

Infantile scoliosis meeting

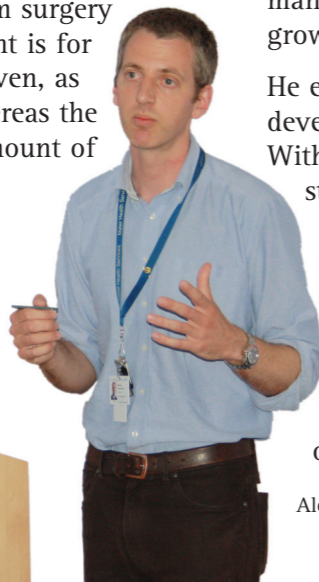
By Sarah Wiles, SAUK Communications Officer

In June, SAUK held a meeting dedicated to infantile scoliosis at the Royal National Orthopaedic Hospital (RNOH) in Stanmore, Middlesex. This was the first meeting that focused on this specific age group for several years. The RNOH treats a third of all scoliosis patients, including the most complex cases from across the UK. The following feature is an account of some of the key points raised at the meeting and the useful advice and information given.

Mr Matt Shaw, FRCS, hailed as the champion of junior doctors by his peers, and soon to become a permanent member of the RNOH team, gave an insightful talk about why a child gets scoliosis and what the disorder is. He spoke of the need for specialists to put themselves in the position of patients. He emphasised that it is essential to take care about the language health staff use, to demystify the medical language used to describe the condition, and so help patients and their families understand the issues. He advised that staff realise and take into account that the hospital clinics are a pressured environment for patients. Taking these things into account should help to alleviate the additional stresses on patients and families.

In describing scoliosis he quoted the Scoliosis Research Society's definition, 'a deviation of the spinal alignment in the frontal plane'. Scoliosis always represents a 3D curvature that affects the whole spine, including kyphosis, lordosis and rotation/torsion of the motion segments (vertebrae) of the spine. Any curvature over 10 degrees is regarded as a true scoliosis, whereas anything less is fairly common and classified as a scoliotic posture. On pain, he said that 20% of scoliosis patients are affected; however, 90% of the general population will have back pain at some point in their lives.

His feeling was that the result from surgery that patients and their parents want is for the shoulders and the hips to be even, as well as the rib bump reduced; whereas the specialist's main concern is the amount of curvature of the spine.



Alex Gibson, FRCS



He discussed the difference between structural and non-structural scoliosis; he described congenital scoliosis, which is seen in a baby born with the condition; neuromuscular scoliosis in which patients have the condition as a co-existing factor resulting from weakened nerves and muscles; and early and late onset idiopathic scoliosis, for which there is no known cause. As you will see in clinic and read about on the Internet, scoliosis comes in many ways, but it is essential to remember that not all curves are the same and that each patient is different. If you would like more details of these specific areas please visit the 'About scoliosis' section of SAUK's website www.sauk.org.uk/about-scoliosis.

Mr Hilali Noordeen, FRCS, gave an informative and groundbreaking talk on treatment in early onset scoliosis. In his presentation he stated that progressive infantile scoliosis is problematic, and can be both disabling and fatal. Having definitive fusion before the age of 10 years can result in severe respiratory compromise. The growing devices that he uses, such as growth rods or the VEPTR system have associated complications. Conservative (non-surgical) management takes advantage of the child's natural growth capabilities.

He explained the benefits of the casting technique developed and practiced by Miss Min Mehta, FRCS. With casting, scoliosis is managed in successive stages with each corrected position held by moulded plaster-of-Paris jackets that are worn for 8-16 weeks. Serial casting is a good delaying tactic and in some cases it can correct scoliosis.

For optimum results casting needs to be started before a child is 2 years old (there will be more on Miss Mehta and her technique in the spring

2011 issue of *Backbone*). He also emphasised the difficulties of lack of compliance with bracing, which can be difficult for young children to tolerate.

As you will have seen in the spring, 2010, edition of *Backbone*, there was a feature on the technique being piloted in the UK by Mr Noordeen at RNOH. From the 1st July, 2010, Mr Noordeen has been exclusively using the new MAGEC magnetically expanding growth rods. These rods remove the need for regular surgery to extend the rods and instead they are lengthened using magnets at the press of a button.

The final specialist to speak was Mr Alex Gibson, FRCS, who discussed current research into scoliosis. He talked about the way advances were made in the treatment of scoliosis, through innovation as opposed to laboratory based research. The direction for the future is less invasive surgery (ie. endoscopic scoliosis surgery), with smaller incisions and a quicker recovery. Scoliosis specialists are also interested in assessing the effectiveness of non-surgical treatments such as bracing and intensive exercise programmes. This is good news for the patients because it will provide clearer information about the benefits of non-surgical approaches.

Carol Richards, SAUK Trustee, emphasised the importance of giving time to your relationship if you are a couple coping with scoliosis diagnosis and treatment, and to also give attention to your other children because it is easy to become fixated on the affected child and his or her prognosis and treatment. She also strongly believes that you should go with your gut instinct, and if you feel



Carol Richards, SAUK Trustee



that things are happening too slowly to push the hospital for speedy referrals and treatment. Acting fast with an infant is essential. Another key point was that with infantile scoliosis parents should become experts on their child's condition because not all medical staff will have a full understanding of the condition, which can result in misinformation and slow action in respect of treatment and referrals.

SAUK member Richard Smith spoke about his family's experiences with his daughter. Naomi has Marfan's syndrome and has had lengthy treatment with casting and now growth rods. Richard and his wife Rachel are more than happy to speak to members going through the same experience. You can read Naomi's full personal account on SAUK's website or you can visit www.spineop.blogspot.com, Naomi's blog, for progress on her treatment.

From the discussions at the meeting, it is clear that parents of children with infantile scoliosis need more support than they get at present, and that they are affected by the lack of information about scoliosis. At SAUK we have begun to act on some of the comments from the day. We are planning to send the new SAUK scoliosis booklet and promotional resource to all GPs in the UK. These booklets have already been supplied to scoliosis centres and the key staff caring for people with scoliosis. In the long-term SAUK will generate a general awareness campaign that will target schools as well as the health service. We appreciate the need for tailored support with coping with the NHS referral system to make sure that the correct care is given in a timely manner, and we are discussing how we can further support families who are not able to get access to the correct care. Certainly the overall feeling was that SAUK needs to take an active role in lobbying on parents' behalves, which is something that will be discussed at the Trustees meeting later in the year. SAUK exists solely to support the needs of scoliosis patients, so please help us to help you by feeding back to us about ways we can continue to be of more help to people coping with a diagnosis of scoliosis.

If you would like any more information about infantile scoliosis, want to be put in touch with a family who is going through a similar experience or simply need support or advice, please telephone SAUK on 020 8964 5343 or e-mail info@sauk.org.uk, or write to us.