



Trustees' Annual Report for the year ended 31 March 2020

Objects and Activities of the Charity

BIRD is an incorporated charity. Its objectives, as set out in the Memorandum and Articles of Association are to relieve sickness and to promote and advance medical knowledge with particular reference to rheumatic diseases; and, to undertake research in relation thereto and to publish the useful results of such research. BIRD funds research and education into all areas of rheumatology and all types of bone and joint disorder. The terms "arthritis" and "bone and joint disease" and "rheumatism" are used in that context throughout the annual report.

Focussing its activities in the Bath area, BIRD seeks to support research and education into many aspects of bone and joint diseases. It does this by raising money to fund research including fellowships, to provide information days for people affected by bone and joint disease, their family, friends and carers, and by organising continuing education events for health professionals.

Grants awarded for Research

BIRD funds research and supports the next generation of researchers into bone and joint diseases. The focus is on pump prime funding for smaller projects, undertaken in or from Bath for the benefit of patients worldwide, in rheumatic diseases which:

- Help to promote and advance medical knowledge
- Improve treatments for patients
- Encourage collaboration between clinicians and research scientists

The guideline for grant amounts is up to £10,000, but greater amounts may be considered, that would be ideally suited to pilot studies, preliminary research,

tests of clinical effectiveness or would enable other grants to be made for the above research.

In total **£105,128** was awarded:

- £17,369 to Dr Latika Gupta for measuring autoantibodies that occur in myositis in a cohort of Indian patients, in collaboration with a centre in Lucknow, India
- £11,865 to Dr Carly McKay to better understand the experiences of young people with early osteoarthritis symptoms after knee injury
- £10,795 to Dr Sarah Tansley to identify Scleroderma autoantibodies in children, a rare auto-immune disease which can cause arthritis
- £4,136 to Dr Dario Cazzola to validate use of 3D ultrasonography for the analysis of spinal load in Axial Spondyloarthritis
- £15,000 to Victoria Riddell towards a PhD studentship focussing on autoantibody sensing for early diagnosis and subsequent monitoring of rheumatic diseases (this is the third year of three years match-funding with the University of Bath)
- £24,107 towards Dr Sarah Tansley's National Institute for Health Research Clinical Lectureship, each year for three to four years, starting in February 2019 (this amount is not shown in the figures of this report because it was inserted last year alongside that year's allocation)
- £10,000 for University of Bath researcher Amel Badoume to complete her PhD to characterise the immune cell populations in psoriatic arthritis and ankylosing spondylitis using single cell RNA sequencing
- £11,856 for University of Bath researcher Amelia Green to complete work looking at factors that may predict the onset of psoriatic arthritis in people with psoriasis, as part of a broader study.



BIRD's Education Programme

BIRD organises a wide-ranging programme for the continued education and training of healthcare professionals, working closely with a range of health and education providers, including the Royal National Hospital for Rheumatic Diseases, the University of Bath and the Bath GP Education & Research Trust. BIRD provided the administration and support, including the accreditation and sponsorship where necessary, for the following educational events, reaching 300 healthcare professionals:

- BIRD assisted in running the biannual University of Bath statistical applied mathematics integrated think tank workshops for 87 post-graduate students and industry leads to solve real life business problems using mathematical and statistical skills
- South West Connective Tissue Disease & Vasculitis Meeting for 21 consultants and clinical staff (the second of these events was unfortunately postponed to Autumn 2020 due to Covid restrictions)
- Bath, Bristol and Weston Axial Spondyloarthritis meeting for 27 consultants and clinical staff
- Bath and Bristol Bone meeting for 33 consultants and clinical staff
- International Skin Conference, Skin@Bath, in collaboration with University of Bath and the Royal United Hospital Bath held its second event 120 skin experts from around the world, including researchers from around Europe and a delegation of eight scientists from China, representing three major Chinese universities. BIRD sponsored the section on psoriatic arthritis and skin

- Axial Spondyloarthritis and Psoriatic Arthritis fellowship programme for the Leeds Rheumatology team of 12 consultants and clinical staff.

The annual Rheumatology study afternoon for GPs, Nurse practitioners and primary care healthcare professionals was unfortunately postponed to Autumn 2020 due to Covid restrictions.

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. BIRD secured sponsorship for meetings in the education programme where applicable, offering stand space to companies that supported the event. All events are operated independently and sponsors had no editorial control over the event content.

A grant was received from Sanofi Pharmaceuticals to support the overall education programme and additional individual event sponsorship was also sourced from various companies including: AbbVie, Novartis, Celgene and Pfizer.



The Patient and Public Engagement Programme

BIRD is committed to encouraging greater public awareness of bone and joint diseases and helping patients, their friends, family and colleagues to understand their condition. The Patient and Public Engagement (PPE) programme has run since 2016 and was evaluated independently in 2019 and this led to Phase Two development for the next two years, 2020 and 2021, that:

- Recognises the strength of BIRD's information days and the importance of an engagement professional, who is also a patient, in leading and shaping the programme
- Adapts how information is provided to increase the diversity of patients reached, especially those in work or time poor
- Sets a new focus on getting patients involved in clinical and academic medical research reflecting BIRD's role as a medical research institute – in 2018-19, 33 patients were involved in research but, following evaluation of the PPE programme, the aim is to substantially increase that number to 90 per year
- Adjusts the way BIRD awards research grants to ensure that every project engages with patients
- Sets more focused objectives around patient outcomes, specifically by the end of 2021, to aim for:
 - Patients have a deeper knowledge of rheumatic diseases, with 900 patient attendees at 7 patient events and piloting webinars for 1000 patient views online. 85% of patients describing their knowledge as improved or really improved since attending. Patients reached reflect the general population in terms of age, gender, socioeconomic group and ethnic background

- Patients are involved in research, with 170 patients participating in focus groups, surveys, apps and workshops
- Patients give high quality input to research as patients develop confidence and understand researchers' needs. BIRD will identify and understand researchers' needs, arrange training and development for patients, and explore the setting up of an expert patient peer group so that 75% of patients are confident and satisfied they expressed their thoughts and needs and 85% of researchers find their input useful.

For the year ending in March 2020, the following information events for patients were organised:

- Rheumatoid Arthritis (40 attendees)
- Lupus (29 attendees)
- Osteoarthritis (45 attendees)
- Ankylosing Spondylitis (71 attendees)
- Fibromyalgia (29 attendees)

Through the PPE programme, 34 patients were involved in medical research opportunities, including workshops, focus groups and survey participation, covering topics such as Axial Spondylitis and Fibromyalgia. Engagement with the patient and general public community was significantly improved through issuing 38 newsletter mailings during the year, 13 relating to workshops and research opportunities, with an encouraging 60% open rate for every mailing. Two printed newsletters were produced for Rheumatoid Arthritis and Psoriatic Arthritis patients and distributed via the hospital networks, BIRD's community and social media channels. A stakeholder community of over 100 people was created for BIRD and its PPE programme comprising expert speakers, medical professionals, charities working in allied arthritis areas, grant givers and healthcare community groups and 4 e-mailings were sent. The PPE programme received grant funding from the J R Tijou, Oakdale and Champliss Charitable Trusts; and was sponsored by Eli Lilly & Co Ltd.



Awareness Raising

BIRD organised a showcase event and said farewell to being located at the Royal National Hospital for Rheumatic Diseases. A toast was raised to the famous Mineral Water Hospital, one of the first national hospitals in the country. Researchers funded by BIRD explained their work to donors, volunteers and staff by presenting scientific posters.

Two new Patrons were announced. They are:

- Professor Bernie Morley, Deputy Vice-Chancellor and Provost of the University of Bath. His previous research focussed on the genetics of autoimmune diseases, specifically Systemic Lupus Erythematosus.
- Sharron Davies, MBE, former British champion Olympic swimmer and television presenter. Her experience of peak fitness, and indeed the injury that often goes with athleticism, gives her insight and sympathy for those with musculo-skeletal bone and joint conditions.

Both the new Vice-Chancellor of the University of Bath, Professor Ian White, and Professor Bernie Morley gave speeches at the Skin Conference with generous mention and thanks given to BIRD.

For the first time, 13 runners took part in the Bath half marathon in late March to raise money for BIRD research grants, raising over £2,600.

Stephanie Lear, trustee, raised £1,960 through a sponsored skydive for BIRD.

Dr Nick Hall trustee was awarded an Honorary Doctorate of the University of Bath for his outstanding contribution to rheumatology. Nick led BIRD for many years and through his efforts made a major impact in ensuring that Bath has flourished as an independent research and education centre for bone and joint diseases.

The offices of BIRD were relocated from the historic Mineral Water Hospital site in the centre of Bath to newly-built rented offices at the Royal United Hospital.

A new website for BIRD was designed and launched, generously sponsored by the Maiden Foundation.

A new LinkedIn page for BIRD was set up.



The main achievements and performance of the charity in terms of public benefit were:

- The total amount of grants awarded for research into rheumatic diseases was £105,128, the higher than budgeted amount reflecting the use of two appropriate restricted funds to extend two PhDships in addition to the £80,000 allocated to grant-making.
- 300 attendees at training sessions, meetings and events for consultants, clinicians, healthcare professionals, researchers and academics.
- 185 patient attendees at PPE information days and 360 registered for newsletters. The total network reached via mailings and social media ad postings was 16,909 patients and members of the public. Newsletter engagement was much greater than previously.
- 87% of attendees on average at information days understood their condition better as a result, up from 74% in the previous year.

(Attendance was lower than last year because the number of events for both patients and healthcare professionals was fewer than the previous year, due to relocation in the Autumn affecting two events and to the Covid pandemic affecting two March events).

Awareness raising took a significant step forward in the year through the showcase event, the new website, the new Patrons and participation in the Bath Half Marathon.

A disappointing year for fundraising is partly explained by the phasing of £10,000 worth of sponsorship income received just before the financial year started, for work undertaken in the year ahead. In total, £10,700 came from charitable trusts and the sponsored half marathon and skydive, £1,409 from individual donations, £5,640 from pharmaceutical company

sponsorships and grants. The effort to raise awareness and nurture donors continued.

Overall, the immediate beneficiaries above, scientific academia in general, and patients, carers and their families benefited from better understanding of rheumatic diseases and their treatment, thereby contributing to the alleviation of suffering.