

CASE STUDY



Bath Institute for
Rheumatic Diseases

BIRD'S PATIENT ENGAGEMENT PROGRAMME

BIRD's Patient Engagement initiative works closely with patients to get them involved in research and deepen their understanding of their rheumatic disease.

BIRD runs an extensive programme of patient engagement and education events. Our live events have grown to over 500 patients attending every year and our patient network reaches many thousands every year. During the COVID pandemic we extended our programme offering support to patients via podcasts and webinars while our established, face to face, disease-specific patient information days were not possible. The response was huge and our podcasts alone have attracted over 8,000 listens. We know that the types of learning interaction we offer through the programme involving Consultants, researchers and healthcare professionals, help to give people a deeper understanding of their condition, medications, treatments and research news. Patients value this and are able to use it to help them increase confidence and better self-manage their condition.



Geoff's story...

Geoff is 72 years old and had his first rheumatic symptoms in 1973 when he was only 24 but was not fully diagnosed until 2010. He tells us he 'had spent 37 years wondering what was going on, getting ever worse'. Geoff had tried all sorts of treatments but says the real breakthrough came when he discovered a specific course for people with axSpA at his hospital. He had already been practicing yoga for over 20 years but hadn't made the connection as to why it felt so good. He tells us the extra information he learnt from the course was amazingly helpful and demonstrates why it's so important for

people to become more self-aware about their disease.

"Adherence to a fitness programme has been key for me"

Geoff says his condition became very poor and that the pain he experienced had stopped him enjoying many activities such as football and cricket, dancing and walking. Having had the diagnosis and some medicines that really helped, he says a better understanding of flare ups was also important and helped with his self-care.

“It was always a gamble as to whether I would be doing too much and cause a flare. Then it would be months before getting out of flare. I believe it’s the combination of medication and self-care together that works. Looking back, I changed my job several times because of the condition, but I did not even know I had a condition. I just had a bad back and these weird pains that made me limp”



Help is at hand...

Geoff says meeting other people with AS through BIRD was vital to his understanding of how much people need guidance for self-care. He says: ‘On the Information Days, I learned so much about the medications, and also how much Rheumatology professionals wanted to develop patients’ stickability with movement, exercise, lifestyle. One key note speaker talked about the microbiome and it was fascinating!’

As well as his own condition Geoff is also a family carer for a relative with scleroderma and was keen to listen to BIRD’s podcast series about it. He says the podcasts are ‘fantastic’ and very much tie in with his knowledge sharing approach. Geoff belongs to several AS organisations and initiatives and is happy to recommend the work of BIRD.

As someone who had always liked to read up on research, he enjoyed learning as much as he could about his own condition and it was very important to him to be able to do so. For many years he worked with the INVOLVE organisation on public engagement in research and says the PPE aspect of BIRD’s programme was ‘music to my ears’.

When you don’t understand yourself what is happening, how can others around you? My Mum probably had AS but was never diagnosed, and her sister, my Aunt, was diagnosed at age 82, some kind of record!

I have worked to support groups of carers, develop user and carer involvement guidelines adopted by many UK hospitals



We know that our patient audiences benefit from our programme. All of our events include feedback with response rates exceeding 67% and information is compiled and analysed and made available to all.

We aim for at least 85% of people engaged with information through the Patient Engagement programme to describe their knowledge as improved or really improved since attending, and for our reach to reflect the needs of the general population in terms of age, gender, socio-economic group and ethnic background.

Bath Institute for Rheumatic Diseases,
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