

CASE STUDY



Bath Institute for
Rheumatic Diseases

BIRD'S PATIENT ENGAGEMENT PROGRAMME DURING THE COVID 19 PANDEMIC

BIRD exists to support arthritis research, healthcare professional education and patient engagement. We strive to put patients at the centre of our work, recognising and encouraging the importance of their voice. Our Patient and Public Engagement initiative aims to help deepen patients' understanding of their rheumatic diseases and medication so they can make informed choices and share treatment decisions with their clinicians.

In phase III of the programme, we made a pivot to digital events through webinars and podcasts due to the circumstances of the Covid19 pandemic. We wanted to enable our patient network to continue to access the quality information and updates about their diseases and to support them - many of whom we knew were significantly clinically vulnerable and shielding. In this case study we share the experiences of three different patients and the benefits they feel they have gained as a result of the programme.



Case 1 - Alison

How BIRD podcasts helped a new patient learn about their condition.

I would like to share my opinion and experience from the perspective of a new patient to the area. I was initially concerned about how my transfer to a new hospital and consultant would happen given these times of the NHS being stretched and under a lot of pressure. I have Fibromyalgia, Limited Scleroderma and Sjogren's Syndrome. Everything went very smoothly, having been referred by my new GP. I have now had some tests including nailfold capillaros-copy and thermography that were not offered to me by my previous Rheumatology dept and I am currently on the Fibromyalgia Self-Management Programme. I have found the BIRD web-site and podcasts

very informative and have learnt a lot more about my conditions. I am so pleased to have all this information to hand and the opportunity to be involved if I can in any research opportunities. I have signed up for the newsletter and applied to come to the RNHRD Research Showcase event in March.

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Case 2 - Karen

How becoming informed led a patient to get the right diagnosis.

I was diagnosed with Psoriatic Arthritis by my local hospital rheumatologist. I had never heard of it before, and it was a bit of a shock. I was given leaflets about the disease and the medications I would have to take and told to read them. Several months later, after trying to explain this all to my family and friends, I had another appointment where my clinician changed their mind about my diagnosis. I was completely floored. I had joined a Facebook group for people with PsA and was about to leave the page and accept the change of diagnosis to enthesitis, tendinitis and osteoarthritis. It was then that I saw a post about the podcasts for Psoriatic Arthritis by BIRD. I decided to have a listen. It all made sense and described the development of my symptoms to a tee. That's when I thought I needed to get a second opinion and I spoke to my GP who did a referral, and I booked an appointment. I was re-diagnosed last April and started treatment. I still have lots to learn but have gained so much information from the podcasts. If I hadn't come across them, I would still be undiagnosed and I dread to think what the consequences of that could have meant.

I hope to learn some more from BIRD's PsA webinar. I am also more than happy to be of any help (as a patient) to the work BIRD do.



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Last year 120 patients attended one of our 3 webinars and over 15,000 people have listened to our information podcasts. In addition, patients were invited to participate in 15 research projects by BIRD.

Bath Institute for Rheumatic Diseases, Registered Charity No 1040650.

BIRD chose to pause face-to-face events during the Covid 19 pandemic, knowing that many patients were significantly vulnerable or too worried to participate and it was absolutely the right thing to do. The digital sharing of information through podcasts and webinars have been a great success and actually increased accessibility of information we provide for patients across the UK. Maintaining a hybrid approach to programme outputs is something we are looking forward to now. Whilst we are aiming to keep online engagement as an option for people who may be too unwell or have commitments that mean they cannot take time out to travel, we also know that a face-to-face event can have its own unique benefits as demonstrated in the statement below, and we are looking forward to trying a few new events out and welcoming people to them in 2023/24:

Alison was keen to tell us how she felt about her live event experience: At our second face-to-face Psoriatic Arthritis information event, I gleaned information which enabled me to be referred to a specialist consultant in London, and this has had a dramatic impact on my treatment and condition. The day was organised really well, with attention to detail. We were made to feel very welcome, and it was wonderful to have the opportunity to talk to the different speakers on a one-to-one basis. The events are really well attended, and it is good to speak to other people with PsA as it can feel very isolating having a more unusual condition.

To find out more: www.birdbath.org.uk or connect with us via social media.

