

# CASE STUDY



Bath Institute for  
Rheumatic Diseases

## BIRD'S PATIENT ENGAGEMENT PROGRAMME

Our Patient and Public 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 switched to offering patients support via podcasts instead of our established disease-specific patient information days and these have attracted over 6,000 listens. We know that both types of learning interaction, 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.



## Jayne's story...

Jayne is 74 years old and had an initial diagnosis of ankylosing spondylitis (AS) in the mid-1980s when the condition was poorly understood and people faced lengthy delays in accurate diagnosis. During this time, and with little expert interaction and information, Jayne felt frustrated and anxious. In 2005, Jayne had a second referral to the Royal National Hospital for Rheumatic Diseases (RNHRD), where BIRD was also based, and was finally able to gain some clarity on her condition.

Jayne's day-to-day living is substantially affected by her condition – she tells us that

things like bending to reach her feet and tie laces are impossible. She struggles to cook and serve a meal, do washing up, Hoover, and many other basic tasks. She cannot carry objects which is very distressing as she has a new baby grandson whom she wants to be able to carry and cuddle. Since her diagnosis of AS, she has also been diagnosed with a spiral scoliosis and fibromyalgia, both of which create further impositions. Jayne's lungs are affected so stress and activity cause her to struggle to breathe.

# Help is at hand...

Jayne first discovered BIRD and the Patient Engagement Programme through literature and mailings from the RNHRD. She signed up to BIRD's patient contact database and attended an information event. She says "I learnt a great deal about my condition and about possible ways to help myself during that experience and I was able to recognise and adapt some of the wider potential impacts of life and health choices". She says it also helped to allay some fears that develop through incorrect information and rumours. More than that, Jayne enjoyed meeting staff and listening to the experts and finding out about new research. Although she felt too shy to connect to other people at that first event, it still didn't put her off deciding to make sure she followed up further opportunities to learn and she felt drawn to helping research and to raising awareness.

***I would definitely recommend the information days to other people - it was a very valuable insightful time***

Jayne has enjoyed hearing the experts speak on BIRD's information podcasts too – being able to find out even more about her condition, medications, treatments and latest research. She is able to sit and listen at a suitable time and replay as needed. BIRD also links to other key support organisations and Jayne told us it was good to listen and find out about what they are doing and how they provide other means of support, such as leaflets and exercise videos which help to improve living with her condition.



***Having access to these sorts of things will directly help me***

Jayne says that accessing information through BIRD's Patient Engagement programme has benefitted her greatly and that her family have also learnt about AS and how they can best be aware and give support. She says "Through my link with BIRD's Patient Engagement programme, I am kept informed of patient involvement in research opportunities too and I have participated in projects. My main motivation to participate in research opportunities is to hopefully help future generations and the current understanding of rheumatic diseases. I have been painfully aware from the start of the lack of understanding, especially in public perception but hopefully BIRD's Patient Engagement programme will help to improve that!"

***I have already given BIRD's contact information to a friend who has AxSpa***

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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