

Welcome

We hope that this newsletter finds you with a bit more of a spring in your step, the lighter, longer days and the trees back in leaf. We also hope that most of you are on your way to having had two doses of vaccine and that you are able to see a little more of your loved ones.

You will see that PAG has had a facelift for 2021—a new logo based on the Rheumatology department's colours and balloons. We plan to bring you a newsletter every quarter and have been working closely with the department to bring you with news from the management, consultants, nurses, research and the wider community. We'd love to hear from you too; the strength of the group is that it brings the patients' voice to the department and it is really valued by staff. PAG is also about sharing with other members of the group; your experience and insights help us support one another. If you have any stories or experiences you like to share or questions that you'd like to pose to staff members or other patients then please get in touch. Mike Deane, Chair of PAG

Clinical News - Dr Liz Perry

Early Inflammatory Arthritis Clinic

We launched our Early Arthritis Clinics in September. These enable us to see patients with suspected inflammatory arthritis quickly and start treatment early. Research shows that early treatment improves outcomes, especially in rheumatoid arthritis, which is the focus for these clinics.

The clinics are one stop, so that if patients need an ultra-sound scan or any additional tests to make the diagnosis where possible these are performed on the day. These are very much multi-disciplinary clinics supporting best practice for the diagnosis and management of Rheumatoid Arthritis, we are working to incorporate administrative support, nursing and occupational therapy within the clinic bundle. They would not have been possible without collaborative working between our nursing, medical and therapies teams. We also have a brand new Ultra-Sound Scanner to give us excellent diagnostic support for

patients both in our Early Inflammatory Arthritis clinics and across our BRI service.



New Faces

Dr Liz Reilly joined our team in December as a consultant. Liz has been essential to the development of our Early Inflammatory Arthritis Service. She also performs ultra-sound within her clinics and has a special interest in the condition Ankylosing Spondylitis.

As well as being consultant, Liz is a clinical research fellow in Bath. Over the last few years she has been working with colleagues from the University of Bath on research around blood markers in Ankylosing Spondylitis. Liz has also been evaluating the importance of exercise in these patients, and the impact of fatigue.

University Hospitals Bristol and Weston UHBW

We are working closely with our Weston colleagues in rheumatology to coordinate and align our services. The Weston team have been a fantastic support to our service during the pandemic and we very much look forward to ongoing collaborative working. Stuart Weber the consultant lead at Weston links in weekly with our triumvirate (management/consultant/nursing leads) meetings.

Clinical Nurse Specialist Team News - Tracy French

In the last 12 months the team have worked incredibly hard to keep our service running and support patients in different ways. Many of our clinics have switched to telephone consultations, but we are also doing face to face clinics at the BRI and at South Bristol Hospital for those we need to see.

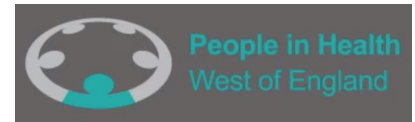
The advice line has been very busy; we initially had lots of calls from anxious patients who were unsure if they should continue their immunosuppressive medications because of Covid (we advised them they should continue their medications!). We then had another surge of calls about Shielding (whether people should be shielding and if they were safe to be going to work). Every time the government announced something about going in or out of lockdown we would receive a surge of calls. We all continue to work very hard as a team to return all the calls in a timely manner and advise and reassure the patients. Some staff were also drafted to go to work on the wards when the Covid numbers were really high which put the team under further pressure but as usual everyone rallied and supported each other and we got through it!

We have taken some positives from the experience – we have realised we can do some consultations over the telephone so moving forward we will continue to do a percentage of the clinics over the phone which will hopefully save patient's time and money travelling into the department.

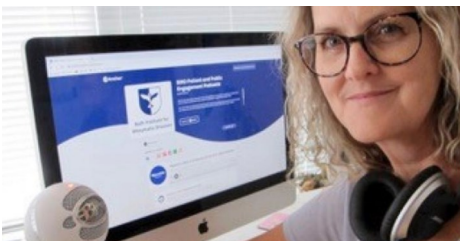
Research News

Dr Emma Dures, Dr Jo Robson and Dr Mwidimi Ndosu have been awarded funding from Above and Beyond, the charity that supports Bristol's city centre hospitals. The funding is being used to analyse information from the rheumatology department's nurse helpline. The researchers will look for patterns to see who uses the helpline, how often and why. The helpline is an important point of contact for patients dealing with their rheumatic condition and the long-term aim is to see what further support might be needed. The project is being undertaken in collaboration with colleagues from Bristol, Bath and Weston.

If you have ever fancied taking part in research but don't know where to start People in Health West of England are running a pilot training session online on Friday 21st May 10am-1.15pm. The course is called Introduction to public involvement in research for members of the public. You can find more details by searching events on their website - www.phwe.org.uk or by using this direct link <https://bit.ly/33yaxKd>



PAG News



Despite not being able to meet up PAG has been busy behind the scenes. Recently we met with the organisers of other patient support groups in the region to see what they do and what works for them. We met Mel Brooke, who leads the psoriatic arthritis group in Bath and is the patient and public engagement officer for Bath Institute of Rheumatic Diseases (BIRD) Mel has been producing excellent podcasts during lockdown in which she talks to researchers

and clinicians about developments in rheumatic conditions. Currently there are talks on Myositis, Osteoporosis, Vasculitis, Axial Spondylitis and Scleroderma and a new Psoriatic arthritis series will be available soon. The podcasts are free and available to all. Visit www.birdbath.org.uk/podcasts to listen to any of the episodes.

Finally, the Facebook group is up and running so please consider joining, or let us know if you'd like help to do so. We'll keep it updated with news and information such as this new online resource called Flippin Pain. The department's website is also a good place to go if you are looking for information or support resources.



Get in touch— If you would like to know more about PAG, would like to subscribe, to contribute to this newsletter or to become a member please get in touch.



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