this rare, severe chronic illness, by highlighting the organs affected though ART and sharing the affected people's VOICE is the core of the way this initiative was implemented.

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