

NEWSLETTER



Did you know that BIRD is a charity working alongside the Royal National Hospital for Rheumatic Diseases to help patients understand and manage their condition better?



Our old home, the Mineral Hospital, Bath

WHO WE ARE

The Bath Institute for Rheumatic Diseases (BIRD) exists to support arthritis research, education, and patient engagement so that we can improve treatment for patients with rheumatic diseases.

Bath has always been at the forefront of bone and joint disease research, education, and patient care, as part of its history as a city with thermal waters since at least Roman times, and with one of the first national specialist hospitals in the country founded in 1738. BIRD was formed in 1975 by the Royal National Hospital for Rheumatic Diseases (known affectionately as 'the Min' and now part of the Royal United Hospital, Bath) and the University of Bath. Although we became an independent charity in 1981, we collaborate closely with both organisations, because bringing clinicians and scientists together is at the heart of what we do.



THE TEAM

BIRD is a small team who lead, co-ordinate and collaborate with many different specialists. We are also fortunate to have very engaged and dedicated committee members and trustees, some of whom come from the Royal National Hospital for Rheumatic Diseases, and we always have a patient on every committee to ensure we are patient focussed.

WHAT WE DO

BIRD provides training and funding for medical professional development and research into rheumatology:

BIRD organises a wide-ranging programme for the continued education and training of healthcare professionals, working with a range of health and education providers, including the Royal National Hospital for Rheumatic Diseases (RNHRD), the wider Royal United Hospital NHS Trust, the University of Bath, and the Bath GP Education & Research Trust.

Last year's educational events reached a record 580 attendance by healthcare professionals, where each of the training sessions was approved for accreditation by either the Royal College of Physicians or the Bath GP Education & Research Trust (depending on whether the attendees came from primary or secondary care) which enabled them to gain continuing professional development credits.

Wherever possible, BIRD secured sponsorship from companies to cover the costs of these meetings. Our thanks to the various pharmaceutical companies we have worked with for supporting our educational programme.



As well as the medical professional development above, BIRD has also awards medical research grants. These grants given to academics and clinical staff are primarily collaborations with the University of Bath and the Royal National Hospital for Rheumatic Diseases. Two examples of recent grants are:

- DATA Analytics for Patient Scheduling (DATAPAS)

An exciting collaboration between practicing rheumatology consultants and machine learning experts at the University of Bath.

- How common is VEXAS syndrome in an adult rheumatology population? Multicentre study over 3 sites in Southwest England

The VEXAS syndrome is a recently discovered condition which causes difficult-to-treat inflammatory diseases and the study has the potential to improve current individual patient care and improve the prospects of future patients in general.



The Patient Engagement Programme:

BIRD supports patients with rheumatic conditions. Each year we run a programme of initiatives designed to help patients understand and manage their rheumatology condition better.

Initially, the programme consisted of Patient Information Events within the old Mineral Hospital in the centre of Bath. Throughout the year each event would cover a different condition theme, with consultant, specialist nurse and physiotherapy speakers. They were always well attended and received.

However, due to the covid pandemic we needed to find new ways to reach patients with information and advice on how to manage their condition in-between appointments. Working with the wonderful staff at the RNHRD BIRD started to record patient information podcasts and host online webinars.

Our podcast library now has over 40 different podcasts, all covering different themes, listened to nearly 20,000 times.

Visit our website to see the full library, search for BIRD on your favourite listening platform or scan the QR code.



Our podcasts come in series where we talk to expert consultant speakers in each condition. Podcasts cover an introduction, an overview of current research and medications available, as well as physiotherapy tips. We currently have series on:

- Axial Spondyloarthritis
- Fibromyalgia
- Lupus
- Myositis
- NICE and BSR Guideline Updates
- Osteoarthritis
- Osteoporosis
- Psoriatic Arthritis
- Rheumatoid Arthritis
- Raynaud's
- Scleroderma
- Sjogren's
- Vasculitis
- Well-being - Fatigue, Social Prescribing and Sleep Tips
- Young Adult Arthritis

We are always recording more, so please do keep an eye on our news.

"The BIRD Podcast Library provides an easy to access, information rich resource, enabling patients living with long term conditions to better understand their disease. The relaxed and friendly format allows listeners to comfortably absorb and understand the disease specific information. The podcasts have been recorded by healthcare professionals who regularly treat patients with the diseases they are speaking about and therefore provide helpful insights in disease understanding and management."

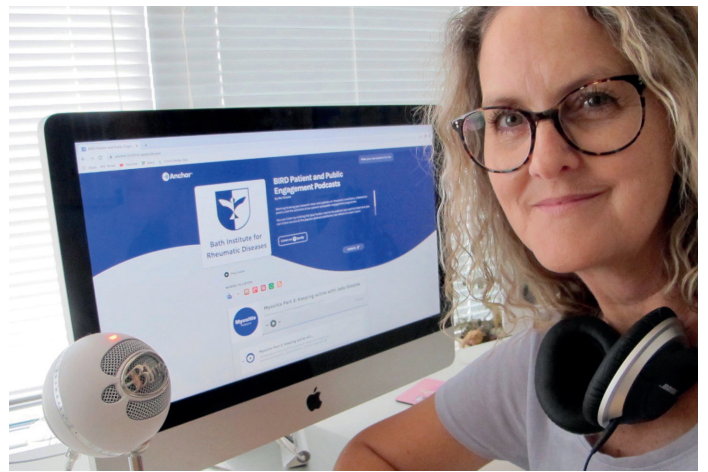
Raj Sengupta, Consultant Rheumatologist
Clinical Lead for Axial Spondylarthritis, Royal National Hospital for Rheumatic Diseases

As a patient do you want to be involved in Research?

Another of BIRD's aims is to enable and give patients the confidence to participate in rheumatology research. We send out research requests through our newsletter (email the below address to sign up) or to our Patient Panel.

The Patient Panel

We currently have around 30 fantastic patients who are signed up to comment on or be involved in the early stages of research design, with the aim of making sure the patient perspective is included. This is very light, duty wise, a few emails a year and possibly a group Zoom call. If you are interested and would like to join, please contact: ppe@birdbath.org.uk



BIRD NEWS...

Bath Life Finalist

In 2023 we were delighted to be selected as a 'Finalist' in the Charity Sector for the Bath Life Awards. Although we didn't win, being a finalist and the only 'Highly Commended' award allows us to celebrate and thank all the wonderful speakers from the RNHRD who support BIRD with the podcasts. These podcasts in turn support many patients at the RNHRD so we are delighted with this recognition.

BIRD at BSR

As part of BIRD's charitable aims to help develop and encourage medical professional careers, we were delighted to fund 7 clinical staff from the RNHRD to attend the British Society for Rheumatology Conference in Manchester. As well as supporting patients, it's vital to help health care providers in their careers in rheumatology. Shannon Gunawardana, Clinical Research Fellow in Rheumatology, one of the bursary recipients said:

"I was lucky enough to receive a BIRD bursary to attend the British Society for Rheumatology Annual Conference in Manchester (2023). I contributed to a poster presentation at this conference on the topic of using PET-CT scanning to measure cardiovascular disease of patients with Giant Cell Arteritis. I was able to attend some interesting lectures on new research within Rheumatology.

I was particularly curious about the use of a new steroid-sparing drug called Avacopan, which has recently been licensed by NICE for use in vasculitis. I also attended some fascinating talks for trainees on the role of diet and fatigue within inflammatory conditions. I was particularly struck by these topics because I am often asked about this by patients in clinic and there has been a large body of research in recent years. The conference was also an excellent opportunity to meet Rheumatology trainees, consultants, and researchers from across the UK (and internationally!) I am very grateful to BIRD for awarding me a bursary to attend this conference. It was an engaging educational experience - I have also been inspired with new research ideas that I hope to undertake in the future."



JOIN OUR COMMUNITY - sign up to receive newsletters or follow us on social media.

We send out newsletters about the work of BIRD and forthcoming patient webinars or events every two months or so. Email admin@birdbath.org.uk or visit our website and follow the links on the home page to sign up at www.birdbath.org.uk.

GET INVOLVED IN RESEARCH

If you'd like to get involved in research, there are a few ways to do this. In clinic at your appointments and then follow BIRD. We occasionally send out requests from Researchers who we work with or who contact us. It will vary according to which condition and what topic, but any support is appreciated.

We also have our Patient Panel mentioned earlier. Contact Mel Brooke if you'd like more details - ppe@birdbath.org.uk

CONNECT WITH US TO FIND OUT MORE

www.birdbath.org.uk

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Bath Institute for Rheumatic Diseases
Supporting arthritis research, education
and patient engagement

I'm listening to lots of BIRD podcasts at the moment. On my 5th and they are brilliant. Listening to myositis ones now, what amazes me is the depth and range of information in each podcast. They are also very accessible. I'm learning new language to explain things.

I just want to thank you very much for your podcasts on the subject of Psoriatic Arthritis. As someone newly diagnosed with this disease, I found them so informative and helpful.

Axial Spondyloarthritis:
Thank you all for an excellent webinar session. Picked up lots of information and ideas too.

Psoriatic Arthritis:
A fabulous webinar! Thank you so much for organizing and for the amazing presenters! Excellent information and I'm floored that the presenters took the extra time to actually answer all the questions asked by us. It made me feel really listened to and included.

DONATE

If you'd like to donate to help the work of BIRD that would be wonderful. We receive grants and support from other sources but always appreciate financial support received from patients.

Donations are used to help fund the podcast programme, fund research projects and to help further medical professionals' careers in rheumatology.

If you wish to discuss a gift or pledge a legacy, please do contact our Director, Celia on director@birdbath.org.uk, she will be happy to talk to you. Thank you!

localgiving

www.localgiving.org/charity/BIRD