

# Musclemania

Autumn 2012 Issue 9



**Surgery pathways**

Turn over to find out more.

# Welcome

to our newsletter



**W**elcome to the Autumn edition of our newsletter. Our special feature this edition is on pathways for gastrostomy and spinal surgery. We have one young person talking about his experience of going through spinal surgery. We have our regular who's who on newcomers to our service and some of the latest news that is around in the neuromuscular world. We would really welcome your feedback on how you find this newsletter and any suggestions on improvements and items you would like in future editions.

**Martin Chainani,**  
**Editor**  
Neuromuscular Care Advisor

Next issue: Winter 2012

Front cover: Credit-Photo of Henry Moore's Large Vertebrae sculpture by Rüdiger Wölk, Münster.

## Who's who

### Newcomers to the Neuromuscular Service



**Kirsty Entwistle**  
Trainee Clinical Psychologist

Kirsty is based at University College London. She is working with Dr Valeria Ricotti and Dr Mariacristina Scoto, Neuromuscular Clinical Research Fellows, on a research study that will form part of her doctoral thesis. The study is investigating how many boys with Duchenne Muscular Dystrophy also have difficulties with their behaviour and learning. She will be contacting families who live in and around London to ask if she can visit them at home to do some questionnaires and interviews with them and a cognitive assessment with the child/young person. The cognitive assessment involves doing some puzzles and games with words and numbers. She would like to meet as many families as she can and it is important that she interviews families who do not have concerns about their child's learning or behaviour as well as those who do. This is so we can understand what proportion of boys with DMD have difficulties with their learning and behaviour.

Kirsty likes to spend time reading (usually psychology related stuff!), watching world cinema and has been a runner since her teenage years. When she finishes her training she plans to do some travelling and visit her sister in Australia.



**Andreas Brunklaus**  
Neuromuscular SPR

Andreas went to medical school in Berlin, Germany, but has done all his practical training here in the UK in exotic places such as East London, Glasgow and Westminster! He started a three and a half year rotational post here at Great Ormond Street a year ago and will be with our team until March 2013.

For fun Andreas likes to play tennis, go mountaineering and cook. His favourite places to go walking are Scotland and the Pyrenees mountains.



**Karen Roberts-Edema**  
Clinical Nurse Specialist

Karen started working with us in August and will be working closely with Ruth Barratt, our other CNS. Karen trained in Hertfordshire, qualifying in 1999. Initially she worked in hospitals in East London on the wards, in outpatients and on A & E, before specialising and doing community and continuing care nursing in Hertfordshire (where she had her first experience of neuromuscular disorders), Hounslow and Luton. Karen came to Great Ormond street at the beginning of 2011 initially working on the Rapid Access Neurology Unit.

Karen is married with three children age twelve, eight and four, her interests include cycling, jogging and going on sunny holidays!

If you have any comments or ideas for next issues, or if you would like to share your story please get in touch...

Email: [muscle.service@gosh.nhs.uk](mailto:muscle.service@gosh.nhs.uk)

# Surgery pathways

Feature  
article

## Spinal Surgery Pathway

Spinal surgery is available at GOSH for any children and young people with neuromuscular conditions who need it. The neuromuscular team work together with the spinal surgeons in a joint clinic, held monthly, to review and assess children and young people with scoliosis (curvature of the spine). At this clinic a decision is made when it is the right time for parents and young people to plan for surgical correction of scoliosis using spinal rods. This is when children and young people are put on the Spinal Pathway.

### What is the spinal pathway?

The spinal pathway has been developed to provide a comprehensive assessment of children with neuromuscular conditions and other complex conditions in order to consider carefully the risks and benefits of surgery for each child/young person. Once on the pathway your child will need to have a number of tests. Initial tests may include an MRI (special scan of the spine, sometimes the heart also needs to be scanned) and a sleep study. Your child will also

be invited to an investigation day when your child will be seen by the anaesthetist, the physiotherapist, the occupational therapist, the surgeon and, if required, other specialists. Your child will also have a blood test and lung function testing.

To assess the risk for each child/young person, all the test results and specialist reviews are discussed in a multidisciplinary meeting which takes place once per month. Decisions are made using a traffic light: green for low risk; amber for moderate risk; red for high risk. Children/young people who are assessed as green or amber are offered surgery and a date

is planned. Those that are assessed as red or high risk are followed up by the neuromuscular team where a discussion is held with the parents.

Those children/young people assessed as green or amber risk are invited to a preoperative assessment where the surgery once again is discussed in detail and consent is obtained and final tests done.

## The Arvind Jain Gastrostomy Pathway

This pathway has been developed with the significant support of the family of Arvind Jain following their experiences. Some children/young people with neuromuscular conditions have difficulty with chewing and swallowing and maintaining good weight. In some cases this means that we need to think about an alternative way for them to achieve a good weight gain and grow healthily. At this time we may talk to you and your child about gastrostomy and discuss planning for this.

### Some useful information about spinal surgery

- Your child will be admitted the day before surgery.
- Your child will go to Intensive care after the surgery for a few days.
- The average stay in hospital is about nine days. Most families need a little extra care provision at home for one to two weeks after going home.

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## Personal Experience of spinal surgery

Batuhan is a young man with Duchenne muscular dystrophy and I interviewed him and his mother on the first anniversary of his surgery in order to find out more about their experience of spinal surgery.

Batuhan told me that over two years ago his mum noticed, whilst bathing him, that his back was starting to change shape. Following that Batuhan started to feel more and more discomfort in his back and was taking painkillers. Mum told the Neuromuscular team about this at his next appointment and an x-ray was done which showed evidence of a scoliosis (curvature of the spine). Batuhan was then invited to a joint clinic with the spinal team where a decision was made to do surgery on his spine by fusing it to two metal rods. Batuhan is a positive individual and said he was fine about this decision but his mum, as mums do, spent many days crying with worry.

In September last year Batuhan was admitted to hospital for the surgery

and again was not upset but instead was looking forward to being in more comfort and sitting in a better position. Batuhan does not remember much about the surgery or post-operative period in intensive care because of the strong medication he was on, whereas mum spent hours crying and reading the Koran whilst he was in theatre. Batuhan spent 11 days in hospital in total. Mum said that she was surprised about how much care Batuhan needed after surgery and realised she would not be able to look after him at home on her own. She thanks the Neuromuscular Care Advisor who supported her through the process.

Both Batuhan and his mum describe the first two to three months at home as very difficult and that life did not return to normality until six months post-surgery. However Batuhan said he would recommend the surgery to anyone who asked because of the way it has reduced his pain significantly and helped him to sit

and look so much better in his wheelchair. The only negative for him is that he now needs to be hoisted to move forward in his chair to be able to use a bottle for urinating. Both say that their strong faith helped them through this difficult time.

### Batuhan's top tips

1. Don't worry about the first six months after surgery, things will get better.
2. Don't let your condition hold you back. By believing, you are on the way to achieving.



## Surgery pathways continued

A gastrostomy is a tube that is placed through the tummy wall directly into the stomach. Your child is fed through this tube.

### What is the gastrostomy pathway?

This pathway was developed to provide a safe and more efficient approach to providing gastrostomies for children with neuromuscular conditions at GOSH.

When we discuss and plan a gastrostomy with you and your child we will:

- Discuss what tests would be needed before the procedure, this may include an Impedence study (a test for assessing whether there is food is coming back up the food pipe from the stomach), echocardiogram (heart scan), sleep study, special x ray of the stomach and intestines. Occasionally it will also involve having an appointment with a gastroenterologist (a doctor who knows about problems with the stomach and gut).
- As far as possible we will arrange the tests together but sometimes this is not possible.
- When all the tests are complete we will invite you and your child to a joint appointment with the surgeon Mr Curry, the anaesthetist and the neuromuscular Team.
- We will agree and explain the procedure and postoperative care and talk to you about the anaesthetic.
- You will usually leave this appointment with a date for the gastrostomy.
- Your child is likely to be in hospital after the procedure for between two to five days.

### Further information

You can download the Scoliosis & Living with Gastrostomy factsheets at [www.gosh.nhs.uk/medical-conditions/procedures-and-treatments](http://www.gosh.nhs.uk/medical-conditions/procedures-and-treatments) and you can register for free at [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org) and download their factsheets 'Surgical Correction of Spinal Deformity', 'Spinal Surgery – Questions To Ask' and 'Gastrostomy' Factsheets, or you can contact the one of the Neuromuscular Nurse Specialists or the Care Advisor.

## What's new

### Paralympic News

In a previous edition of this magazine we profiled Ollie Hynd who is a patient of the Neuromuscular Service and was about to compete in the 2012 Paralympics Games. As you will all be aware of now Paralympics GB performed fantastically coming third in the medal table and Ollie also had a very successful time. He won Gold in the 200m Individual Medley, Silver in the 400m Freestyle (beating his brother Sam, an ex-patient of ours, into third place) and Bronze in the 100m Backstroke. Our congratulations go out to him.



### WellChild Awards

Three of our patients, Pooja Deshpande, a girl with Spinal Muscular Atrophy, Declan Spencer and Matthew Merritt, boys with Duchenne Muscular Dystrophy, won Wellchild awards and these were presented to them by Prince Harry at a recent ceremony. Pooja won the award for the Most Inspirational 12 to 15-year-old girl, Declan for the most inspirational 12 to 15-year-old boy and Matthew for the most inspirational 7 to 11-year-old boy.

### GSK Imaging study in Duchenne muscular dystrophy

GSK Imaging study is a collaborative project between the Dubowitz Neuromuscular Centre and GlaxoSmithKline, which aims to try to understand how the condition changes in boys who are not walking. This will be done by looking at MRIs (Magnetic Resource Images) of the arms, legs and, if possible, the diaphragm, and also by doing newly developed physiotherapy assessments of the arms. It is hoped in particular that these assessments, by monitoring changes to the condition, will help us see how different treatments could change its natural history.

We aim to recruit 15 boys with DMD who are not walking and are older than 12 years, and we are hoping to start in October of this year. The study will last one year and the boys will have three MRI scans & physiotherapy assessments in total. We are also looking for 10 healthy volunteers, boys between 12 and 17 years, who will be happy to have a MRI scan of their legs and arms. Any sibling, cousin or school friend is welcome to contact us.

If you would like to find out more please contact either Valeria Ricotti at [v.ricotti@ucl.ac.uk](mailto:v.ricotti@ucl.ac.uk) or call her on 02079052151 or Naomi Antcliff by email at [naomi.antcliff@gosh.nhs.uk](mailto:naomi.antcliff@gosh.nhs.uk) or call her on 020 7762 6892.

## Muscle project news

### The Kings Fund/Health Foundation project

The Neuromuscular Service has won the opportunity to work with The Kings Fund & Health Foundation on a project that aims to improve the quality of our service.

The King's Fund is an organisation that seeks to understand how the health system in England can be improved. Using that insight they work with individuals and organisations to shape policy, transform services and bring about behaviour change. The Health Foundation is an independent charity working to continuously improve the quality of healthcare in the UK. The funding we have received is part of their joint Patient & Family Centred Care programme.

We want to understand what the experience is of patients and staff in our service. From doing this we aim to improve the patients journey in our clinics. This project will run from September 2012 to December 2013.

We feel that the pathway for boys with Duchenne muscular dystrophy, focusing on the Wednesday clinics will be the most useful. Some of you have already helped by agreeing to be shadowed and interviewed when you have come to clinic.

We hope that the things we learn and develop will be useful across other clinics. We hope we find gains for everyone coming to the service.

Thanks for your help so far and in the months to come!