

Great Ormond Street Hospital for Children NHS Foundation Trust

Clinical Nurse Specialists (CNS)

Monday to Friday, 9am-5pm

Ruth Barratt

Tel. 020 7405 9200 Ext 0517 or bleep 2123

Karen Roberts-Edema

Tel. 020 7405 9200 Ext 1195 or bleep 0228

Email: <u>muscle.service@gosh.nhs.uk</u>

OUT OF HOURS / WEEKENDS URGENT CONTACT:

In an emergency use local A&E Local Doctors can contact: Neurology Spr On-Call at GOSH: 0207 405 9200

Ways the CNS can help:

- Any medical issues
- 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 on-going 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 or other services

Social Worker/Care Advisor

Monday to Friday, 9am-5pm

Ruth Haslett

Tel. 020 7405 9200 Ext 0529 or bleep 0253

Email: ruth.haslett@gosh.nhs.uk

Otherwise, ask to speak to Ruth during your appointment.

Ways the Social Worker/Care Advisor 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
- Advocacy support in for example, education and housing needs and adaptation
- Support with emotional and practical issues related to the on-going changes in your child's neuromuscular condition



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Family Therapist:

9am-5pm Wednesday, Thursday and alternate Fridays

Kate Waters

Tel. 020 7405 9200 Ext 5056 or 5323

Ways the Family Therapist 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

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

Secretaries to Consultants:

Monday to Friday, 9am-5pm

Tel. 020 7405 9200 Dr Robb's/Dr Sarkozy Ext 0632 Dr Manzur Ext 0338 Prof Muntoni/Dr Quinlivan Ext 5849

Ways the Secretaries can help:

- Enquiries about follow up appointments
- Enquiries about clinic letters
- Questions for consultants for example about test results

Clinic Coordinator:

Monday to Friday, 9am-5pm

Tel. 020 7405 9200 Ext 1132

Ways the Clinic Coordinator can help:

- Booking Patient Hotel
- Any queries about appointments
- Booking Transport
- Booking Interpreters