

### Got a webcam?

Get virtual



### Who's new?

So many people!



### Umbrella study

What's it all about?



### Lung function

Why do i need one so often?



Issue 2 March 2015

# IMMUNOLOGYMATTERS



Welcome to Issue no. 2 of our patient newsletter. We hope you find it interesting and continue to enjoy hearing about what's happening at the department of clinical immunology at the Royal Free Hospital.

Continued inside...

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## Congratulations to Andrew and Sary!

Many congratulations to Andrew and Sary (our Clinical Nurse Specialist and Research Sister) for winning a Royal Free Hospital (RFH) OSCaR in December.

The OSCaRs are an annual event to celebrate excellence within the Trust and prizes are awarded in 8 different categories. They were up against some stiff competition but were overall winners in the Research, Innovation and Quality category for their efforts in setting up a virtual web-based training service (more of which later), organising the recent patient education symposium, writing the patient newsletter and helping to set up, organise and raise money for the RFH Immunodeficiency patient support group ([www.pidpatients.org](http://www.pidpatients.org)). They were both delighted to receive their award from Richard and Judy who hosted the ceremony but were happy to point out that winning was only possible from the support given by the rest of the clinical team.

## Spotlight: Lung Function

**This issue we're taking a look at lung function and why it's important to have one regularly.**

Your lungs are a pair of spongy organs which allow gas exchange between blood and the air we breathe. When breathing, oxygen (O<sub>2</sub>) is absorbed into the blood whilst carbon dioxide (CO<sub>2</sub>) is removed. Your lungs can become damaged after repeat infections, especially if they're not treated promptly, and so their ability to exchange gases becomes reduced. This can be felt during exercise when your body needs more O<sub>2</sub>, produces more CO<sub>2</sub> and you breathe faster.

A lung function measures these extremes and calculates how well they work compared with predicted values depending on your age, gender and height. Apart from the information you tell us about how you feel, a lung function is the safest way of monitoring how your lungs are working. It's safe because, unlike an x-ray or CT scan, there's no radiation used. By having one regularly we can compare results and detect if there's any gradual loss in function which can then help us decide if any further investigations are needed.

If you can't remember when you last had a lung function test, tell us the next time you're in clinic and we'll arrange one for you.

# Web-cam and training at home

**The internet is a wonderful thing and our department is now able to take advantage of it a bit more.**

Many of you are regularly in contact with us via email but we now also have access to a super-secure virtual meeting room which can be used by our patients for a variety of different things:

- Home therapy assessments
- Troubleshooting infusion problems of any kind
- Any additional top-up training sessions
- Certain psychology sessions with Mari Campbell, our Clinical Psychologist

Don't worry if you don't have a webcam, you can still access this service as we can provide one free of charge. All you need is a computer connected to the internet and setting up is very easy to do. If you would like to know more about how to access this service contact [andrewsymes@nhs.net](mailto:andrewsymes@nhs.net)



## Version 8 of our Umbrella Study

**The Umbrella Study is a general term used to cover the majority of research projects carried out within the department. This means that, for anyone who has consented to it, anonymous information about them can be included in any of our researchers studies.**

From time-to-time we need to update the study in accordance with new regulations. It also allows us to make slight amendments to increase its inclusion criteria, meaning we will also be able to use results from all routine investigations, questionnaires, stool, sputum and skin biopsies. For those of you already consented, a copy of the latest version will be posted out to you.

To find out more about the Umbrella Study please contact [sarita.workman@nhs.net](mailto:sarita.workman@nhs.net)

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# New faces

We'd like to introduce you to some of the new members of staff you might meet at your next visit and tell you more about what they're doing here.

## Welcome Chanell!



**It's been a long time coming but we've finally got a permanent secretary! except secretaries are now called Pathway Co-ordinators.**

Anyway, Chanell is here Monday to Friday and, as well making sure you get all your letters, she is also happy to help with questions to do with clinic appointments and scans, especially if you're having trouble getting them arranged for the same day. Our specialist nurses, Andrew and Sarita, have been doing a lot of this during the (long) period we didn't have anyone filling her post but, now that we do, **Chanell should be your first port of call.** This will help our nurses concentrate on their main responsibilities and give them more time to look after you. To contact Chanell call 02077940500 x34519 or email [chanell.pritchard@nhs.net](mailto:chanell.pritchard@nhs.net).

## Hello, my name is Giulia...

**I am 30 years old and I come from Pisa, Italy. I have been working as an immunology fellow-in-training for the past 4 years, dealing mostly with autoimmune and allergic disease and I am now one of the registrars here at the Royal Free Hospital (RFH).**

I have always wanted to be a doctor and I am really enjoying my studies to become an immunologist. I love to listen to people and to be part of a team (I have been playing volleyball for 15 years now!) working together to make things better for patients with chronic diseases.

I'll be spending seven months here at the RFH department of Immunology, seeing Primary Immunodeficiency (PID) patients in a specialist environment. I am also completing a clinical project that will study the long-term outcome of adult patients with Chronic Granulomatous Disease. I look forward to meeting you in clinic or on the infusion ward.



## Had a referral made lately?

**A lot of our patients have problems affecting their health and not just from their immune systems.**

If you are or have been referred to see a specialist by your GP (or by any other doctor) then it's always a good idea to think about getting the referral made to the RFH. It's always more difficult making decisions about complex care when multiple teams are in different places. This is especially true if the treatment involves your chest, gut or liver as specialists outside of the RFH might not understand how your symptoms relate to your immunodeficiency. If you would like to discuss whether this is necessary for you then contact [andrewsymes@nhs.net](mailto:andrewsymes@nhs.net).



## Hello, my name is Vanessa...

**I am a specialist in immunology from Venezuela and completed my training in Spain in 2012. I am currently a clinical research fellow at the UCL Institute of Immunity and Transplantation where I am undertaking research in PID for a PhD.**

I will be working as a registrar in the out-patient clinic gaining experience treating patients with immunodeficiency.

As a clinical immunologist committed to PID I value the opportunity to share ideas and knowledge with professionals from different countries as well as collaborating with the study of PID.

I am currently researching the pathophysiology (disease mechanism) of certain immunodeficiencies but, as a keen musician, a lot of my time is also spent researching the musicals playing in the West End!

## Nonzame is still here!

**We're delighted to say that Nonzame, our Junior Infusion Sister, is still with us as her temporary funding has been extended.**

She had a lovely break over Christmas visiting family in South Africa but is back and ready to stick needles in to everyone again! Her work on the infusion ward has been invaluable over the past year and we're really happy she's still with us.



## Research project updates

**This issue, medical student Johannes Sperlich explains about the respiratory symptom study:**

"Hello! My name is Johannes. May I ask you some questions?" That is how I have approached many patients since I joined the clinical team in September 2014. As part of my medical doctoral thesis, I am taking a closer look at the type of infections patients with immunodeficiency get, compared with the general population. I mainly work with questionnaires, interviews, and diaries.

I would be very grateful if you could fill in the diary I recently posted out to all patients with COVID. By doing so, you will help us to keep up with the symptoms you might experience during the winter. From this I will explore how well the medication you receive protects you from infections. Eventually, my research will hopefully work towards improving treatments and helping to prevent infections.

Most of all, however, it is a great pleasure to get to know everybody treated in the immunology service at the Royal Free Hospital.

If you'd like to know more about research within the department then contact [sarita.workman@nhs.net](mailto:sarita.workman@nhs.net)

# Special Feature: What you need to know about antibiotics

## What are they? Let's start with the basics.

Antibiotics are medicines which act to kill or stop the growth of bacteria (a type of harmful bug). The idea is to remove infecting bacteria from where they shouldn't be and restore the 'normal balance' in the remaining bacteria, which always live in and on our bodies. Treating bacterial infections with antibiotics can help prevent permanent lung damage (i.e. conditions like bronchiectasis).

What are bacterial infections? Bacterial infections cause conditions like pneumonia (severe chest infection) and cystitis (bladder infection). Antibiotics do not do anything against viruses like the common cold, although you may need them if a cold becomes 'complicated' by a subsequent bacterial infection. They also do not work against fungi like thrush, and in fact can often make fungal infections worse by killing the bacteria and allowing the fungi to grow instead!

## ...so far we have encountered surprisingly little resistance to antibiotics...

### When will people with immunodeficiency be given antibiotics?

There are two main reasons:

- 1) To treat bacterial infections. We recommend taking them if you develop a new cough with green or yellow sputum, and certainly if you also develop a fever. Any fever which does not go within a few days needs assessment so, if in any doubt, contact us or your GP.
- 2) As prophylaxis. This is where we give long-term antibiotics to try and prevent infections from developing and can be given even if you're already on replacement immunoglobulin infusions.

Some people just take prophylactic antibiotics over the winter, when the chances of infection are higher.

### How should I take them?

As directed by the doctor or pharmacist, but remember that we treat infections in people with immunodeficiency for longer, i.e. usually two weeks for a chest infection, instead of one. It is essential that you finish the full course otherwise all the bacteria might not be killed off and your infection can come back. This can increase risk of long-term lung damage.

### I have been taking antibiotics for a long time. What about resistance?

We always need to be aware of this issue, but so far we have encountered surprisingly little resistance to antibiotics in the bacteria from our patients. Even if you've been on the same type for a long time they should still be just as effective. We may be doing some research into this soon, but overall the antibiotics seem to be doing a lot more good than harm so no need to panic!





## Plans for Research Centre Approved

**Planning permission for the Pears Building, which will be home to the UCL Institute of Immunity and Transplantation (IIT), has been granted by Camden Council.**

The £42 million building is a partnership between the Royal Free Charity, the Royal Free London NHS Foundation Trust and the University College London (UCL) and will be constructed next to the RFH, where the multi-storey car park currently is.

The building will enable the second phase of the IIT, which is currently situated in the main hospital building. Scientists at the IIT are carrying out research into immune-related conditions such as immunodeficiency, autoimmunity and cancer. Scientific breakthroughs have already been made by IIT researchers and their work could bring benefits to thousands, if not millions, of patients across the world. The new building will also mean that more of our patients will have access to ground-breaking medical treatments through clinical trials.

As well as the IIT, the Pears Building will include patient accommodation, office space for volunteers and a car park.

Planning permission has been given subject to the completion of a S106 legal agreement and a range of planning conditions. Construction work is expected to begin in the spring and to finish in 2017.

David Sloman, the chief executive of the Royal Free London NHS Foundation Trust, said: "I am delighted that planning permission for the Pears Building has been granted. The new building will bring huge benefits to patients, including providing on site accommodation for out-patients who live far from the hospital.

"Research being carried out at the IIT will bring benefits to patients across the world as new treatments for cancers and immune-related conditions are developed."



## 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](mailto:andrewsymes@nhs.net)



## Immunodeficiency patient support group update

**The PID patients' group now has over 150 members and numbers are rising steadily. Since August 2014 it has been organised by fellow patient and volunteer Caroline Richmond.**

Caroline comes to the department on Wednesdays and Fridays to recruit new members, and says that most people join when she invites them. But if you haven't joined yet, please do. "We'd love to have you" says Caroline, "and it doesn't cost anything." If you're interested in joining and Caroline hasn't spoken to you yet, please go to: [www.pidpatients.org](http://www.pidpatients.org).

The next meeting will be on Tuesday 28th April, 6-8pm in the clinic waiting area of the Institute and there will be the usual wine, soft drinks and nibbles. You can hear about treatment advances and meet fellow patients. Bring a friend/relative. Last but not least, we will report on the progress of the new Institute of Immunity and Transplantation building, for which planning permission has just been granted.



## CONTACTING US

Here's a reminder of how to get hold of some of us during different times throughout the week:

**Secretary (Chanell):** via switchboard  
(020 7794 0500) ext 34519

**Infusion ward (Irene and Nonzame):**  
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

