



SPONSORSHIP NEEDED FOR THE ROYAL FREE IMMUNOLOGY PATIENT GROUP

With summertime still just about hanging in there Andrew will be dusting off his wetsuit to complete another triathlon to raise money for the Royal Free Immunology patient group. It's still in its infancy but has grown since it started last year and has plans to expand further still, all with your help.

Whether it's maintaining the website, identifying ways to improve our service or providing a forum for patients to discuss things that really matter, the patient group needs money to help you help yourselves.

If you'd like to sponsor Andrew then follow the link to his JustGiving page where you can find out more about how he's doing:
www.justgiving.com/Andrew-Symes4

JOIN THE IMMUNODEFICIENCY PATIENT SUPPORT GROUP

The group was formed to represent the interests of patients with Primary Immunodeficiency (PID) who are managed by the UCL Centre for adult PID at the Royal Free Hospital.

If you would like to join up or just want more information about when the next meeting is then please go to www.pidpatients.org. The website has lots of information, including details of the different types of conditions treated at the Royal Free, recent fundraising and minutes of previous meetings.



PSYCHOLOGY SERVICE RECENTLY EXPANDED

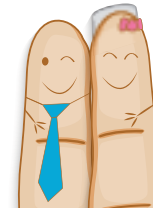
Mari Campbell, our clinical psychologist, has been part of our team for almost four years but has, so far, only been able to see patients on immunoglobulin replacement therapy.

We know that managing a long term health condition can be difficult and Mari works with people to help them rediscover and develop strategies to live life a little easier. She is now able to provide short term psychological therapy to most patients with a diagnosis of immunodeficiency and is now screening all patients seen in clinic.



For more information about her service please go to the Royal Free website and look under clinical immunology.

NEED A BUDDY?
GET A HOME THERAPY PARTNER...



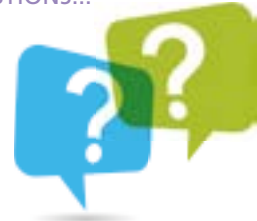
WHO'S NEW?
DAVID'S NEW...



HOW MUCH BLOOD?
RESEARCH PROJECT UPDATES...



THE ESID DATABASE
WHY WE ASK SO MANY QUESTIONS...



ISSUE 1 SEPTEMBER 2014

IMMUNOLOGY MATTERS



WELCOME TO YOUR NEWSLETTER...

A lot has happened at your immunology department at the Royal Free over the last few years and we thought you might like an update about where we are and where we're going. A new home, new staff and new projects mean lots of change but all working towards making your service better for you.

RESEARCH PROJECT UPDATES

Thanks to all of you who very kindly give us an extra tube or three when you're in clinic. Sary is always looking for more blood but if you've ever wondered what it's used for then we'll be explaining different studies in each edition.

This issue, researcher Jenny Wanders explains about the B and T-cell study:

I've been conducting research into COVID, and how it affects B and T-cells, for several years. How these cells communicate plays an important role for a healthy immune response. My work aims to find out the differences in B and T-cell interactions between COVID patients and healthy individuals. A greater understanding in this area will help us develop new tests leading to better management for all COVID patients. You might see me asking Andrew for blood samples on a Wednesday so, if he mentions it's for Jenny, you know where this will end up and how useful it will be!

If you'd like to know more about research within the department then contact sarita.workman@nhs.net

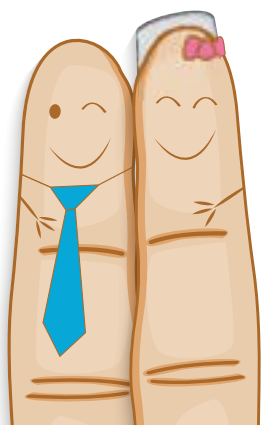


ARE YOU A HOME THERAPY PATIENT? WHY NOT BUDDY UP WITH SOMEONE JUST LIKE YOU, ONLY DIFFERENT!

It doesn't matter how long you've been infusing at home, there can always be times you feel a little isolated when it comes to doing your own infusions.

If you've ever wanted to speak to someone who knows what you're going through but don't want to "bother" the team about it, why not pair up with someone else who understands what it's like to stick needles into themselves on a regular basis?

For more information about pairing up with a home therapy buddy contact: andrewsymes@nhs.net



NEW FACES

We're very happy to introduce David Lowe, our newest consultant.

David went to medical school in Cambridge and completed his medical training in London. He has a background in infectious diseases and has also worked throughout Southern Africa so knows plenty about antibiotics and the joys of travel. He has an interest in chest symptoms so will be working with Dr Hurst in our joint respiratory clinic every month. He also helps to run the hospital's TB clinic and participates in the acute medicine rota for urgent hospital admissions. His favourite colour is green.

A new home, new staff and new projects mean lots of change but all working towards making your service better for you

OUR NEW HOME IN THE INSTITUTE

We've been in the new institute now for a year and, we think you'll agree, it's a much nicer place than anywhere we've been before.

We know that clinic waiting times are still too long and we're working towards improving this with more specialist clinics on Fridays to reduce the pressure on the general clinic on Wednesday. We really appreciate your patience when things start running late but you can be sure we're trying our best to get things running smoothly as soon as possible.

We have IVIg infusions now all day Tuesdays, Wednesdays and Thursdays and every 4th Tuesday have our late evening infusions until 8pm.



YOUR QUESTIONS ANSWERED

We'd like to hear what matters to you and in each edition we'll have a special section where one of our experts will answer a question sent in by a patient.

It can be about anything you like, ranging from what treatment options do I have, what do I need to do to prepare for a holiday to why can't I have live vaccines. It's up to you so let us know what you want us to answer. Send your questions to andrewsymes@nhs.net

CONTACTING US

THE UKPIN ESID DATABASE

The UKPIN ESID (United Kingdom Primary Immunodeficiency Network European Society for Immunodeficiency) database is a collaborative effort between immunology centres throughout Europe aiming to pool its collective wisdom all in one place.

Doing this means research questions can be answered to a higher standard than could otherwise be done by any single centre. The more people who give us information, the better we can understand what it means to have an immunodeficiency. Your generosity with the time spent filling out the UKPIN ESID forms in clinic mean that the Royal Free has enrolled more patients in to the database than any other centre in the UK, so a big THANKS to you all.

“the Royal Free has enrolled more patients into the database than any other centre in the UK”

Since we've moved to our new home we know some of you have had trouble getting hold of us. As we're not always in the same place each day of the week, here's how to get hold of some of us during different times throughout the week:

Secretary: via switchboard (020 7794 0500) ext 34519

Infusion ward: Tuesday, Wednesday & Thursday ext 22525 & 22526

Mary (ward administrator): Monday & Friday ext 37387 Tuesday, Wednesday & Thursday ext 22524

Andrew (clinical nurse specialist): 020 7830 2140, ext 34425 or bleep 2029 via switchboard

Sary (research sister): ext 33832 or bleep 2861 via switchboard

