

Great Ormond Street **NHS**
Hospital for Children
NHS Foundation Trust

Musclemania

Spring 2012 Issue 7



Welcome

to our newsletter



Welcome to the spring edition of our newsletter. We have a feature on disability sports, including an interview with a patient in the Neuromuscular Clinic who hopes to win a medal at the London 2012 Paralympic Games. We have our usual 'who's who' on newcomers to the 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 ideas about what you would like to see in future editions.

Martin Chainani
Editor
Neuromuscular Care Advisor

Next issue: Summer 2012

Oliver Hynd – paralympic swimmer



Oliver is a 17-year-old young man who attends the Neuromuscular Centre here at Great Ormond Street Hospital and has a muscle disorder. He and his older brother Sam, who also has the same condition, are, as I write, about to take part in trials to qualify to participate in the London 2012 Paralympic Games later this year. They will find out in May if they have been chosen for Team GB.

The boys' mum, Helen, told me how they got involved in swimming from a young age.

"Sam, my older son, was born with talipes and the physiotherapists recommended swimming as a good exercise from an early age. Sam joined Sutton Swimming Club and was a good swimmer at competition level. However, due to how the muscle disorder changed Sam's muscle strength, his swimming stroke became ineligible for general competition. It was suggested that he join the Nova Centurion Swimming Club, which is an inclusive club and takes part in disability swimming. This is the club that Rebecca Adlington, Olympic gold medal winner, belongs to. Sam went on

to win the gold medal in the 400-metre freestyle in the S8 Classification in the 2008 Paralympic Games in Beijing.

"Ollie did not appear to have any difficulties from birth, but as he entered adolescence, it became evident he had the same condition as Sam. He joined his brother in competitive swimming and received his S8 classification in April 2011. In the 2011 IPC European Championships in Berlin, Ollie won gold in the 200-metre individual medley, breaking the European record at the same time. He also won silver in the 400-metre freestyle and bronze in the 100-metre backstroke."

Ollie told me that he is feeling confident about the trials because his preparations have gone well. He said about the Paralympic Games that he is "quite excited because they are becoming really real now as the time gets closer". Ollie told me that he is very fortunate to be funded by UK Sport through a lottery grant.

Sam's three top tips for young disabled people interested in getting involved in sports are:

- 1 Get involved. Try different sports and see what's out there.
- 2 Never give up.
- 3 Enjoy and you will succeed. Just because you have a disability does not mean you cannot take part in sports.

Above: Oliver and Sam celebrate success at the pool.

Who's who?

Newcomers to the Neuromuscular Service



Dr Irene Colombo
Clinical Research Fellow

Irene is spending a year with the service to learn more about paediatric neuromuscular diseases. She chose this service because of its great reputation for combining research and clinical practice.

She is an adult neurology registrar in the Centre for Neuromuscular

Diseases in Milan, Italy, and is in the third of five years of training. Even though her speciality is adults, she does see some children and young people in her service.

Irene is really enjoying London because of its beauty and cultural diversity. Her pastimes include swimming, skiing, cooking biscuits, shopping and going to the cinema.



Jo Innes
Physiotherapist

Jo is with us for the next six months as the first placement in her new job as a physiotherapist, doing rotation here at Great Ormond Street Hospital.

She previously worked in Hounslow in community paediatrics where she got to know some of the patients we jointly share. She trained at the University of

Hertfordshire and qualified in 2008, and her first job was in Hertfordshire doing a general rotation between children and adults.

Jo is a very keen netball player and also enjoys swimming, spending time in her garden and playing with her cat.

Disability sports

Feature
article

The young people who attend the Neuromuscular Centre in Great Ormond Street Hospital are involved in various sports.

Powerchair football

Quite a few of the boys who attend the centre are involved with the Aspire Club in Watford. One of them, Stevie, went to World Cup Finals last November as part of the English team, where they, despite being unseeded, got to the final before eventually losing to the USA 3-0.

There are teams in many parts of England now and to get involved, you can find out more at www.thewfa.org.uk

Wheelchair basketball

Two of the boys who attend the centre, Shaye and Euan, are involved in wheelchair tennis, playing for the Richmond Knights team. One of them travels a long way across London just for the opportunity. They are classified at Level 1 and play in the team as tactical blockers.

The Richmond Knights team are always looking for new players and, if you would like further information, please contact coach, James Merchant at jambasketball@gmail.com

If Richmond is too far for you to travel, you can find out about clubs in your part of the country at www.gbwwa.org.uk

Boccia

This is a target ball sport where athletes throw, kick or use a ramp to propel a ball onto a court with the aim of getting closest to a 'jack' ball, similar to bowls or curling. Most of the children from the Neuromuscular Centre are in the BC3 classification, meaning they play in their wheelchairs and use a ramp to propel the ball. The Muscular Dystrophy Campaign has written an interesting article about this in their first 2012 edition of their target *MD* magazine.

You can request a copy of this or see an online version at www.muscular-dystrophy.org,

or alternatively you can call them on 020 7803 4800. You can find out how to get involved at the following website www.bocciaengland.org.uk/lords_taverners.php

Try it out

If you want to try out different disability sports, an organisation called Wheelpower runs camps and events where you can get involved. These are mostly run at Stoke Mandeville Stadium in Buckinghamshire. This venue is synonymous with disability sports and is often called the "birthplace of the Paralympics". Other sports available there include archery, athletics, wheelchair rugby and racing. You can find out more at www.wheelpower.org.uk

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

Email: martin.chainani@gosh.nhs.uk Tel: 020 7405 9200 ext 0529.

What's new?

East of England neuromuscular services

There are now two care advisors in post:

Andrea Russell, Neuromuscular Care Advisor for Norfolk and Suffolk
Tel: 07976 896387
Email: andrea.russellscg@nhs.net

Carol Wood, Neuromuscular Care Advisor for Essex and Cambridgeshire
Tel: 07904 116965
Email: carolann.wood@nhs.net

There is a third vacant post which will cover Hertfordshire, Bedfordshire, Luton and Peterborough. Until this person is in post, the other two will cover any urgent referrals between them.

London neuromuscular services

A steering group has been set up to look at how London neuromuscular services can be improved and the first meeting was held at the beginning of March. Three of the main issues they looked at were care advisor support, transition, and respiratory services.

Parents Education Network

Parents Education Network (PEN) is a peer-to-peer support network set up by the Muscular Dystrophy Campaign. It will put parents in touch with other parents so they can talk about the issues they are facing in trying to ensure their child gets the best possible education. Parents will have the opportunity to discuss anything and everything relating to their child's education. PEN will also offer parents advice from a number of educational experts who will be on hand to answer any questions you may have. If you would like to join PEN, or you would like to find out more about it, please contact David Moore-Crouch at the Muscular Dystrophy Campaign Information team on 020 7803 4800 or information@muscular-dystrophy.org

Research news

A new post has been developed to help with the clinical trials that the service is doing. Naomi Antcliff will be starting in May as a neuromuscular research nurse. Look out for her profile in the next edition of *Muscle Mania*.

Duchenne muscular dystrophy heart protection trial

This is a trial to look at whether a combination of two different types of heart medicines, beta blockers and ace-inhibitors, can delay the age of onset and/or slow the rate of progression of heart muscle weakness (cardiomyopathy) in boys with Duchenne age seven to 12 who do not already have a cardiomyopathy.

It will be double-blind, randomised and placebo-controlled, meaning that 50 per cent of boys will get the medicine and 50 per cent will get a placebo (false medicine). The results will be compared to see if the medicine works better than the placebo. Boys will be recruited from here and four other muscle centres over the next two years, and the study will last for five years. We are aiming to recruit between 60 to 70 boys and so far we have recruited five boys. If you would like to know more or are interested in being involved, please contact Dr Mariachristina Scoto at mariacristina.scoto@gosh.nhs.uk or call her on 0207 905 2639.

Muscle project news

Education pack

The care advisor is looking at developing an education pack to support you as parents and carers of children and young people with muscle disorders in nurseries, schools and further and higher education.

He is also aiming to support the staff in those organisations in looking after your children and young people.

The first step has been to devise a short questionnaire which he is giving out in the clinic until the end of April. He will then analyse the results before taking any further steps.

Look out for the results of the study in the summer edition of *Muscle Mania*.

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

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