

## Jean's Story

**Jean Armitage from Huddersfield has an interesting story to tell about how Paget's disease has affected her family**

Going back to my early childhood it seems I grew up with Paget's disease. My maternal Grandfather had it, and all my mothers' four sisters, her brother and herself all had Paget's disease in some form. I vaguely remember them talking about it when they got together. All the sisters but one who moved to Blackpool, lived in Armitage Bridge, all on one road so were really close. I still live in the house pictured, I was born there.

All I can think of is that we must have had a very good local doctor for them to know about this. (He operated on me at 9 months on the kitchen table to take a bunch of veins from my neck).

My mother's eldest sister had Paget's worst; she ended up in a wheel chair with one leg extremely bent. She is the smallest one 2<sup>nd</sup> from the end on the right of the photo. Another sister the one on the right of the photo had bad legs and arms and limped badly. I remember she used to have hot flushes a lot of the time way past the menopause, (this was one of my symptoms as well).

You can see from the photo the various deformities they all had, the brother on his forehead (same as me).



**Jean's Aunts and Uncle outside the house in which she was born**

My mother had a stroke when she was 64 and a few days later slipped into a coma for 6 weeks from which she never recovered. I used to visit her every day, and was distressed to see her forehead grow bigger very quickly. Paget's was detailed on her death certificate.

Feeling quite scared as I was only 33 years old, I asked for tests to be taken in case I had it. All they did was take ordinary x-rays and told me I was O.K.

When my eldest son was in his mid 40's he had gout quite badly. Then he was diagnosed with something wrong with his liver, he had a biopsy but it was normal... He now has Paget's disease. (See why I refer to this below).

I mentioned the above because I had a cholesterol test and was recalled to the doctor's surgery and told they thought I had something wrong with my liver. I had to cut various things from my diet, which made no difference, and then was told it was something to do with my bones. I said straight away was it Paget's disease. The doctor looked surprised and asked how I knew about this. My only other symptom was hot flushes (like my aunty above) and I also had gone through the menopause. I was told that this was because the blood in Paget's can get hot. I also had bad headaches and feeling everything was getting on top of me. I was 59 and couldn't cope with my job which was on a computer 8 hours a day, 5 days a week. I have Paget's mainly in my skull and some in my pelvis.

Anyway I was referred to the Rheumatology department at Huddersfield Infirmary and eventually put under Alan Fairclough who gave me Pamidronate treatment by drip, one morning every month for 4 months. (Since then I have felt much better).

Whilst at Oxford at the 2007 AGM, I got talking to Stuart Ralston and told him about our family history.

He was very interested and suggested we all did genetics tests (I have 2 sons and 3 daughters). My eldest son and all 3 daughters and myself carried out these tests and we all carry the Paget's gene. My daughters have been told they all will probably get Paget's in later life.

It has been a very upsetting time for them as they all have 2 children each and they are frightened of passing the gene down once more. I have told them to be positive as now there are good treatments and a lot can be done for them.



**Jean's aunt ended up in a wheelchair – as you can see her right leg is badly affected**

I wonder does it ever die out, or will it be in our family forever?

I would like through your magazine to say how grateful we all are to Stuart Ralston and his team for the time and effort that was put into all our testing and various emails between me and Stuart that he dealt with. What would we do without dedicated people like him?

I would also like to thank yourself and your staff for all the help I have received from you all in the past.