

The ZiPP Study

By Professor Stuart Ralston - Edinburgh

We are still looking for people with Paget's disease and their families to help with the ZiPP study, a clinical trial which aims to determine if early treatment can prevent Paget's disease occurring in people who are genetically predisposed to the condition.

What does the study involve?

The study involves screening for the presence of a genetic change that predisposes to the development of Paget's disease. The way we do this is to offer people who already have Paget's disease the chance of having this test and then inviting the children of people that test positive also to take the test. The testing is done on an ordinary blood sample which is usually taken by the person's own GP and sent to us in Edinburgh for analysis.

Once the analysis is complete we feed back the results by phone and invite people who have tested positive to take part in the ZiPP trial. People who consent to take part in the trial are given some questionnaires to fill in and have some blood and urine tests performed prior to having a bone scan. They are then given an infusion of either Zoledronic acid (a drug that is used to treat Paget's) or placebo (a dummy drug). The initial visit is usually performed over a 2-day period and then patients come back once a year for follow up visits.

A large number of Paget's patients and their families are already taking part in this study and so far we have screened about 130 families and enrolled 14 people into the ZiPP trial in Edinburgh alone.

What it's like to take part?

Alison Rigby and Andrea Dolley are sisters who have a strong family history of Paget's and who were the very first volunteers to take part in the ZiPP study. Below they describe what their trip from Huddersfield to Edinburgh was like...



Alison (left) and Andrea

"Our journey started at Huddersfield Railway Station at 6.25am. It wasn't a very nice day and the wonderful scenery from the train was ruined by low cloud and mist. We hadn't been able to eat or drink anything until our samples had been taken and the smell of coffee from the hostess trolley smelt delicious.

Due to time restrictions we had to literally jump off the train and into a taxi in order to arrive at the hospital in time. The taxi dropped us off right in front of reception, which was quite

amazing as neither of us had our paperwork to hand and we were a little vague as to where we needed to be (this must have been nerves I think). Within a few minutes we had met with Cathy and Helen and what a delight, we were put at ease straight away and told what to expect. In fact, I can still hear Helen's lyrical twang now as I write. We were also introduced to Professor Ralston at this time who made us feel rather special due to the fact that we were the first 'guinea pigs' in the ZiPP trial.



Andrea and Alison with Cathy Hall

Once we had completed all our blood samples and done our urine tests we were allowed to run amok in the café downstairs. This came as a great relief as we were both starving by this time. After our lunch we had to go and have the dye injected into our arms prior to the bone scan the following morning. This literally took a few minutes and wasn't anything to worry about. We were now free to enjoy the rest of the day.

We had booked into overnight accommodation which was literally a 15 minute walk from the hospital and then 15 minutes into the town centre. After booking in and unpacking our few bits we headed for the shops (it's a girl thing).

The next day we had to return to the hospital for the bone scan. I was up first and disappeared into the room with a little trepidation. The machines are huge and it does seem a little scary as they reach down and stop inches away from your face. Andrea said she felt a little claustrophobic, but I quite enjoyed the 20 minutes of complete peace and quiet.

That's all folks, as they say on the cartoons. It really is that simple and straight forward, all over for another year, nothing to worry about. I should just add that the magnificent views of Edinburgh Castle are best seen from the comfort of the café in BHS, massive glass windows to peer through, and that it was a much better day going home and the views from the train are stunning. In fact we are already planning our little break for next year!"

More volunteers are needed!

We are very grateful for the time and effort that Andrea, Alison and all our other volunteers have given to take part in the study. However we still need many more volunteers so that we can meet our recruitment target of 870. If you have Paget's disease and you have children above the age of 30, you and your family would be eligible to take part. If you are interested in the study, please contact us on the numbers below or by email and we will send you an information pack!

There is a ZiPP centre near you!

Although the ZiPP study is based in Edinburgh we have many other centres across the UK where volunteers can be treated. There are two centres in London as well as other centres in Liverpool, Manchester, Oswestry and Nottingham. We are also hoping to open up new centres in Bristol and Portsmouth. Paget's specialists from around the UK have also helped spread the word by sending information to their patients about the study. If you have received an information sheet about the study from your own consultant and are interested in taking part please get in touch by contacting us at one of the numbers below.

Today the UK, tomorrow the world...!

Although the ZiPP study is mainly based in the UK we have had a lot of interest in the study from Paget's specialists around the world and have opened up centres in Sydney, Melbourne and Perth Western Australia, as well as centres in Italy, Spain and Belgium. We have already identified some people in Australia who would like to take part through their relatives in the UK so if you think that you have a relative overseas that might want to take part who lives in Australia, Italy or Spain, please get in touch!

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