



Welcome to our summer newsletter

IMID-Bio-UK has now moved from concept to reality and it has been such an exciting transition! Our consortium has formed, and different groups have met on several occasions with several workstreams now up and running.

Our initial focus is on harmonising our datasets – these studies led by Prof Mike Barnes are now moving ahead with the recruitment of data management expertise. Our inaugural scientific day led to the establishment of new thematic groups and will focus on common progression patterns across immune mediated diseases and on co morbidities in the first instance. In due course, our focus will move more to the precision medicine principles empowered by establishing our datasets in searchable formats.

In the wider arena there is increasing interest

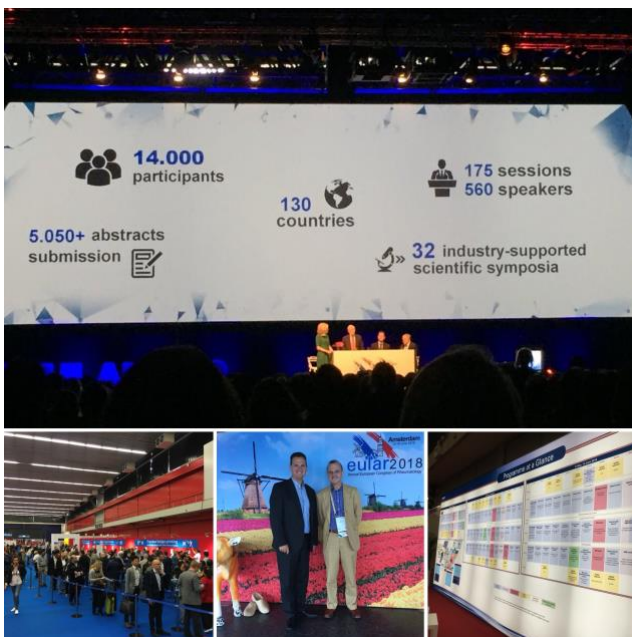
in the common pathways that link Immune-mediated diseases – overtures from MRC, Arthritis Research UK, Wellcome Trust and other funders signal the need for relevant disciplines to work ever more closely – IMID-Bio-UK is tangible evidence that such interactions can yield significant progress and possibilities.

- Professor Iain McInnes
Lead Investigator, IMID-Bio-UK



Network Updates

Many teams from across the IMID-Bio-UK network attended the European League Against Rheumatism (EULAR) Annual European Congress of Rheumatology in Amsterdam in June. EULAR represents the patient, health professional and scientific societies of rheumatology of all the European nations and this was a fantastic opportunity for many of our groups to present their work to the research community in order to show patients the advances being made.



Having never attended EULAR before, I initially found the sheer size of the meeting intimidating - so many people! But intimidating soon became amazing when I started to consider the fact that all these people (and many of their teams who weren't physically at the meeting) are working together to advance the knowledge, understanding and treatment of those affected by immune-mediated inflammatory disease. That's quite an army when you think of it like that.....

Personally, I enjoyed the People with Arthritis and Rheumatism in Europe (PARE) activities at the congress. These sessions involved the

people living with Rheumatic and Musculoskeletal Diseases (RMDs) every day and those supporting them (either directly or indirectly) with their healthcare choices, supporting their day to day living and/or raising general awareness of the conditions. It provided a forum for those affected by disease to tell their story and to share their experiences of living with immune-mediated conditions with those of us who don't necessarily really understand what it is to be in debilitating pain, to be unable to open the coffee jar, being unable to get down on the floor and play cars with our children or to carry on working every day in a job we love.

The Danish Rheumatism Association showed a video which brought the realities of living with the invisible pains that arthritis patients experience every day in a poignant and moving film which followed a father and daughter getting through the day. I highly recommend having a watch and/or sharing the video so others can understand the debilitating nature of these conditions. You can watch the video [here](#) - it's only 90 seconds and well worth a watch.

If you'd like to read more about the PARE activities you can do so by following this [link](#).

The reality is that those living with these conditions every day are the very reason we carry out our research. Our work is focused on providing better options, more informed and realistic treatment options for them. We couldn't do our research without those who participate in clinical trials, who provide samples and who agree to share their anonymised data so we have research projects that will help advance our knowledge. We cannot say thank you enough to them.

Thank you. Thank you. Thank you.

OTHER ACTIVITIES & ADDITIONS

We have been busy with conference calls, meetings and conferences since our last newsletter. Much of the focus has been on auditing the types and quality of samples available from each of our associated partner massive datasets. We hope to be able to introduce them (the data manager and the datasets!) to you in our next newsletter. We are also reviewing the pathway, logistics and timings of sample & data access. We aim to provide a smooth and transparent access procedure to simplify the procedures for utilising multiple cohorts in research by bonafide researchers, whether they are from the academic or commercial sectors.

We are delighted to let you know that Dr Colette Inkson joined IMID-Bio-UK as Industry Liaison Manager in April 2018 and is based at The University of Manchester. She also serves as Industry Liaison for the Manchester Molecular Pathology Node – MPathIC (Director - Professor Tony Freemont), as well as The Manchester NIHR BRC (Director - Professor Ian Bruce). Colette has professional experience working across a variety of life sciences sectors and institutions, delivering projects that span multiple HEI and industry. Prior to joining IMID-Bio-UK Colette spent the past 4 years as the Project Manager of a 12-partner academic-industry consortium (EC-FP7 funded) called FungiBrain which focused on using high-throughput Live-cell imaging techniques for anti-fungal drug discovery and evaluation. She obtained a PhD in Bone Biology from the University of York in 2003 and has >10 post-doctoral research experience working across a number of clinically related areas (Musculoskeletal Pathologies, Cardiovascular Diseases, and Immunological responses to chronic infections).

cohorts as well as assessing the clinical/meta data available. The amount of data available is amazing but does bring its own challenges. We are in the process of recruiting a data manager to join our team to help us wrangle these

I hope you enjoy reading our update. If you would like to get in touch, I'd be happy to hear from you, so please don't hesitate to reach out. Our contact details can be found at the end of this newsletter.

- *Sancha Martin, IMID-Bio-UK Project Manager*

Don't Delay, Connect Today

The 2017 / 2018 'Don't Delay, Connect Today' is a EULAR Campaign that, for the first time, engages all three EULAR pillars – patient organisations (PARE), health professional associations and scientific communities. Rheumatic and musculoskeletal diseases (RMDs) often receive delayed or no diagnosis.



As many of us know, early diagnosis is key to preventing further damage, but a diagnosis of RMDs is often delayed or is never received. This is often due to a lack of awareness, reducing peoples' quality of life and affecting physical abilities. The EULAR Campaign aims to raise awareness of the importance of early diagnosis in preventing further damage to those living with RMDs, and to encourage timely access to evidence-based treatment. For example, if pharmacological treatment for rheumatoid arthritis is started within 12 weeks after the onset of symptoms, this could minimise the level of joint impact over time and increase the chances of remission.

In May Rheumatosphere, a rheumatology public engagement group based at the University of Glasgow's Institute of Infection, Immunity and Inflammation, was awarded funding from the European League Against Rheumatism's (EULAR) to implement the Don't Delay, Connect Today (DDCT) campaign in Scotland. The aim of the campaign is to raise awareness of the importance of early diagnosis for diseases like rheumatoid arthritis.

The group cycled 185 miles in 4 days across 10 islands via 6 causeways and 2 ferries. They actively promoted the European League Against Rheumatism's (EULARs) 'Don't Delay, Connect Today' campaign along the way and carried out public engagement events in various locations across the 10 islands North Uist, Leverburgh, Tarbert, Callanish and Stornoway, maximising the number of individuals that they interacted with. The largest events were held at the Callanish Standing Stones visitor centre and the local co-operative supermarket, where both tourists and local residents could meet the team and discuss rheumatoid arthritis.



Another aim of the campaign is to educate primary healthcare providers about the early warning signs of RMDs and the importance of early referral to rheumatology. Due to the remote location and population size on the islands there is limited access to rheumatology and RMD services making the education for the primary healthcare providers (HCPs) - including

GPs, nurses and physiotherapists – all the more essential. Capitalising on this, the team developed and ran an event for all primary HCPs through which they were able to reinforce the early warning signs of RMD conditions and highlight when individuals should be referred to the (limited) rheumatology services.



Rheumatosphere partnered with the National Rheumatoid Arthritis Society (NRAS) for this exciting campaign. NRAS supplied invaluable support to those on the island already living with disease by providing a wide range of education material for those living with RA.

Further to the engagement work carried out along the way, seven members of the Rheumatosphere team also cycled the Hebridean cycle way to raise money for NRAS. The team completed the expedition in 4 days, some days were more challenging than others thanks to the wind and rain (and on occasion sunshine), the need to cycle against the clock to make connecting ferries and ascending over 600ft to conquer the Clisam in Harris. Having been successful in completing the cycle, the team were able to raise over £3000 for NRAS, helping them to continue their fantastic work. It's not too late to sponsor the team though, just hop over to their Just Giving page to send them a congratulations and a donation.

The Rheumatosphere team, along with NRAS

have taken on the challenge of delivering the Don't Delay, Connect Today campaign in Scotland and enjoyed every minute of it! They are currently planning to extend its reach through more of the Scottish islands further raising the profile of the Don't Delay, Connect Today campaign in Scotland. Louise Bennett, Project Manager for Rheumatosphere, strongly encourages anyone interested to get involved in this worth-while cause to go to the EULAR website to find out more.

A video of the Rheumatosphere Do Don't Delay Connect Scotland Today can also be found on YouTube or on the EULAR website.



The NHS is 70!

To tie in with the 70th birthday of our National Health Service, many people have been voicing their support for this amazing institution which has supported most of us at one point in our life or another. The NIHR have a fascination summary of the various important discoveries made during the lifetime of the NHS so far which is an interesting [read](#).

"Patients are absolutely critical and central to our research endeavours. We are incredibly fortunate to be working within, or in partnership with, the NHS. And the NIHR in England, and Chief Scientist's Office in Scotland, ensure that the NHS supports research of the highest quality". - Prof John Isaacs, University of Newcastle.

There are a number of medical claims to fame (general anaesthetic, penicillin and saline drips for example) which predate the NHS. The pace of clinical innovation development in the last 70 years since the inception of the NHS have been increasing year by year.

The increasing interactions between the NHS and the academic sector are the foundation for many clinical trials and these days the UK has the third highest number of clinical trials in the world behind the USA and Germany.

The [Medical Research Council](#) has funded many of those clinical trials and associated research projects that have influenced the services and treatments offered within the NHS. The MRC further acknowledge that the NHS has been pivotal to the discoveries made by the researchers they fund. IMID-Bio-UK is funded in the main by the MRC.

For those involved in IMID-Bio-UK, the NHS has a central role in their careers, their aspirations and it is pivotal to the future of clinical research. We are grateful to the staff of the NHS who often go above and beyond expectations in the support and treatment of more than half a million people who help the NHS to improve healthcare and develop life-saving treatments by taking part in research each year.

"The world is moving away from 'silo medicine'. Increasingly, different disciplines are talking to each other and working with each other. Our consortium brings together arthritis doctors, skin doctors, liver doctors, lung doctors - all sharing their data, looking for common pathways that drive immune-mediated diseases, potentially looking for common solutions."

- Prof Iain McInnes, University of Glasgow



Participate in clinical research

Pustular psoriasis, eLucidating Underlying Mechanisms (PLUM)

Pustular psoriasis is a rare but very severe skin disease. Current therapies have limited efficacy and may cause significant side effects, partly because the cause of the disease is not fully understood. The PLUM study aims to find the genetic defects that may cause pustular psoriasis and so understand how they change immune responses and result in disease. The study also hopes to confirm if pustular psoriasis and autoinflammatory disorders (a group of inherited diseases that manifest with recurrent fevers and skin rashes) are caused by similar disease mechanisms. This knowledge will help to guide the development of more effective, less toxic treatments in the future. The study is currently trying to recruit healthy volunteers - find out more about how to take part [here](#).

General Research Studies

Whilst many clinical trials require patients affected by specific diseases, there is also a great demand for healthy volunteers or those with common & rare diseases. There are many simple ways that participants can provide samples and/or data for research.

In Scotland, patients who have blood taken for a routine clinical test may consent to allow any blood left in the tube afterward to be used for research purposes by opting into the [SHARE](#) initiative. By consenting to participate in

SHARE, people agree to allow their coded NHS data to be reviewed in order to identify those that might be suitable candidates for health research studies. To date 212,422 people have registered with SHARE.

Similarly, in England, the NIHR BioResource was established through a partnership with [NHS Blood and Transplant](#), and builds on the expertise of the [NIHR's Biomedical Research Centres](#) and [NIHR Clinical Research Facilities](#). It provides researchers with access to highly characterised patients with common and rare diseases and/or healthy volunteers. Find out more about these initiatives by clicking the links above and registering to participate.

Giving Blood

Giving blood is probably one of the easiest things to do if you are generally healthy. Today (July 17th) in:

- [Scotland](#) - a range of donors are needed to top up supplies, particularly AB-.
- [England](#) - O- donors are urgently required.

Did you know that if you donate serum for example, this can be used to create eye drops which ease the suffering of those affected by Sjogren's Syndrome? You can also donate platelets or become an emergency donor if you have a rare blood type.

If you are able, or know someone who is, do encourage them to pop along to their nearest centre.

An Update From The Psoriasis Association

The Psoriasis Association is the leading national charity and membership organisation for people affected by psoriasis in the UK. Through their hard work, which includes funding research, providing information and raising awareness,

they help people whose lives are affected by psoriasis and psoriatic arthritis.



As part of their 50th anniversary celebrations this year, the Psoriasis Association will be sharing the stories of 50 people who have been affected by psoriasis and psoriatic arthritis. Want to get involved & help them reach 50 stories? Please contact them at mail@psoriasis-association.org.uk or find out more on their [website](#).

You can read the stories on their webpage [here](#), you can follow them on [instagram](#) or join their [WhatsApp service](#)! You can read about the latest news items related to psoriasis and psoriatic arthritis on their [webpage](#) too.

Finally, last year the Psoriasis Association conducted a survey asking people with psoriasis, their carers/family and healthcare professionals what unanswered questions they had about psoriasis. There were 819 respondents who in total submitted 2,185 questions! With the help of their steering group they made sure that the questions submitted had not already been addressed by existing research. They then grouped together similar questions and summarised the wording.

The Psoriasis Association are now asking for help shortening this list in order to help them understand which questions are

most important to patients, carers and families, and healthcare professionals for future research.

Please take part if you are a:

- person who has psoriasis
- carer/relative/friend of someone who has psoriasis
- healthcare professional working with people with psoriasis
- from an organisation representing the interests of people with psoriasis.

You can choose up to ten questions that matter to you the most from the list of 55 questions. On the first page you can select all that you think are of interest to you and on the second page you will be asked to reduce your choices to ten or less. Further information about this project can be found on the [Psoriasis Association website](#). The survey should only take a few minutes to complete.



Can you run? Will you run?

Professor [John Isaacs](#) is Director of Newcastle University's Institute for Cellular Medicine and Professor of Clinical Rheumatology and a Honorary Consultant Rheumatologist with the Newcastle upon Tyne Hospitals NHS Foundation Trust. John is internationally renowned as a pioneer of translational rheumatoid arthritis

research, and is the Chief Investigator of the MRC/ABPI [RA-MAP](#) Consortium.

John is running his 14th consecutive [Great North Run](#) (which is a half marathon) in September to raise funds for Arthritis Research UK. He has raised a whopping £40,000 over the last 14 years. If you'd like to join John and the rest of Team A, you can find out how to do that [here](#).

Enter the [Big Fun Run](#) and fundraise for LUPUS UK ...an Official Charity of the Big Fun Run. The Big Fun Run is a growing series of 5 kilometre (about 3 mile) Fun Runs being staged across the UK. There's lots of dates available across the country. Why not sign up and raise some money for this fantastic charity? The Big Fun Run website has [training plans](#) to help you prepare too. Find out more here: <https://www.lupusuk.org.uk/big-fun-run-5k/>

There is also the option of raising funds for the National Rheumatoid Arthritis Society by taking part in the National Parks Half Marathon in October. Register now and save £10! Find out more [here](#).

PhD Opportunities - Glasgow

The University of Glasgow have a number of [PhD opportunities](#) available. One in particular will link closely with IMID-Bio-UK. Supervised by [Dr Thomas Otto](#), [Prof Carl Goodyear](#) and [Dr Simon Rogers](#), the "Universal methods to analyse clinical data" project will aim to build models to interpret multi 'omic and other metadata data in order to visualize outcomes. Studies will initially focus on rheumatoid arthritis data generated at the University of Glasgow. In the first instance, different classifiers will be tested on expression data to predict the outcome of treatment (precision medicine). Subsequently, proteomics and

clinical data will be integrated into the analysis pipelines. The models will be designed to work on the IMID-Bio database and therefore will be useful to the community to query the data.

A further study is planned to investigate computational modelling of targeted transcriptional signatures to enable patient stratification. Supervisors for this study include Prof Goodyear, Dr Otto and [Prof Iain McInnes](#). Rheumatoid Arthritis (RA) is associated with considerable morbidity and premature mortality. The therapeutic options for patients have increased with the arrival of a number of biologic therapies, which are now an integral part of the management of patients with RA. However, there is still a substantial proportion of patient who only partially respond or do not respond to these therapies.

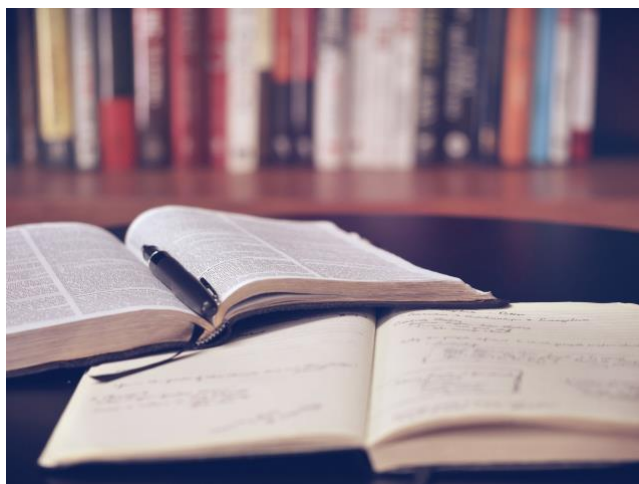


The ability to stratify patients a priori into responders and non-responders would be an invaluable clinical tool to define which patients will or will not respond. Using pre-treatment samples acquired in a recent clinical study evaluating response to two biological therapies (ORBIT; Porter et.al., Lancet 2016), we have identified via machine learning approaches two discrete transcriptional/clinical covariate signatures that can stratify patients into responder and non-responders. This raises the possibility that stratification of patients could be

achieved using baseline transcriptomic and clinical profiles in order to improve patient outcomes. In order to develop predictive tests for use in routine clinical practice, several steps need to be undertaken.

This studentship will focus on (a) translating these translating these transcriptional signatures into a molecular modality (Targeted RNA-seq) that is compatible with clinical laboratory testing and (b) applying machine learning techniques to create new predict models that will eventually enable clinicians to stratify patients prior to therapy.

Interesting Reads



The [United Kingdom Primary Sjögren's Syndrome Registry](#) has published research recently which looked at the factors that stop those affected by Sjögren's syndrome from carrying out normal, daily activities that the rest of us may take for granted. The team found that in addition to managing the symptoms of the disease, interactions that provide empowerment of patients, improved well being, access to health care, improving patient knowledge and social support are important in the facilitation of improved participation in daily living activities. You can find out more and can read the research paper by following this [link](#).

In a "News & Views" published in Nature Reviews Rheumatology in May this year, Myles

Lewis and Mike Barnes discussed the use of machine learning to integrate detailed knowledge of disease with 'omics data. They suggest that new methods can provide unique clinical insights and discuss papers published earlier this year in the article entitled "[RNA sequencing and machine learning as molecular scalpels](#)".

A slightly older paper, but still worth a read for those new to the area of immunometabolism (including rheumatologists and other inflammologists), this paper in Nature Reviews Immunology from 2016 provides, the author's own words, a great refresher course of the six major metabolic pathways and how changes in the metabolites they produce shape the immune cell response. Read more: "[A guide to immunometabolism for immunologists](#)".

In the [Ethics of Genomic Data Sharing: An Interview with Bartha Maria Knoppers](#), Prof Knoppers discusses the Global Alliance for Genomics and Health's Framework for Responsible Sharing of Genomic and Health-Related Data, broad consent, GDPR and planned REWS activities for the coming year.

[2018 EULAR recommendations for physical activity in people with inflammatory arthritis and osteoarthritis](#) have been published in the Annals of the Rheumatic Diseases. Regular physical activity is recommended for most people however those affected by RMDs are generally less active for varying reasons, such as concern at aggravating disease or fears of a flare-up. This article outlines EULAR guidance and advice for physical activity for those affected by inflammatory arthritis and osteoarthritis, patient organisations and policy makers.

Dataset Release

A team of postdoctoral and research scientists at the Broad Institute has made a [data set of](#)

[half a million human immune cells](#) openly accessible on a preview site that provides initial access to data for the [Human Cell Atlas](#) initiative. The data set, one of the largest of its kind, includes primary data and associated metadata from nearly 530,000 immune cells from umbilical cord blood of newborns and bone marrow of adults. Additional data sets were also provided by Wellcome Sanger Institute and collaborators.



Upcoming Meetings of Interest

[Europe Biobank Week 2018: Biosharing for Scientific Discovery](#)

September 4 @ 8:00 am - September 7 @ 5:00 pm
Flanders Meeting & Convention Center
Antwerp, Koningin Astridplein 20, 2018
Antwerpen
Antwerp, Belgium [+ Google Map](#)

[UK Biobanking Showcase 2018](#)

November 27 Prospero House, 241 Borough High St, London, SE1 1GA United Kingdom [± Google Map](#)

[GA4GH 6th Plenary Meeting](#)

October 3 – 5, 2018 Basel, Switzerland.

[6th European i2b2 Academic Users Group \(AUG\) Meeting](#)

October 31 – November 1, 2018 Geneva, Switzerland

Contact Us



That's all for this update - thank you for taking the time to read our newsletter! If you'd like to get in touch with us at any time, please email us at: sancha.martin@glasgow.ac.uk, visit us on the [web](#) or follow us on [Twitter](#).