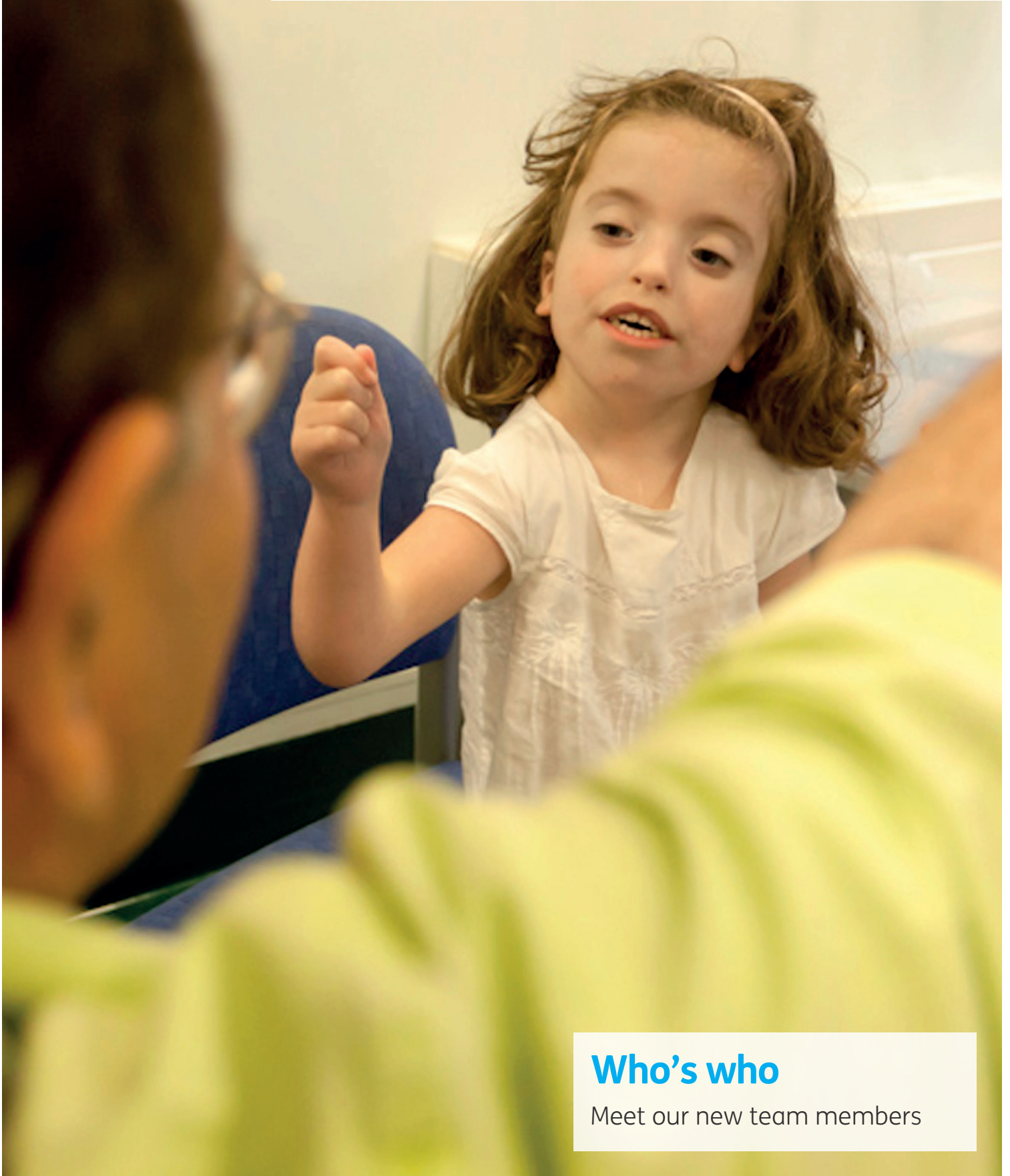


# Musclemania

Autumn 2013 Issue 9



## Who's who

Meet our new team members



# Who's who

Meet the new members of the Neuromuscular team at Great Ormond Street Hospital (GOSH).

Feature  
article



**Rob Brown**  
Social Worker  
Rob spent 13 years at the Princess Margaret Hospital for Children in Perth, Western Australia. As the only children's hospital in the state that provided a tertiary paediatric service, Rob understands the challenges facing children and families who are coping with lifelong and life-limiting conditions. He moved to the UK in 2008 and has worked for three local authorities before joining the Neuromuscular team at GOSH.

**Kate Waters**  
Family Therapist  
Kate has many years of experience in family therapy and joined the team in April 2013, working part time. Kate is a member of the new Psychosocial team, which includes a Social Worker (Rob Brown) and hopefully a part-time Psychologist in the future.



**Mindy Chana**  
Clinical Respiratory Physiologist  
Mindy graduated in Medical Physiology in 2010 and gained experience in respiratory physiology as a Pharmacy Assistant and Research Assistant for the Portex Respiratory Unit at GOSH. Mindy joined the Neuromuscular team earlier this year and carries out lung function tests on children during clinics.

**Vasanth Gowda**  
Locum Consultant  
Vasantha studied medicine at Bangalore University, India, before completing her general paediatric training in the UK. Having finished her paediatric neurology grid training at the Oxford Deanery, Vasantha joined the Neuromuscular team at GOSH as a Clinical Fellow. She continues as a Locum Consultant.



**Anna Schugal**  
Neuromuscular Fellow  
Anna qualified as a General Paediatrician in Germany and came to GOSH in 2009 to start her paediatric neurology training. Most recently, Anna has been working in the Neuromuscular department at the Evelina Children's Hospital. Anna returns to GOSH for a 12-month fellowship in the Neuromuscular team.

**Valerie**  
Volunteer  
Valerie has joined the team on Wednesdays as part of a King's Fund project. She aims to help families navigate various hospital tests and procedures, including blood tests, ECHOs and DEXA scans. Valerie also aims to keep parents informed about when doctors will be available to see their child. We hope parents find her helpful and welcome any feedback.



# Who can help and how?

There are lots of different roles in the Neuromuscular team, each offering different kinds of support. Here, we outline how different staff members can help. The details below aren't exhaustive, so do ask about any areas you or your child may need help with.



Ruth Barratt



Karen Roberts-Edema

**Clinical Nurse Specialists**  
Ruth Barratt and  
Karen Roberts-Edema

- Ways Ruth and Karen can help:**
- new diagnoses and their implications
  - support during outpatient appointments at GOSH
  - guidance on how to talk to children and young people about their condition
  - advice and support with managing medications for your child's condition
  - information on all areas of your child's condition
  - liaising with local doctors, nurses and school teachers about your child's condition
  - how to manage and cope with ongoing changes in your child's neuromuscular condition
  - help with the co-ordination of your child's care when multiple teams are involved
  - referral to palliative care services and children's hospices

**How to contact Ruth and Karen**  
Monday to Friday, 9am–5pm

**Ruth Barratt**  
0207 405 9200 ext 0517 or bleep 2123  
**Karen Roberts-Edema**  
0207 405 9200 ext 1195 or bleep 0228  
Email: [muscle.service@gosh.nhs.uk](mailto:muscle.service@gosh.nhs.uk)

**Family Therapist:**  
Kate Waters

- Ways Kate can help:**
- helping your family recognise and use your own resources to overcome difficulties
  - supporting you through stresses and worries
  - dealing with a change in function, such as losing the ability to walk
  - how to manage behaviours, for example if your child is struggling to express their feelings

**How to contact Kate**  
Wednesday, Thursday and alternate Fridays  
0207 405 9200 ext 5056 or 5323  
Email: [kate.waters@gosh.nhs.uk](mailto:kate.waters@gosh.nhs.uk)

Kate can also meet with families when they come for outpatient appointments, talk by telephone or arrange to meet at other times.

**Social worker**  
Rob Brown

**How to contact Rob**  
Monday to Friday, 9am–5pm  
0207 405 9200 ext 0529 or bleep 0253  
Email: [rob.brown@gosh.nhs.uk](mailto:rob.brown@gosh.nhs.uk)

Otherwise, ask to speak to Rob during a clinic

- Ways Rob can help:**
- support with a new diagnosis and the emotional and practical implications of this for your child and your family
  - information and/or signposting on all areas of your child's condition
  - putting you in touch with relevant support groups and/or other families in a similar situation as yourselves
  - support at outpatient appointments at GOSH
  - support with emotional and practical issues related to the ongoing changes in your child's neuromuscular condition





# Muscle project news

## Fund Health Foundation project

The Neuromuscular team won the opportunity to work with The King's Fund and the Health Foundation on a project that aims to improve the quality of our Duchenne muscular dystrophy (DMD) service. This has been ongoing for the past year.

The King's Fund 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 and Family-centred Care programme.

Parents, patients, charity groups for DMD and staff have helped us to understand what the experience is of patients and staff in our service.

Our areas of improvement include:

- Communication between GOSH and parents, which includes sending clinic letters out faster, calling families before appointments to confirm attendance, text alert reminders for families and providing more information about patient plan changes on arrival.
- Offering longer appointment times for families.
- Ensuring the right information is in the right place for clinicians, so that patients can be seen in a timely way.
- Introducing a volunteer to help parents and children during appointments.
- Providing privacy screens in the gym, to improve privacy and dignity for children and families.
- Trialing a shared care file for parents of boys with DMD

# Patient registries

## UK Duchenne Registry

The UK Duchenne Registry, which is run by the charity Action Duchenne, was set up to find patients with Duchenne muscular dystrophy for new clinical trials. For more information, contact Angela Stringer on 0208 556 9955 or visit [www.actionduchenne.org](http://www.actionduchenne.org)

## Facioscapulohumeral muscular dystrophy (FSHD)

There are a number of patient registries across the world that collect data on patients with FSHD to help advance the research and development of treatment, therapies and care for all those diagnosed with this condition. For more information and to register in the UK, visit [www.fshd-registry.org/uk](http://www.fshd-registry.org/uk)

## UK SMA (spinal muscular atrophy) Patient Registry

This registry is for patients in the UK and Ireland with SMA. The goal of the registry is to quickly identify suitable patients for clinical trials, inform patients about new treatments that might be relevant to them and give scientists important information about SMA. For more information and to register, visit [www.treat-nmd.org.uk/registry](http://www.treat-nmd.org.uk/registry)

## The UK Myotonic Dystrophy Patient Registry

This national registry is for all patients in the UK who are affected by myotonic dystrophy type 1. The aim of the database is to help advance the research and development of treatment, therapies and care for all those diagnosed with myotonic dystrophy. For more information and to register, visit [www.dm-registry.org/uk](http://www.dm-registry.org/uk)

## Congenital Muscular Dystrophy International Registry (CMDIR)

The CMDIR was created by the patient advocacy group Cure CMD to identify patients with congenital muscular dystrophy (CMD) on a global scale. This information is used to raise awareness, improve standards of care, accelerate clinical trials and work towards finding a treatment or cure. People with all forms of CMD can register. For more information and to register, visit [www.cmdir.org](http://www.cmdir.org)

## Global FKRP (fukutin-related protein) registry

The Global FKRP Registry is an international database of genetic and clinical data about people affected by conditions caused by mutations in the FKRP gene.

These include limb girdle muscular dystrophy type 2I (LGMD2I), and the rarer conditions of congenital muscular dystrophy (MDC1C), muscle eye brain disease and Walker-Warburg syndrome. The information collected will help to identify patients suitable for clinical trials and allow them to participate more easily. For more information and to register, visit [www.fkrp-registry.org](http://www.fkrp-registry.org)

## Myotubular and Centronuclear Myopathy Patient Registry

This international database records information about patients with these conditions. The aim of the database is to help identify patients for relevant clinical trials, encourage further research into these conditions, provide researchers with specific patient information to support their research and offer up-to-date information to health professionals to help them deliver better standards of care for their patients. For more information and to register, visit [www.myotubulartrust.com](http://www.myotubulartrust.com)

Leaflets for all registries are available in clinic.

If you have any ideas for future issues of Muscle Mania, or would like to share your story, please get in touch...

Email: [muscle.service@gosh.nhs.uk](mailto:muscle.service@gosh.nhs.uk)  
Tel: 0207 405 9200 Ext: 0529