

Community news

Pears

In association with



Building

Issue 3 October 2017



Understanding
primary immune
deficiency

You said ... we listened

Q&A with patient
Jose Drabwell

Welcome to the third edition of our newsletter, keeping you up to date with progress on the Pears Building

Patients who have had immune defects from birth or go on to develop them later in life will benefit from the ground-breaking work which will take place at the Pears Building, home to the UCL Institute of Immunity and Transplantation (IIT).

What will make the IIT so unique is that doctors, nurses, patients and researchers will all be under one roof. This will ensure that treatment is totally integrated, instead of clinical and research teams working separately.

This approach is absolutely vital if we want to see better treatments available for patients. At the moment it takes an average of 17 years for research to lead to potential new treatments for patients and we think that's just too long.

Bringing researchers together with patients and the people who treat them will help us develop much swifter treatments that can benefit patients.

Practically that means us coming together for meetings, sharing equipment, receiving training together and building personal interactions to achieve common goals. This 'bench to bedside' approach will be game-changing for patients.

Car park update

The Royal Free Hospital multi-storey car park closed on 3 September. The hospital trust is now going through the process of decommissioning the area, including ensuring the ticketing equipment is removed and the services – for example, electrics – are made safe.

Once this work has been completed, the car park will be available for the contractor who will be carrying out a series of surveys to make sure everything is safe to go ahead.

Car parking has now switched to the south car park for staff and patients and the Lawn Road car park, which is now dedicated to staff parking. The new building, when complete, will house a car park for patients and visitors.

You said ... we've listened

We have listened carefully to concerns raised during two public consultations and a working party made up of representatives from local neighbourhood schemes, local residents and businesses. We are doing all we can to ensure that the building work runs as smoothly as possible and causes the minimum disruption possible to our neighbours.

You said: "Local road congestion will increase."

We will make sure deliveries are brought to site in a phased way to avoid queuing traffic and we will restrict the number of deliveries to a level which can be suitably managed. We will be closely monitoring traffic movements and encouraging suppliers to consolidate deliveries to reduce visits to the site. If necessary we will use an off-site holding area.

You said: "We want confirmation that construction vehicles will stick to the agreed traffic routes and avoid using side roads."

The route will be agreed with all our sub-contractors and individual drivers. The routes chosen are suitable for the size of vehicles and avoid high risk junctions, major cycle routes and heavy residential areas. Spot checks will be carried out by the site team to ensure compliance.

You said: "What if structural damage arises from construction activities?"

Condition surveys will be undertaken on neighbouring properties ahead of work starting on site to establish a baseline from which

measurement can be taken. A rigorous monitoring regime will be implemented to raise awareness of any potential structural impact that may occur from site activities.

You said: "Will there be job opportunities during and after completion?"

We shall advertise apprenticeships within the King's Cross Training Centre, and job vacancies within the project will be advertised on project hoardings.

You said: "Residents are concerned about the noise, vibration and air quality for children at the school. How will this be managed?"

Due to the relatively low number of construction vehicle journeys anticipated, a maximum of four in and four out each hour, the emission of carbon monoxide (CO₂) is expected to be relatively low. However CO₂ monitors will be located in sensitive areas and if levels are too high, action will be taken such as erection of screens, restricting vehicle movement and looking again to improve traffic flow.

You said: "Where can I find all the documents relating to the construction?"

All documents submitted are available on both Camden Council's and the Royal Free London NHS Foundation Trust's websites.

If anyone has any further questions they can email us at: pearsbuilding.community@willmottdixon.co.uk

The Institute in focus

Research at the Pears Building could make all the difference for patients

The Royal Free Hospital has the largest clinical service for people with primary immune deficiency disorders (PID) in the UK.

This group of people have what is largely believed to be inherited disorders where individual components of the immune system are missing. In essence this means people with these disorders get severe recurrent infections and in addition have a higher risk of developing blood cancers. In addition to not working properly their immune system can also be over-active as well as under-active and this can often lead to inflammation.

The result of this can have a profound influence on the quality of life for the individual and can also potentially shorten their life.



Dr Siobhan Burns

Dr Siobhan Burns, runs a research group at the IIT which focuses on understanding the underlying causes of PID.

“Without understanding what causes PID it’s hard to develop specific treatments for patients to improve their quality of life and improve their health,” she explains.

“In recent years there has been a major explosion in genetic sequencing trying to find out the genetic basis of these conditions. Now we understand there are almost 300 genes that can cause immune

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deficiency and it’s about trying to understand how those genetic mistakes in patients affect immune cell function.”

Currently an exact diagnosis is mainly reserved for those people who develop immune deficiency in childhood. Having a diagnosis enables treatment to be tailored. This could mean using new or existing drugs that are used for different conditions. It could also mean treatment using stem cell transplantation – in effect a bone marrow transplant.

Key to the success of developing new therapies is having access to patient cells so that scientists can design experiments to specifically test the function of the gene. The good news is that multiple new genes are being identified as causes of deficiencies of the immune system in adults.

“The pace of genetic discovery is incredibly fast,” says Dr Burns. “That gives us the opportunity to be able to diagnose and ultimately treat individual patients. If we can understand what the impact of genetic changes are for immunity at cellular level and what the basic biology is of those diseases we can then design treatments for what has gone wrong.”

Dr Burns says the key to success is the ability for clinical academics to work alongside basic scientists who have an insight into particular parts of the immune system.

“There is an incredible depth to our community which will be further strengthened in our new home. The more scientific groups we can bring in, with slightly different interests, the richer the research. It is having the co-location of biologists, clinical researchers and patients that gives us the all-important focus on developing new medicines. ”



Jose meeting Prince Andrew at the opening of the Institute in 2013

Q&A

UCL

with Jose Drabwell,
a patient at the IIT

Why do you attend the Royal Free Hospital?

I have what's known as a primary immunodeficiency and every three weeks I have to come to the hospital from my home in Hertfordshire to have a life-saving infusion of antibodies, as essentially I have no immune system. Without this treatment I'd be in a very bad state; in fact, most likely I wouldn't be here. I am convinced my mother had the same condition as me as she had many of the same symptoms and this condition is largely inherited. Sadly, she was never diagnosed and died aged just 53. So you can see this treatment is absolutely essential for me and my fellow patients.

How does your condition affect your life?

My job involves a lot of travel around the world as I'm chairperson of the International Patient Organisation for Primary Immunodeficiencies (IPOPI), but I have to schedule my diary so that every three weeks I can come back to the Royal Free and receive my infusion of immunoglobulin, which is a human plasma derived product containing antibodies. If I try and push it to four weeks I can tell my body isn't happy and I'm slowing down. The treatment itself takes about two and a half hours and I just tend to work while I'm hooked up to a drip for my infusion. Before I was diagnosed nearly 30 years ago I had years of ill health including bouts of diarrhoea, bad skin problems and persistent coughing. I really couldn't function properly. Getting the diagnosis and treatment enabled me to start living my life and I've grasped it with both hands.

Why are you passionate about the Pears Building?

I run the patient group for primary immunodeficiency at the Royal Free and obviously it's of huge importance for us patients. But we are also talking about research that will have wider benefits for people with all sorts of autoimmune

conditions such as arthritis and Type 1 diabetes. One in three people are predicted to get cancer, but by understanding how the immune system can cause this disease we could see scientists develop new ways to successfully fight it. The research done in this building could be life-saving and life-changing for so many people.

Do you understand why people might have reservations about the building?

I think Hampstead has such a unique reputation for literature and artists and I think it would be wonderful to have this world class centre for scientists. This institute will make such a difference to so many people's lives. I know that it will be set within a thriving and busy community and I do understand residents' concerns about the disruption the two year build will bring, but I strongly believe the results will be worth it and it will be a real source of pride for the area.

What are your hopes for the future?

The immune system plays such a huge part in so many diseases from rarer conditions that perhaps haven't even got a name, right through to cancer. I'm excited to be a part of the whole immunity community and I want to see the Pears Building up and running as soon as possible so that the work going on at the Royal Free Hospital can develop and grow. When I first started my treatment all those years ago I received my treatment in a hair dressing salon in the basement, which was allocated for two days of the week to treat patients. So much has changed since then for the better and there is a much greater understanding of the immune system and its importance. But there is still so much for scientists to discover and I think that by giving them a dedicated building where researchers, clinicians and patients are all under one roof, we can look forward to many scientific breakthroughs that will transform people's lives.