The family history of Derek and Ann

May 26th 2005

When we first got married in 1971 everything was fine. We had no idea that there was an inherited disease in our family. We had two children and they were quite young (2 or 3 years old) when we got a letter from St Marks hospital to ask if Derek would go to be screened for polyps in his large bowel.

Derek had a younger brother who also went for screening at the same time. He was found to have dangerous polyps and a total colectomy was arranged. Derek was clear at this time and for several years afterwards.

Derek had his colectomy operation in 1981 (at the age of 35). The emotions that we went through at this time were very mixed. We were angry with Derek's parents who had not seen the need to warn us about this disease even though they had been told that their children should be checked. Derek felt incredibly guilty that he had brought two innocent children into the world who might have to go through the same agonizing as he was going through and we felt so helpless at what seemed a real possibility of it spreading relentlessly through the digestive system. We also felt extremely lonely in that no-one understood or had even heard about this disease. We had the added concern in our family that Derek's Mum (who passed the disease to im) died of duodenal cancer and then his brother also died in the same way.

As a family we got involved with the Royal Victoria Infirmary, Newcastle when some funding was made available to look into our condition. We had an eye examination, which was concentrated on looking for black areas on the back of the eyes. They were also talking about the density of the jaw bone, but cannot remember having an x-ray. At the same time blood was taken to obtain a genetic DNA fingerprint. Derek's dad also gave blood as by this time his mum and younger brother had both passed away. They both had, had total colectomies and were being checked on a regular basis, but only sigmoidoscopy

Both the eye examination and the fingerprint found that one of our children did not carry the gene. They were in their early teens at this time.

The child who had inherited the FAP gene had yearly sigmoidoscopies and by the age of eighteen needed a total colectomy followed by a pouch operation ten years later.

After the operation Derek was diagnosed to have pernicious anaemia due to vitamin B12 deficiency for which he is taking the following - A 5mg tablet of folic acid and an injection of Hydroxocobalamin 1000MCG/1ML (form of vitamin B12). Originally this injection was monthly but now it's been changed to three monthly. Derek tends to get tired towards the end of the three monthly period.

We are very interested in meeting and talking to anyone with the same condition. We feel it would be really helpful to begin a support/self help group.

Over the last few years we have talked to our local genetic councillors (based in Newcastle) and have created leaflets advertising the fact that we would like to set up such a group, but we have had no response to the leaflets even though they were put in all the local hospitals and doctors surgeries.

We are therefore extremely excited to be able to make contact with Mick through his website. He has done what we would have really liked to do but were not computer literate enough to start our own website. We still haven't the skills required so must thank Mick for all his hard work in setting all this up and enabling us to tell our story so far.

Mick also suggested that we could have an email address where you could contact us if you would like to talk about anything or would like to think about setting up some sort of meeting in the North of England.