

# Helping the children to walk tall...

To see three-year-old Thomas Smith running around his garden kicking a football, it is hard to believe this is a child who will need two operations a year until he is a teenager.

Thomas was born with scoliosis – curvature of the spine – and the diagnosis was that it would get progressively worse, leaving him crippled by the time he reached his late teens.

But a revolutionary operation using hi-tech instrumentation will mean that Thomas will grow into a strong, tall and straight-backed young man, able to enjoy life to the full.

At the beginning of April, he underwent six hours of surgery at the Norfolk and Norwich University Hospital to straighten his spine with screws and "growing rods" beside it.

Consultant orthopaedic and spinal surgeon Am Rai says the reason Thomas will need two operations a year until his teens is that every six months the rods will be extended.

"Effectively, the instrumentation will grow as Thomas grows," said Mr Rai.

More than a dozen children are seen at the N&N's spinal clinic each week with the condition and three major operations on the scale of the surgery Thomas had are carried out each month to straighten curved spines.

His parents Iain and Lorna from Hemsby noticed that Thomas was not standing up straight just before Christmas 2004. But it was only later, when his mother took him to the doctors with a cough, that suspicions were aroused.

Mrs Smith said: "The doctor asked me to take his top off and he saw straight away that his shoulders were not correct."

The GP, it emerged, had seen cases of scoliosis before and made arrangements that eventually led to a referral to the N&N to see Mr Rai.

"It was awful for us when he said it was his spine," said Mrs Smith. "We thought that perhaps

Scoliosis – curvature of the spine – is a condition that can leave children crippled for life, but revolutionary surgery at Norfolk's flagship hospital is offering hope to families across East Anglia that their children grow up straight and tall. Health Correspondent MARK NICHOLLS reports.

he would have a brace on for a year or two, we did not know anything about scoliosis. But then we were told that Thomas would have to have an operation because it was so severe, we were devastated.

"We were told that if he did not have it done, by the time he was eight he would be leaning right over and it could affect his lungs."

His parents are pleased the major operation is over, though realise that he will need two hour-long ops a year for a decade.

"We feel as though we have got over the biggest hurdle and we were glad to have it done and are now just looking forward to the time when it is all over."

Speaking to a family in a similar position offered them support at a difficult time in the process, and that is a factor in Mr and Mrs Smith, who have a daughter Natalie, 6, deciding to speak about the operation that will help Thomas lead a normal life.

Like many parents faced with such a major operation, the Smith family had doubts over whether they could or should put their son through such a trauma.

"I kept thinking what if anything went wrong, but if we hadn't had it done he would perhaps blame us for not having the operation," said Mrs Smith.

But Mr Smith added: "We always knew that we would have it done. We are just taking it six months at a time, but looking forward to the time when he comes through it, but I think we

are now through the worst of it. We are very grateful to Mr Rai for what he did."

Surgeon Mr Rai concedes it was one of the more difficult operations he has carried out, for a number of reasons.

"He is about the same age as my son and it was very difficult for me to detach from the patient. His parents were extremely anxious, which is what is to be expected and as he was about to go down to surgery his mother said to me 'he is my only son, his life is in your hands, please take care of him.'"

During Thomas' operation an incision was made along his back to expose the vertebrae and screws inserted as anchor points above and below the curve to which rods were attached to straighten the spine.

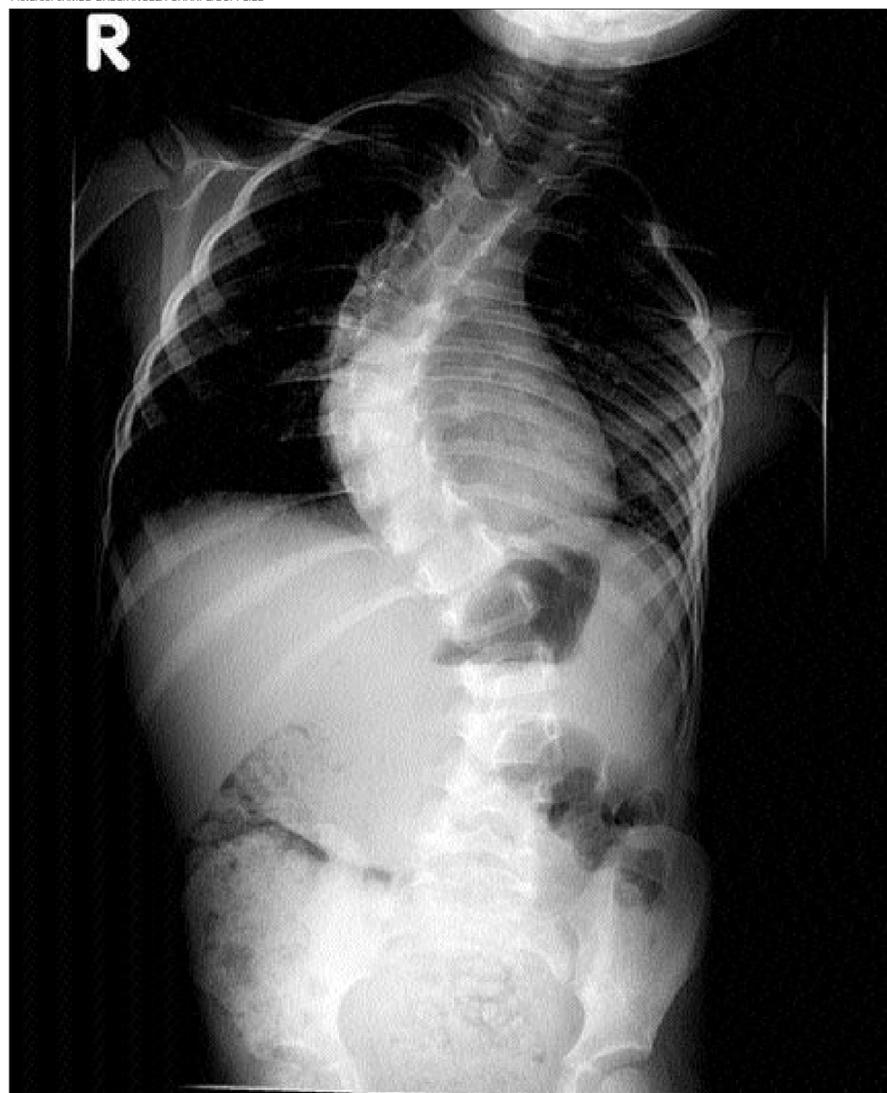
During the operation nerves on his legs and arms were monitored to ensure the neurology of the spinal cord was not affected.

"One of the dangers is that this can cause paralysis which would be a disaster in anyone, but especially a child. There is an inherent risk of this between 1-500 and 1-1000," said Mr Rai. "We monitor to see if we cause nerve damage, particularly when straightening the spine."

"As Thomas grows the instrumentation will grow with him. At the end of his treatment, which may be another 10 years, hopefully he will have a normal trunk length and be a normal individual."

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## I'm so happy to be standing straight at last

Teenager Francesca Hilliard, pictured right, lived with scoliosis for much of her life without realising it.

Her mum Marianne often asked her to "stand up straight" but the family never suspected anything untoward until December 2002 when Francesca was 12.

Now 15, she said: "I was lying on the floor and I felt quite uncomfortable. I asked mum to have a look at my back. It looked like it was out of place."

Francesca went to see her GP who referred her to consultant orthopaedic and spinal surgeon Am Rai who decided to operate.

"Until that point I had a fairly normal childhood," she says. "I had never broken any bones before and had been really healthy."

"But I didn't find it difficult to decide to have the operation. I just wanted to have it put right."

Francesca was 13 when she had the five-hour op, which saw long metal rods straighten the middle part of her spine. The results are significant. She now stands upright and has more confidence.

"Now I get out a lot more, I do more active things and I have a lot more confidence about myself."

"I am now just determined to go out and enjoy myself," said Francesca, who is studying for GCSEs at Wymondham High School and plans to go on to Norwich City College to do her A-levels and later to university after that.

"Whenever I meet Mr Rai I am so thankful that he has been able to help me and make me so much happier with myself."

After the operation, Francesca who lives with her family at Maple Close, Wymondham, was on her feet within a week.

Her mum said: "When she got out of bed the biggest thing I noticed was that she was so much taller, about three inches, and she looked so upright, it was a big moment for us as parents because over the years it seemed as though



she was losing height."

Like many parents of children with Scoliosis, Mrs Hilliard feels she should have spotted Francesca's condition earlier.

"She kept saying she was uncomfortable and at one time I felt really awful when I told her to stand up straight and she said 'I am standing up straight' and I said to her 'no you are not.'"

Mr Rai said: "While Francesca did not have an obvious curvature of the spine, it was quite noticeable to the trained eye."

"Her curvature was of 65-70 degrees and that is quite significant."

"Our concern with this was that it would progress as she got older and she would not be able to lead an active lifestyle with the curve moving at 0.5-1 degree a year."

"It was quite a major operation and one of the biggest risks is that damage can be done to the nerves and cause paralysis."

Unlike Thomas, Francesca will only need one operation. Her spine has been fused in position with titanium screws and rods and because she has finished growing they will remain in place for life.

**BEFORE AND AFTER:** Main image, an X-ray of of Thomas Smith's spinal deformity. Below, from left, Thomas Smith with his mum Lorna, his X-ray after the operation, Francesca Hilliard's pre-operation X-ray and how her spine looked after surgery.

### THE SPECIALIST TEAM BEHIND THE LIFE-CHANGING OPERATIONS

Scoliosis is a condition that is tackled by a specialist team at the Norfolk and Norwich University Hospital.

It involves spinal surgeons, physiotherapists, anaesthetists and patient liaison staff who can talk to families about the operation and what it entails or put them directly in touch with other families who have been through a similar experience and help them understand the decision-making process.

The team also includes surgeon Robert Crawford; two dedicated consultant

anaesthetists in Dr Paul Barker and Dr Lorna Kerr; patient liaison officer Ann Chandler, who is also the Scoliosis Association regional representative; paediatric physiotherapist Veronica Van-Ree; Gordon Lindsay who is responsible for measuring patients and fitting braces, ward nurses and a skilled team of theatre nurses as well as a muscular-skeletal radiologist.

Consultant orthopaedic and spinal surgeon Am Rai explained that before major surgery all the cases are fully discussed by the specialist team at the N&N, which is the only

unit in East Anglia offering a comprehensive spinal service.

The surgery can often be risky and lengthy with a key element being the careful monitoring of the nerves to ensure that damage is not caused to the spine during the operations.

The unit sees 10-14 cases of scoliosis a week from the region, most referred via GPs, and performs up to three major operations such as those on Thomas every month.

While some cases need surgery, many can be treated by a body brace which helps to

straighten the spine naturally. But if scoliosis is untreated the curvature gets worse and eventually leads to increased pain, causes lung problems and difficulty in breathing.

Mr Rai said: "The operations are pretty high risk, but the results can be very good. It is satisfying to give a good cosmetic appearance for the child and also give them an opportunity to lead a normal life."

The patient liaison officer enables families – and children – in a similar situation to talk to one another.

Mr Rai said: "Sometimes making the

decision to have the operation is the most difficult one and it can be a great help if that experience can be shared.

"Patients who come in with significant curvatures are often introverted, particularly adolescents, and it can have a profound influence on their outlook in terms of confidence."

"But it is a privilege to be able to offer this type of service to patients. We see them at clinic and then see them go out mostly with a happy outcome."

The unit deals with all aspects of spinal

surgery from scoliosis, fractures, tumours, and degenerative conditions such as disc pro-lapses.

There are hopes that the team can see the expansion of the special spinal injuries clinic and eventually work toward having a spinal injuries rehabilitation centre.

Links

■ Scoliosis Association:  
www.sauk.org.uk or telephone 0208 964 1166