

John

GPA patient

Primary disease presentation:

Kidneys, Lungs, Sinuses, Joints

Day-to-day living

- John and his wife and carer, Susan, are from the UK
- Head of the charity Vasculitis UK and a founding member of Vasculitis International

Disease history

First symptoms: In November 2000, suffered from sinus problems and ankles were aching

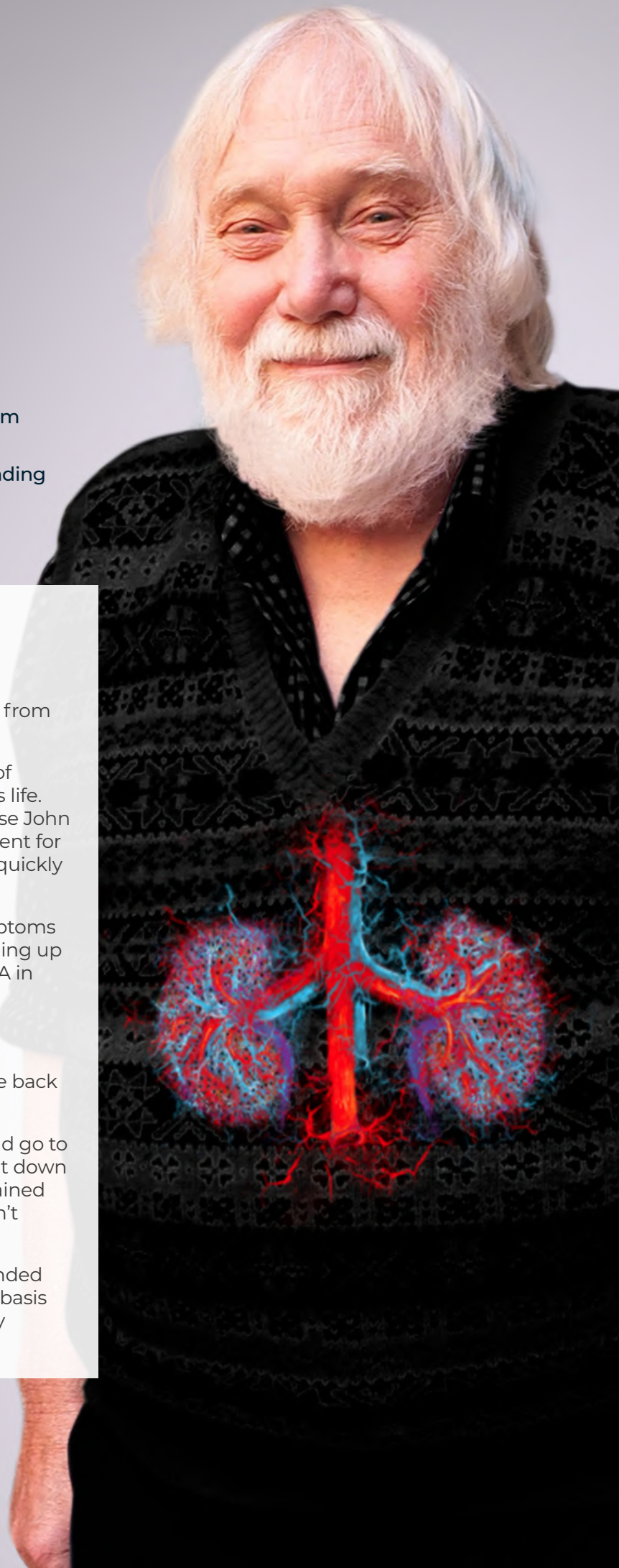
Early progression: When skiing, lost control of his legs/skis. Afterwards he continued with his life. A few days after doing repair work on his house John began coughing up blood. Saw GP and was sent for X-rays. Doctor was unsure of condition. John quickly became bedridden and required oxygen

Delay to diagnosis: 6 months from first symptoms to ending up in hospital. 6 weeks from coughing up blood. Had a lung biopsy. Diagnosed with GPA in April 2001

Treatment: Prescribed 6 cycles of high-dose steroids (glucocorticoids). Given azathioprine as maintenance therapy, the symptoms came back and he was prescribed cyclophosphamide

Struggles with fatigue: Used to go home and go to sleep directly after work. Felt that he had to sit down or he would fall down. All the strength felt drained from his muscles and his brain felt like it wasn't working very well

Supportive care: 5 years post-diagnosis attended a support group. Now helps others on a daily basis as part of the support and information charity Vasculitis UK and Vasculitis International



In their own words

Diagnosis:

Susan – “At work or anywhere else nobody had even heard of GPA so I couldn’t talk to anybody about it. So finding that support group was essential for me.”

Long-term impact of ANCA vasculitis:

John – “I regarded vasculitis as something very annoying. I was quite angry that I got vasculitis because I didn’t think I was the sort of person who became ill, I just kept on going.”

Personal advice:

John – “Well I share my experiences, my knowledge with people on a daily basis and it’s difficult. I can’t say anything specific because each person is different.”

Patient support groups:

Susan – “I think people need to talk to other people who have got the same condition as they have, and the carers as well so that they know what each of us is going through.”

Being a team:

John & Susan – “I think the main thing that got us through was, I know it’s a bit soppy, love and a good sense of humour.”



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