

'Foundation' engineering

Few articles in *The Endocrinologist* are inspired by geotechnology and written by a civil engineer - but please trust me and read on! My story started on a canal boat holiday, a marvellous opportunity to observe civil engineering in its purest and simplest terms: cuttings, embankments, locks, bridges and aqueducts. As you steer the boat, there is plenty of time to look around, stare into the distance and notice that, if you close one eye and then the other...

Are you getting the picture? I wasn't. My optician tested my visual fields and sent me to hospital with a note saying 'suspected pituitary tumour'. It was actually a craniopharyngioma but, as the neurosurgeon said, 'it was tangled up in the clockwork' and as a result 'the pituitary stalk became severed' during its removal.

Well, it could have been worse. If it hadn't been removed, I would have first become blind and then dead. But what was all this about replacement hormones? What was this diabetes that wasn't the same as ordinary diabetes? What do they mean when they say I have to increase my cortisone if I am poorly? Can my GP help? He is struggling. He tells me that, on average, he will see just one patient with my condition in the whole of his career.

All of this was 12 years ago. Somehow my wife and I muddled through. Then we heard of a new organisation that was trying to provide information to pituitary patients. It had brochures that described the various conditions that might result from pituitary disorders. It had a helpline that people could phone for support. It was proposing to have a regular newsletter and to start up local support groups, where pituitary patients and their carers could meet and share their experiences. This was brilliant. Recalling our dark days just after my operation, this support would have been marvellous back then. Furthermore, my own problems hadn't gone away. There was still a substantial difference between managing my own hormones and relying on a feedback loop that had evolved over millions of years.

Consequently, we helped to start a pituitary support group around Bristol. We were overwhelmed by the number of people who, like us, had been struggling to understand pituitary disease and how it was affecting them. People with acromegaly had the chance to meet others with the condition for the very first time. Sufferers of Cushing's described their desperation in trying to persuade anyone that they were seriously ill and not just overeating. We heard about people who were so thirsty that they drank out of puddles and were told that they urinated a lot because they drank so much. And while local groups started up

around the country, the organisation went from strength to strength, building up its available literature, creating its own web site, winning lottery grants to start up more local groups, and battling with NICE on the national stage to try to secure replacement growth hormone for patients.

This was the Pituitary Foundation 18 months ago. At its inception in 1994, those who had initiated it, including Sue Thorn, John Wass and Stafford Lightman, had recognised the need and had had the vision, the determination and the contacts to forge an organisation that was able to support and inform people who were affected by pituitary conditions. They now felt that it was time for the Foundation to be led by the people it was created for and, as a patient, I was asked to become Chairman of the Trustees.

An engineer needs a plan. If he is going to make things happen - build a canal, build a bridge - he first needs to understand all the issues that will influence his design. Will the foundations be in sand or clay? How far can we stretch the aqueduct's spans to save the cost of extra pillars? Where will the raw materials and money come from? How long have we got to build the project? How long does it need to last? There are two watchwords that, for me, underlie all these considerations: quality and sustainability.

I have no doubt that the bedrock of quality that supports the Foundation is the information provided by our Medical Committee, on which key endocrinologists from around the country serve. Our ability to provide first class information adds tremendous strength to our ability to support patients and carers.

As for sustainability, another whole article is waiting to be written. The next step will mark the Foundation's 10th anniversary on 24 November 2004, with a National Pituitary Awareness Day to raise the profile of pituitary disease. But 10 years is not enough. We must find the right way to engineer the Foundation so that it is always there - so that, for as long as there are going to be pituitary patients, there will be a Pituitary Foundation.

ANDREW HEWITT BA CENG MISTRUCTE MICE



THE PITUITARY FOUNDATION

National Pituitary Awareness Day

Wednesday 24 November 2004

The Pituitary Foundation will mark its 10th anniversary in November 2004 with its first health awareness day. The aim is to promote public understanding of the importance of the pituitary gland, and to highlight how it can disrupt the whole body when things go wrong.

If you would like to support this event locally and can arrange a display or local press cover, or if you would like more information, contact Jan at the Pituitary Foundation (janpacker@pituitary.org.uk).

Thank you to all members of the Society for Endocrinology for your continued support.