

# People's Needs Patient Choice Every Voice



## PEOPLE'S NEEDS...

Often people call their rheumatic disease 'Invisible Illness' because chronic pain is not something that others can see, but the emotional and financial impact of these illnesses can have a wide range of repercussions for people and their families. There are other needs outside the clinic that are not being met and BIRD want to help.

## PATIENT CHOICE...

BIRD have been listening to patient feedback from their information days for years, we intend to use that feedback in new ways to create even more support & choices for people suffering with rheumatic disease and chronic pain.

## EVERY VOICE...

It's not only patients who are affected by disease - often it impacts on families, work/social life - and that's why we feel it is important to listen to all the voices behind invisible disease and do our best to make sure they get heard.

## BIRD Patient & Public Engagement



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Rheumatic Diseases**

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Bath Institute for  
Rheumatic Diseases

# BIRD

## Patient & Public Engagement



## OUR HISTORY

The Bath Institute for Rheumatic Diseases (BIRD) is an independent registered charity formed in 1975.



Since then we have been raising funds to support research and education into many aspects of bone & joint diseases and have trained PhD students, Clinical Research Fellows and Post-Doctoral Research Assistants. In addition, we have also been sincerely committed to encouraging the wider public's awareness of rheumatic diseases and to helping patients, their family and friends to better understand their conditions.

The institute has always had close links with both the Royal National Hospital for Rheumatic Diseases (RNHRD), the University of Bath and Bath GP Education & Research Trust. More recently, since the acquisition of the RNHRD, we have been forging new links with the Royal United Hospital Bath (RUH)

## OUR FUTURE

Times have changed greatly since we first set up in 1975 - not least for patients who, thanks to a world of online information and social connection, have a more powerful influence on the kinds of treatments & options and have been able to communicate what is really important to them.

BIRD are increasingly working closely with patients & support groups and want to build on those strengths.

We can see gaps that need filling so have lots of exciting new plans underway! More than that, we know it's about helping real people - not just those who feel labelled as 'patients'.



## BRINGING PEOPLE TOGETHER...

Bone and joint diseases affect all ages - including children - and with many people suffering from some sort of rheumatic complaint you would think that everyone would know someone with the same disease! However, this is not always the case and people can feel very anxious or isolated when they are first diagnosed - which really doesn't help them feel any better! We recognise that finding other people to talk to is an invaluable means of support and it is our intention to help facilitate this through a range of patient events.

We also want to help people set up their own support groups - and will give them as much support as they need to get going and keep going!

## CURATING INFORMATION, PROVIDING EDUCATION & SUPPORTING PATIENT OPPORTUNITIES IN RESEARCH

Through our experience of running patient information days and listening to feedback, we want to put the following plans into place:

- Help pull all the useful information & resources into one place that's easy to access - and we don't just mean medical information...
- Run a wider range of information days, 'think tanks' & focus groups that gives everyone a chance to network, be inspired & have a voice.
- You have told us that research, learning about new medicines & treatment approaches is something that you would like to be involved in, BIRD aims to make this more accessible to you.



## JOIN US....

A leaflet like this is simply not big enough to tell you all our plans and this is just the beginning. Please join us and share ideas from the patients, family & friends perspective - we invite and encourage everyone to get involved - you can even find us on Twitter & Facebook!

To register & find out more about our Patient & Public Engagement Events you can email us at [PPE@birdbath.org.uk](mailto:PPE@birdbath.org.uk)

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