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**Peter Rutherford**

Vifor Pharma, Switzerland

## Patient experience in ANCA - associated vasculitis demonstrates evolving challenges following diagnosis and major adverse impacts from current therapy

ANCA-associated vasculitis (AAV), a rare small vessel vasculitis, is a relapsing remitting disease that can cause rapidly progressive glomerulonephritis and progressive chronic renal failure. Diagnosis can be challenging, and remission induction and maintenance treatments include a combination of high dose glucocorticoids (GC) and immunosuppressants. Few studies have examined the patient experience in AAV. Qualitative research was performed using one-on-one interviews with 33 AAV patients (11 male) in four European countries. AAV duration (median 3.5 years, range 1-32) and age (25 in peak age group 40-80 years) provided insight into the patient journey from diagnosis to follow up. Thematic analysis of the interview transcripts demonstrated problems with: (1) referral - a long journey to diagnosis led to long lasting psychological damage, worsened with treatment burden; (2) recognition - concern over low empathy and understanding of their needs by professionals; (3) knowledge gaps - patients want to understand their future and return to normality; (4) measuring response - they have a low awareness of how their response is assessed clinically and categories of response; (5) decision making - they had a low involvement in treatment decisions; and (6) unmet needs - while they are grateful for the efficiency of GCs, they feel major side effects which impair function with evolving problems over their journey. In conclusion, patient experience in AAV is challenging both pre- and post-diagnosis and treatment and evolves over time. Physicians need to consider AAV patients' needs and wishes, and new therapies which reduce the significant treatment burden are needed.

### Biography

Peter Rutherford qualified in Medicine from Newcastle University, UK, completed Nephrology Training in the UK and at the Yale School of Medicine, USA, and obtained his PhD in 1994. Following 11 years as Senior Lecturer in Nephrology and as Consultant Physician, he moved to Pharma in 2007 and is now Global Medical Lead for Rare Renal Diseases at Vifor Pharma. He has over 70 peer reviewed publications and has a particular research interest in patient education and decision making.

[peter.rutherford@viforpharma.com](mailto:peter.rutherford@viforpharma.com)

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