The Third IgA Nephropathy Information Day
7th May 2016
Salford Royal Hospital

The usual grey skies of the North West of England did not make an appearance on the 7th May and the weather was beautiful for the third IgA nephropathy (IgAN) information day, which took place in Salford Royal Hospital.

The event started with Professor Phil Kalra welcoming everyone to Salford. Professor Kalra is Consultant Nephrologist at Salford Royal NHS Foundation Trust and Honorary Professor at the University of Manchester.

Dr Edmond O’Riordon chaired the morning session and introduced Professor John Feehally. Professor Feehally has treated IgAN patients and carried out research looking for the cause of the condition for over 30 years. Professor Feehally gave an introduction to IgA nephropathy from its original characterisation in 1968 to the current understanding today. It is a complex disease which affects both kidneys and requires a renal biopsy for diagnosis. Most commonly IgAN patients go to their doctor when they see that they have urine the colour of cola (haematuria).

Haematuria does not necessarily mean that the patient has the severe form of the disease but lots of protein in the urine (proteinuria) and high blood pressure is more worrying. Although there is, at present, no cure for IgAN Professor Feehally explained how most treatment regimens are aimed at reducing proteinuria and blood pressure. Predicting, at diagnosis, whether a person will develop the severe form of the condition is difficult, however some information can be acquired from renal biopsy material using the Oxford Classification of IgAN.

Questions from the audience included; is funding for IgAN research a problem (yes), are there any treatments that resolve blood in the urine (not in particular, it is more important to reduce protein in the urine) and are fish oil tablets a good treatment (there are mixed reports of the efficacy of fish oils for the treatment of IgAN, however 12 tablets a day are required and they will have a detrimental effect on your social life).
Dr Alice Smith, the lead scientist in the Leicester Kidney Exercise Team, gave an interactive talk about the benefits of an active lifestyle for people with renal disease. She outlined the fact that any activity is good for you if it is regular and enough to make you slightly breathless. She did not recommend exercising if you were feeling ill or had painful side effects. Alice used a person from the audience to demonstrate a couple of exercises she suggested we all did when sitting for any length of time, at work or home.

Complementing the exercise information, Sarah Brooks gave an informative talk about eating well with renal disease. Sarah explained the benefits of reducing sugar, fat, salt and alcohol intake. She pointed out that by reducing salt intake a patient could increase the benefits of blood pressure medication and that there is lots of hidden salt in processed food. She advised getting into the habit of reading the labels on food packaging and understanding the food traffic light system. Sarah suggested the audience watch her youtube video at https://www.youtube.com/watch?v=gWOb1DEiyBQ which gives advice about controlling salt intake with chronic kidney disease.

Questions included the benefits of a gluten free diet for IgAN patients (the data is not strong enough for this to be recommended for IgAN patients).
Dr Patrick Hamilton, a nephrologist at Salford Royal, presented information about renal transplantation in IgAN patients. Dr Hamilton explained that a transplant is required when a patient’s eGFR is 15 or below and the predialysis work up starts when their eGFR is 20. He explained the difference between haemodialysis and peritoneal dialysis and the process a patient goes through before dialysis. The average wait for a transplant is 3 years but there is still a need for kidneys for transplant. The renal transplant operation usually takes 3-4 hours, the old kidneys are left in the body because they are difficult to take out and the new kidney is transplanted in the abdomen.

Patients are often discharged from hospital 1-2 weeks after the operation. IgAN reoccurs in 50% of patients but only 15-30% of those patients have any symptoms. Even with the chance of recurrence, transplant is still considered the best treatment option for patients who have the severe form of the condition and progress to renal failure. Questions included; the possibility of reducing immunosuppression after transplant (this was strongly not recommended).

Donald Jones III was a professional American football player who had to give up his career playing in the NFL because his IgAN led to the need for a kidney transplant. Donald spoke to the group about his background, his diagnosis and the implications of IgAN on his life. Donald was brought up in a deprived area of New Jersey, USA. Members of his family were involved with gangs and drugs but sport kept him from joining them, he excelled in American football and baseball. Donald was diagnosed with IgAN during his second year at college when he noticed blood in his urine. He said that his doctor did not know anything about the condition. Donald was treated minimally and carried on doing well in his sport while noticing he had dark coloured urine after exercise. He was scouted by the NFL while at college and had a medical examination. When the Dallas Cowboys found out about his IgAN they decided not to sign him for the team. He was able to join the Buffalo bills as an undrafted free agent but had to work hard to get into the team. During his first 2 seasons Donald sustained a number of injuries, not unusual among American football players, and was taking ibuprofen and having non-steroidal inflammatory injections before matches, this medication together with becoming dehydrated during matches and a high salt diet contributed to the deterioration of his kidney function. During Donald’s 3rd year he collapsed and changed his doctor. With a change in medication Donald was able to carry on playing
until the end of the season however he was very ill and his home life was suffering. He changed teams to the New England patriots but stopped playing American football when it was recognised that he needed a kidney transplant. Donald’s dad gave him a kidney. Donald has now set up a sports tournament company and has written an autobiography. He is keen to share his experience of IgAN with other patients and donates the proceeds from his book to charity.

During the lunch break Donald signed copies of his book and had pictures taken with the people at the Information Day.

Dr Fed Tam chaired the afternoon session which started with Dr Jonathan Barratt, a consultant nephrologist and researcher from Leicester explaining where we are with research into the cause of IgAN and why this research is important for the development of new treatments. Despite research into the disease the mechanisms which result in IgAN are not fully understood. The condition is generally accepted to be the result of a number of steps, some which are genetic and others environmental. Dr Barratt explained how biopsy tissue and blood from patients who have consented to have these samples used in research are very important resources in helping us understand IgAN. He explained the mechanisms behind some of the treatments which are being investigated in clinical trials at the moment, details of these trials were included in a leaflet included in the pack given to the people attending the meeting. He suggested that if patients wanted to share their medical details with researchers to help in the understanding of their condition they could sign up to the RareRenal. Org website. Dr Barratt recommended becoming a member of the IgA Nephropathy UK Support Facebook group. Questions included whether the clinical trial treatments were suitable for IgAN patients who had had a transplant (they are being tested on patients without a transplant and so are not suitable for post-transplant patients without more trials) and if the incidence of IgAN is increasing (no)

John Roberts gave a talk about Personal Independence payment and how to work your way through the paperwork. He stressed the importance of getting help to fill in the form and suggested a BKPA advocate. He pointed out that the assessor will not be aware of your condition and you are the expert, so give as much information as possible. Each question stands alone so you should fill them
in even if they are repeating information from a previous question. Payments are backdated if your application is accepted.

After the afternoon break a group of patients led by Phil Smith (Chair of the UK IgAN Patient Support Group) shared their experience of IgAN with the audience. They described their symptoms before and after diagnosis, their treatment and how their lives have changed since being diagnosed. This part of the event was the most personal and the most powerful. Lots of questions were answered by the panel covering subjects including depression, treatment options and the positives and negatives of home dialysis.

Thanks were expressed to the National Institute for Health, Kidney Research UK, the British Kidney Patients Association, The Mayer Family Trust and Salford Royal Hospital for funding event and to John Roberts who organised the room, the catering and the parking.