

Musclemania

Summer 2012 Issue 8



Dreams and Wishes

Turn over to find out more.

Welcome

to our newsletter



Welcome to the Summer edition of our newsletter. We have a feature on charities that provide support to children with neuromuscular disorders by granting their wishes and funding equipment. As part of the feature we have an interview with a patient of our service about the wish that she received. We also 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 to see in future editions

Martin Chainani,
Editor
Neuromuscular Care Advisor

Next issue: Winter 2012

Front cover:

Who's who

Newcomers to the Neuromuscular Service



Naomi Antcliff

Neuromuscular Senior Research Nurse

Naomi trained in Oxford at the John Radcliffe Hospital where she developed an interest in neurology. She has been working in the Neuromuscular service since May of this year. She worked as a research nurse in the Clinical Research Facility (CRF) at GOSH for three years where she was involved in early clinicals trials in Duchenne muscular dystrophy. This is an exciting new post working closely with Dr Valeria Ricotti and Dr Mariacristina Scoto in clinic and the CRF, conducting medicine and non-medicine trials. Naomi is a key link between the research and clinical team to ensure the smooth running of the trials. If anyone has any questions regarding clinical trials in neuromuscular please do not hesitate to contact her on: tel: **020 7762 6892** or email her at: **naomi.antcliff@gosh.nhs.uk**.

Naomi is a keen sportswoman enjoying swimming, cycling to work and currently training for the Dublin marathon in aid of the muscular dystrophy campaign in October.

Dr Guja Astrea

Clinical Research Fellow

Guja is spending time with us until September as a Clinical Research Fellow. She is a Paediatric Neuropsychiatrist and has a special interest in neuromuscular

disorders particularly muscle MRIs, a tool used to help with diagnosing muscle disorders. Guja is with us until September and will then go back to work in Pisa and continue her research.

Guja's hobbies include clown therapy (you may remember the movie 'Patch Adams' a true story about a doctor who used laughter to help treat children), running, skiing, swimming and drama. She loves everything about London except our favourite subject, the weather!



Dr Sophelia Chan

Clinical Research Fellow

Sophelia is spending six months here as a clinical and research fellow to learn from the Dubowitz neuromuscular team, and to participate in some of the clinical research.

She is a Paediatric Neurologist from Hong Kong with a special interest in neuromuscular disorders. In Hong Kong she works in the Queen Mary Hospital under the Neurology team of the Department of Paediatrics and Adolescent Medicine. Sophelia says she has found that London, like Hong Kong is a very busy, multicultural and international place and that it also has a lot of beautiful places, galleries and museums that she hopes to visit whilst she is here. She likes jogging and swimming during her free time.

Eden's wish- a day fit for a queen

Once upon a time there was a six-year-old girl named Eden and she was on holiday in the US with her parents when her father received a telephone call from the Muscular Dystrophy Campaign. They told him they had nominated Eden for a wish from the Starlight Foundation as long as she chooses it herself.

Eden is a unique girl, she does not want the usual treats like Disneyland Florida and Lapland. She wants to lead a horse by the reins on her own! On it's own it may not seem a very special treat, but what a day she had!

The day started with being put up in the Penthouse suite in the Park Lane Hilton. Eden said this is the bit her parents liked best! A black cab took her to the Kensington Barracks, where the Queen's own soldiers are stationed. She was then

looked after by the handsome Captain Nicholas, a close personal friend of Prince William. Eden said meeting him is her mum's favourite part. Daddy wasn't so happy about this! Eden then became a Queen by being allowed to give a soldier the permission to dismount the horse called 'Ebony' that she was going to lead. Eden then got to lead the horse and was so excited. This was definitely her favourite bit. The day was capped off by the family having a ride through Hyde Park in the Queen's own carriage.

But of course Eden had to be different. She did not want to ride in the carriage, she wanted to ride with the driver. Eden's mum said it was amazing as the Queen's soldiers rode with them stopping the traffic to let them through. Eden said the day was fantastic and Ebony was so much bigger than the horses she normally rides.



Eden's top tips for fulfilling your own dreams:

1. 'Make it good'.
2. 'Do what you want to do, not what your parents want'.

Wishgranting charities

Feature
article

Children with serious illnesses and life-threatening medical conditions have an opportunity to have a special wish granted as in the one described earlier for Eden. Patrick a boy with Duchenne muscular dystrophy also had a wish granted to meet all of his favourite Disney characters and Sian a girl with Spinal Muscular Atrophy got the chance to meet her favourite boy band, Take That! There are various charities that provide wishes with some differences and these are listed here:

The Muscle Help Foundation

Any child or young person aged between eight to 28 years with muscular dystrophy and who has NOT been the recipient of a dream within a two year period.
www.musclehelp.com

Make-A-Wish Foundation UK

Grants wishes to children and young people fighting life-threatening illnesses aged between three to 17 and cannot have had a wish granted by any other charity. The whole family are included on a wish including siblings under 18.

They will visit your child to find out what they would like. Anyone can refer.
www.make-a-wish.org.uk

Starlight Foundation

Grants wishes to children aged four to 18 years old who are facing a life-threatening or life-shortening illness and have not had a wish granted by another charity. Anyone can refer.
www.starlight.org.uk

Dreams Come True

Provides wishes for children aged two to 21 who are seriously or terminally ill and have not had a wish granted by any other charity. Will fund for one adult and the child. The whole family can go but they have to fund the rest of the trip.
www.dctc.org.uk

Dreamflight

Arranges trips for seriously ill and/or disabled children aged eight to 14 years to theme parks in Florida. Children are accompanied not by their families but by a team of escorts! **www.dreamflight.org**

When you wish upon a star

Grants wishes for children between two and 16 years of age with a life threatening or terminal illness who have not had a wish granted by another charity.
www.whenyouwishuponastar.org.uk

Caudwell Trust

They are better known for providing funding for equipment needs but also offer a seven day family holiday (siblings under 18 included) to Florida, USA for children with a chronic illness or disability.
www.caudwellchildren.com

Rays of Sunshine

Grants wishes to children aged three to 18 facing a terminal or serious illness and should not have had a wish granted within the last 12 months. This is great news for families whose child had a wish granted by one of the above charities when their child was younger.
www.raysofsunshine.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...

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What's new

Association Francaise Contre les Myopathies (AFM) natural history study in Duchenne muscular dystrophy

This is an organisation that is the French version of the Muscular Dystrophy Campaign and they have funded this study which is an international (France and UK) multi-centre natural history study which will run over two to four years and aims to recruit 20 boys with Duchenne Muscular Dystrophy at Great Ormond Street Hospital. The goal is to get a more in-depth understanding of the progression of the condition and produce an assessment tool which could be reliably used in clinic and in clinical trials. Recruitment has recently commenced and this will include both ambulant and non-ambulant DMD boys. The primary aim is to look at clinical outcome measures (focusing on the arm, as very little information is available) and biomarkers (urine and blood). 'In this study clinical outcome measures are a way to understand how the condition changes naturally and whether future clinical trials alter the way the condition changes. The biomarkers are to measure some of the body's chemicals and again to see how these change over time naturally and whether any trials affect this.'

If you are interested in finding out more or becoming involved please contact Dr Valeria Ricotti at valeria.ricotti@gosh.nhs.uk or call her on **020 7905 2639**.

Cardiac protection in Duchenne muscular dystrophy Trial

We have now recruited a Clinical Research Fellow in cardiology to help do the Echocardiograms for those on trial. We have now recruited 17 boys for the trial and are aiming to have 35 boys by the end of 2012. If you are interested in finding out more or becoming involved please contact Dr Mariacristina Scoto at mariacristina.scoto@gosh.nhs.uk or call her on **020 7905 2639**.

New Neuromuscular Clinical nurse specialist

We have appointed a second Clinical Nurse Specialist to work alongside Ruth Barratt who most of you know well. She is due to start in August and we will have her profile in the Autumn edition of this newsletter.

A sad farewell

After being with us for two years, we have said goodbye to Reghan Foley, one of

our Clinical Research Fellows. She has been involved in a Congenital Muscular Dystrophy project and has become popular with colleagues and many of our patients because of her passion, warmth and hard work. She has left us this goodbye message:

'It has been a great privilege to have been part of the Dubowitz Neuromuscular Centre clinical and clinical research teams these past two years, and I am most grateful to the Muscular Dystrophy Campaign for providing me with this opportunity by funding my clinical research fellowship here. To have had the opportunity to meet and care for such a wonderful group of patients has truly been an honour. You and your families have certainly taught me volumes about your conditions and have inspired me with your courage.'

As I return to the United States where I will continue to care for patients with neuromuscular disorders, you can be sure that I will be thinking of you and all that you have taught me. You can also be sure that I look forward to hearing updates from the fantastic Dubowitz Neuromuscular Centre Team on how you are doing.'

Muscle project news

Education pack

The Care Advisor has been giving out questionnaires in clinic with the idea of looking at producing an education pack for to provide to parents and education providers for children with neuromuscular disorders. After initial analysis it looks like this would be a welcome tool to improve the experiences of children in school especially at the beginning of

their education. More than a third of respondents felt that their children's education provider did not have a good understanding of their needs. At primary school level this figure was higher and up to 45 per cent of parents felt that their children's schools did not have a good understanding of their needs. The next step is for an education pack to be produced and more news about this will follow in future editions of the newsletter.

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

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