

## EDITORIAL

# Abdominal Aortic Aneurysm (AAA) UK

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**Background**

Abdominal Aortic Aneurysm (AAA) UK is a newly formed patient representative group giving national representation to AAA patients and their loved ones, providing a platform for national discussion on the impact of – and potential policy changes relating to – the condition.

For too long the patient voice has not been a focal point of conversations about the condition. AAA UK will amplify the voice of patients diagnosed with AAA and ensure that those directly affected by the condition are never overlooked in discussions about their care again.

Launched at the Houses of Parliament on 11th May 2022, AAA UK seeks to bring together people with lived experience, alongside renowned clinical experts, to represent those affected by AAA. We aim to address the imbalance of voice by promoting the views of patients and loved ones, providing a vehicle for patients to become more involved in policy and decision-making about AAA.

AAA UK serves a dual purpose: to provide a forum for support, information and advice for people affected by AAA, and to advocate for the interests of people living with AAA with stakeholders in Government, the NHS, and wider society. We aim to raise the profile of the condition among the general public and policymakers to drive policy change to benefit those affected by AAA, centring the patient voice at the heart of everything we do.

AAA UK believes patients should have access to the full range of treatment options recommended by clinicians. Patients should be consulted at each stage of the pathway, involving them in decision-making and empowering them to have an informed choice in treatment selection. Different treatment options will be appropriate for different patients in their particular situation and circumstance, and the decision of which treatment option is best suited to an individual

patient should be left to the discretion and opinion of the medical practitioners responsible for an individual patient's treatment.

Although AAA UK seeks to gather contributions from clinical experts, all AAA patients should first consult their own medical practitioner for information and advice about their individual treatment and care. AAA UK seeks to educate patients and supporters on the different stages of an AAA diagnosis and the different treatments available; however, this should not be viewed as instructive of individual patient treatment. AAA UK hopes that the community and information provided by the group will help provide additional support to those with an AAA. However, this should always be viewed within the context of advice from a patient's own medical practitioner.

**About the Group**

Every year, 80,000 men are diagnosed with AAA in the UK, and it accounts for 2% of all deaths in men over 65.

Despite this prevalence, to date there has been no established patient advocacy group to support those affected by the condition. The establishment of AAA UK aims to address this by providing a national voice to those impacted by AAA, including advocating for policy changes to help improve the provision of relevant services within the field of AAA.

AAA UK exists to build a community of patients, clinicians, experts and policymakers, and aims to provide information, support and guidance to all AAA patients and their supporters, wherever they are on their patient journey. AAA UK hopes to build relationships between those who are at similar stages in their screening or treatment, and to connect patients and supporters with those who have gone through similar experiences of an AAA.

Since its launch, AAA UK has engaged with patients, researchers, leading clinicians and

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representative bodies, as well as national bodies such as NHS England, to build and develop its network of advocates and supporters, and plans for its work programme for the upcoming year. Clinicians, practitioners and researchers are vital to our work, informing and enriching our ability to make the case for AAA patients to policymakers and Parliamentarians. We are looking forward to engaging with many within the system – including the esteemed readership of the *Journal of Vascular Societies of Great Britain and Ireland (JVSGBI)* – over the coming weeks and months as we build our coalitions, develop our positions and deliver our policy recommendations.

### Group constitution

This Group consists of an Executive Committee made up of people with first-hand experience of AAA. The Executive Committee will be supported by an expert Advisory Committee consisting of leading clinicians and experts in the field as well as selected patrons and parliamentary champions.

The group Executive Committee is made up of three Executive members including Chair, Duygu Yenidogan-Schmidt; Patient Affairs Officer, Les Ruffell; and Clinical Liaison Officer, Usman Jaffer, alongside a wider group of supporters and advisors.

Duygu, Chair AAA UK, is a passionate advocate for patient-centred care and became involved with AAA when her father went through emergency open surgery in the UK while he was visiting her in 2017. Duygu takes a leading role within AAA UK on promoting the interests of patients and carers, and is working to ensure that patients are given the voice in national discussions on their care and treatment.

Les, AAA UK's Patient Affairs Officer, was an AAA patient, having been diagnosed in 2014, and underwent open surgery in 2015. After his operation, Les was invited to join the Vascular Patients Interest Group in Leeds General Infirmary. This led to him becoming a Lay member on the NICE AAA Guideline Committee and patient representative on Leeds AAA Screening MDT. He has also sat as a patient representative on the NHS AAA Advisory and Research Committees and is a patient representative on research projects led by Leeds University and Leeds Hospital Trust, University of Leicester and Imperial College, London.

Usman Jaffer is a consultant vascular surgeon and senior lecturer at Imperial College NHS Trust. He has a passion for training as well as having published and led on numerous high impact papers. Usman is now supervising PhD and MD students through postgraduate degrees. As a day job he practices the full spectrum of vascular procedures at St Mary's Hospital and West Middlesex Hospitals. Usman holds a postgraduate certificate in medical education and is a full fellow of the Higher Education Academy. He has authored the 'Manual of Vascular Ultrasound' and developed a training simulator and assessment framework for vascular waveform assessment for frontline clinical staff.

The Secretariat for the Group is delivered by Healthcomms Consulting, who also run the Secretariat of the Vascular and Venous Disease All Party Parliamentary Group, providing expert

public affairs, policy and engagement to the Executive Committee, as well as management of the day-to-day work of the Group.

The Group has been engaging with national, regional and local stakeholders and building collateral around AAA, screening and treatment for patients (including blogs and articles, video interviews with clinicians and patients, web and social media content), as well as planning for events and meetings for the upcoming year on issues such as AAA screening.

It has also engaged with and supported other organisations with their national engagement such as the Association of British HealthTech Industries (ABHI) Cardiovascular Group in their call to Government for a National Cardiovascular Strategy, which was signed alongside the President of the Vascular Society of Great Britain and Ireland; President of the British Society for Interventional Radiology; President of the British Society of Endovascular Surgery; and CEO of Heart Valve Voice.

### Future work

Recent AAA screening data have highlighted the negative impact of COVID-19 and consistent regional disparities, with lower screening rates in areas of higher deprivation, leading to poorer outcomes for those demographics. Those most at risk of AAA are also most at risk of missing screening, and therefore suffering potentially deadly consequences. AAA UK will be working to bring together supporters and advocates, groups and coalitions, and patients to highlight these inequalities and promote policies to tackle them.

The Group will also look to promote best practice within current screening as it moves out of the challenges from the pandemic and as local screening teams begin to engage with the new Integrated Care System (ICS) structures.

Most of all, the Group will look to continue to develop its network of clinicians and patients. It will reach out to pre-existing networks within the clinical space to develop its range of supporters and advocates, and is open to engaging with everyone who has an interest in AAA. It aims to share knowledge and best practice, increase its footprint in the policy space, and develop its voice on a national parliamentary and policymaker stage. We are also keen to speak to readers of the *JVSGBI* to help in that regard, and would ask you to contact the Secretariat team on details provided below to learn more about how you can get involved.

Above all, AAA UK is a community to discuss AAA, give a collective voice to patients and experts to decision makers. Ultimately, AAA UK aims to improve outcomes for patients across the country so that we can level up screening, treatment and positive outcomes for patients whoever and wherever they are.

For more information, please contact Roger Greer, Secretariat of AAA UK, on [roger@healthcommsconsulting.co.uk](mailto:roger@healthcommsconsulting.co.uk)

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