



Network Clinical Leads Update



Adult Neuromuscular Services in BNSSG, BANES, Somerset, Glos & Wilts Dr Andria Merrison, Consultant Neurologist

I have recently taken on the role of Chair and Clinical Director of the SW Neuromuscular Network. We are working closely with commissioners to improve clinical services for people living with neuromuscular disease in the South West so that we can provide specialist patient-centred care, near to where you live, in an accessible and equitable way. The network's ethos crosses traditional boundaries of health and social care and seeks to work across organisational divides.

With the team in the North of the region, I will continue to provide clinics for adults with neuromuscular disease in Bristol, Gloucester and Taunton. This includes transition clinics for young adults and joint clinics with the respiratory team in the Bristol Royal Infirmary. I'm pleased to say that we now have a full team of neuromuscular specialists working across the South West (see page 4 for staff update) who will be working closely with your local healthcare providers.

We will aim to keep you updated on developments via this twice yearly newsletter, our events (see page 2 for next event) and our new website: www.swneuromuscularodn.nhs.uk. We would encourage you to take part in our occasional surveys (see page 3), as your views are essential in helping us develop a service that meets your needs now and into the future.



Adult Neuromuscular Services in Devon, Cornwall and Isles of Scilly Dr Elizabeth Househam, Consultant Neurologist

I'm really excited to be developing neuromuscular services in the South of the region with my Network colleagues. The recent recruitment of two Neuromuscular Advisors and Adult Physiotherapist is going to have a really positive impact for people in Devon, Cornwall and Isle of Scilly. The whole team will continue to provide support for patients and we aim to deliver regional workshops and events to support you in managing your neuromuscular condition. We hope you can get involved in helping us shape services in the region.

Paediatric Neuromuscular Services SW Wide



Dr Arni Majumdar Consultant Paediatric Neurologist

Dr Kayal Vijayakumar Consultant Paediatric Neurologist



We want the SW Neuromuscular Network to go from strength to strength and become one of the premier Neuromuscular networks in the UK. It should be a shining example of excellent practice and care delivered close to where patients live. Our ultimate goal will be to show that outcomes in paediatric neuromuscular disorders can be improved. We will collaborate with cutting edge researchers to deliver better care and outcomes for patients and their families and bring access to clinical research trials into the SW. We want the service to be an example of successful collaborative working between Trusts, commissioners and patients and show that we have achieved our objective of better survival in neuromuscular conditions with better quality of life and better attainment of potential for all patients and families affected by neuromuscular conditions alike. We want you to feel proud of the South West Neuromuscular Network and feel part of its success.

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A Day in the Life of a Specialist Paediatric Physiotherapist

Bev Toms, Specialist Paediatric Physiotherapist, Bristol Royal Hospital for Children

I am based at the Bristol Royal Hospital for Children and work two and a half days a week. I only treat children and young people with neuro-muscular conditions. Today is Monday, my longest day.



At 8 am I have my yearly appraisal with my manager. I set objectives for the coming year; focusing on improving patient care and service development. I then pop on to the ward to see one of my children who has just had scoliosis surgery and I arrange to see him with the in-patient physiotherapist tomorrow.

Then I have a 45 minute drive to see a young man at home who recently broke his leg. I meet his community physiotherapist and we treat him together. We teach him and his dad some exercises he can do until his next physiotherapy session. I drive back and e-mail his head teacher to update him on progress.

I check phone messages and new e-mails; around 30 today. I answer the urgent ones and flag the rest for later. Several e-mails are from community physiotherapists, some asking for advice; for example, one asks for information about a very rare neuro-muscular condition that they have not encountered before. I send some information and suggest we assess the child with the condition together. I have a telephone message from another therapist asking for advice for a patient whose spinal curve [scoliosis] has worsened and is in discomfort. I contact the orthopaedic surgeon and we arrange to see him in the scoliosis clinic next week.

I collect the notes for today's clinic and review any updates from community physiotherapists regarding the children we are seeing today. Then I head off for the pre-clinic meeting with the two paediatric neuromuscular consultants, neuromuscular advisor and secretary. We discuss the children in today's clinic, as well as any other children we need to discuss as a team and plan future clinics. I haven't had time for lunch yet, so eat it during the meeting!



I see four children today in clinic for assessment and advice. Each has around 45 minutes with me, and then sees the consultant and neuromuscular advisor. The first child comes with her parents and community physiotherapist too; this is something I really welcome as I do think it is helpful for everyone. Clinic finishes around 4.30pm.

Back in the office I send some secure e-mails to the physiotherapists who couldn't attend clinic today, updating them with the main findings and recommendations made today for their patients. I dictate the clinic letters for typing and then write an exercise programme for a child I have just seen and post it to his parents.

I contact one of the speakers for a respiratory conference I am organising and answer an e-mail from the lead researcher of a Hydrotherapy Research Project for boys with Duchenne Muscular Dystrophy that we are hoping to be involved in. I get the notes ready for our transition clinic tomorrow; this is a clinic we do together with the adult neuromuscular team for older children before their transfer to adult services.

It's now 5.45 pm; time to get the bus home.

Once home I spend half an hour helping my youngest son with his homework and try in vain to get the older one to finish his computer game! Then it's time for tea which, thankfully, on Mondays, my husband cooks!

Under duress the kids wash up, while I sink in to the sofa with a cup of tea and a Garibaldi!

Today has been particularly hectic, but hopefully it has given you a small insight in to a day in the life of a children's neuromuscular physiotherapist!

Independent Living Day

Wednesday 15 July 2015 at [Fry Club & Conference Centre](#), Keynsham, Bristol

Following on from a similar event held in Devon in 2014, the SW Neuromuscular Network is holding a FREE event for adults living with Muscular Dystrophy, or a Neuromuscular condition, in Bristol and surrounding counties. A full programme is in development. We hope to provide workshops on:

- Accessing financial advice and support
- Housing adaptations
- Living well with a muscle disease
- Exercise and healthy lifestyle

Along with information stands on:

- Independent Living
- Driving Assessments
- Local leisure facilities/disability sports
- Accessible tourism
- Muscular Dystrophy Campaign
- and more

To register to attend please complete visit: <https://www.eventbrite.co.uk/e/independent-living-day-for-people-with-a-neuromuscular-condition-tickets-16050995961> or call Sharon on 0117 41 41184.

In Focus!

Health & Social Resources

Here at the Neuromuscular Network, we want to provide you with as much information as we can about local, regional and national resources for you, to support you in your daily life. In this edition we are focusing on Health and Social welfare and you will find below some useful links that you may want to look at more closely. Don't forget, your Neuromuscular Advisor is around to provide advice on services in your region whenever you need them.



The Family Fund is a UK-wide charity, that supports families on a low income raising a disabled or seriously ill child with grants. In 2013/14 the Family

Fund was able to support over 68,500 families with £33 million in grants for essential items such as washing machines, sensory toys, family breaks, bedding, clothing and computers.

More information about the Family Fund, including how to apply, can be found by visiting www.familyfund.org.uk or joining the conversation on Facebook – www.facebook.com/familyfund or Twitter www.twitter.com/familyfund.



**Compass
Disability
Network**

Compass Disability is a Network of disabled people, their carers and support organisations which operates in Somerset to improve access and inclusion to services and facilities. Their recent event in September 2014 saw a record number of visitors and over 100 stands!!

Members have an opportunity to participate in consultations to give their views on a range of issues that are important to them. To find out more, call 0330 3330089 or visit:

www.compassdisabilitynetwork.org.uk/



**DEVON Parent Carers'
Voice (DPCV)**

DPCV is an independent, parent-led organisation which helps parents and carers of children with additional needs have a say in improving services. They also assist in helping families find the services they need, with links to professional contacts to help accessing support faster. It is the recognised representative of parents and carers to the local authorities, service providers and charities working with children and young people across the county. To join, or for more information call 07975 506069 or visit: <https://www.devonparentcarersvoice.org/>

Sibs

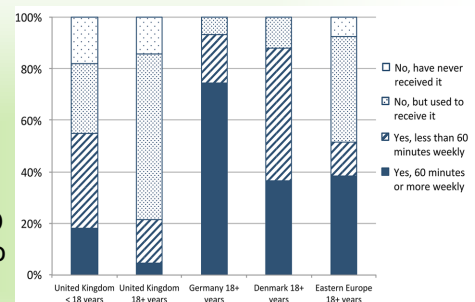
Sibs is the only UK charity representing the needs of siblings of disabled people, recognising that siblings also have a lifelong need for information and want to have positive relationships

with their disabled brothers and sisters and to have a role in future care. Sibs works with siblings of all ages, as well parents and service providers, to offer support, training and information. For more information or to get involved with activities and workshops, call 01535 645453 or visit

www.sibs.org.uk/

Help us review Physiotherapy and Hydrotherapy Services in the South West

Physiotherapy and hydrotherapy (or exercise in water) can be a vital component in keeping people with a neuromuscular condition mobile and active to enjoy a healthy life. We know that these services are readily available for children, but when transferring to adult services (although there is now access to Specialist Physiotherapists through the Network), it can be more difficult to access this type of support locally. A recent paper comparing the UK with other European countries entitled "[Adult Care for Duchenne MD in the UK](#)" reported that 64.3% of adults with Duchenne MD received physiotherapy prior to 18 years of age, but after turning 18 they no longer received it. The SW Neuromuscular Network would like to ask all our adult (aged 18+) service users (no matter what your condition) about your experience of accessing physiotherapy and hydrotherapy. Whether you already access these services or not, we would be really grateful if you could complete a short on-line survey so we can find out what is available and where there are gaps that we may be able to improve. Visit: <https://www.surveymonkey.com/s/SWNODN001>. If you are unable to access this on line, please call 0117 41 41184 and we can either send you a postal survey or go through it on the phone with you.



Other News!

Muscular Dystrophy UK

Fighting muscle-wasting conditions



MD UK Support Groups

Muscular Dystrophy UK has recently scheduled

their Muscle Group Meetings which are aimed at providing support and opportunities to meet others with similar issues and to socialise. The meetings will take place on 28 March in Plymouth followed by 9 May in Bristol. Further details can be found on the MD UK website here:

http://www.muscular-dystrophy.org/get_involved/campaigns/campaign_muscle_groups/1465_south_west_muscle_group

If you would like to attend the meeting, or for more information, please contact Jonathan Kingsley on 020 7803 4839 or e-mail j.kingsley@muscular-dystrophy.org

New Name for the Muscular Dystrophy Campaign

Muscular Dystrophy UK

Fighting muscle-wasting conditions



As of Monday 23 February 2015, the Muscular Dystrophy Campaign will become **Muscular Dystrophy UK**. They will shortly be launching their new website at www.musculardystrophyuk.org which includes their new **Neuromuscular Hub** detailing neuro-muscular services across the UK.

Sad Farewells

We said sad farewells to:

- Dr Sadie Thomas-Unsworth, Specialist Clinical Psychologist in Bristol
- Jane Kinney, Network Coordinator
- Jessica Romero, Dr Arni Majumdar's Medical Secretary at the Bristol Royal Hospital or Children

They all contributed a great deal to the development of the Network and we wish them all the best in their new ventures.

Cornwall - Specialist Physiotherapist



Janet McCay joined the Network in December 2014. She will be based at Camborne Redruth Community Hospital and will provide a specialist physiotherapy service for adults in Cornwall as well as providing a training resource for local physiotherapy teams.

Janet's contact details:

e-mail is janet.mccay@pch-cic.nhs.uk

Tel: 01209 318106.

Working days: Tuesdays and Wednesdays.

Over the Wall Camps for Children

Over the Wall is a UK children's charity that provides FREE residential activity camps for children aged 8-17 who are living with the challenges of a serious chronic illness. They offer opportunities to children with a wide range of diagnoses and are keen to reach out to more children with Muscular Dystrophy and other muscle diseases. They also run Sibling Camps and Family Camps. To find out more visit www.otw.org.uk or telephone Hayley: 07818 424 850 or e-mail: info@otw.org.uk.



Laugh Club for Parents and Carers of Specials Needs Kids

It is said that laughter is the best medicine, which is why the Laugh Club at Riproar Comedy in Bristol was set up in partnership with Bristol Autism Support. Laugh Club is pan-disability, pan-charity and a non-profit event.

To find out more visit:

<https://www.eventbrite.co.uk/e/laugh-club-daytime-comedy-show-for-comic-relief-tickets-15760269390> or call Riproar Comedy on 0117 985 6767

Bristol - Specialist Clinical Psychologist

Joining the Bristol adult neuromuscular team at the end of April, **Dr John Ashworth** will be part of the multi-disciplinary team based at Southmead Hospital, Bristol. He will take forward the work started by Dr Sadie Thomas-Unsworth and collaborate with his colleague, Dr Craig Newman, in Plymouth to provide a valuable and equitable service for patients across the region.

Devon and Cornwall - Neuromuscular Advisors

We are delighted to inform you that we now have Neuromuscular Advisors based in Derriford Hospital, Plymouth with Dr Liz Househam.

Clare Stayt joined the Network in January. She will be providing support and advice for children and adults in Devon. Clare has a background in Occupational Therapy and has worked with adults in and around Plymouth for the last 18 years; most recently within a Community Therapy Team providing rehabilitation and assisting people to manage long term, complex conditions. Contact: clarestayt@nhs.net or 01752 432912.

Tamara Eaton joined the Network this month. She will be providing support and advice for children and adults in Cornwall. Tamara brings a range skills from her training as a social worker and as an advisor within the social housing sector. She joins us from the Stroke Association's national helpline, where she provided a variety of information, guidance and support to people affected by stroke. Contact: tamara.eaton@nhs.net or 01752 432911.