



# Neuromuscular News

## Welcome from Network Clinical Lead

September 2014  
Issue 1



Dear Network members,

It is a pleasure indeed to be able to write this introduction at all. Approximately a year ago, the situation was entirely different as the service was going through an enormous change. I didn't even know if, after the changes had all occurred, we would be a viable entity after all. I am, however, now able to say with some pride that this network has come through the changes in very good shape indeed. We are now an Operational Delivery Network (ODN), one of five in the South West, under the auspices of the NHS England. This gives us a scope we didn't have before and I am happy to say that we are now in a position to deliver what had been promised; a better and more equitable service for those with neuromuscular conditions near where they live.

Some of the other notable highlights that have happened in the last year include the appointment of new Network staff - see our Who's Who section overleaf, and the imminent release of a new Network Website. In addition to this we have started some initiatives such as Transition workshops and Members days, so watch out for future Network communications to keep updated on forthcoming events near you.

The Network does depend very strongly on your participation and we currently hold information on approximately 1500 people with neuromuscular conditions in the South West. However, our models suggest we are only capturing approximately a third of all the neuromuscular patients that are out there, so we will continue to work hard to improve and update our Network database and statistics.

Finally, as a Paediatric Neurologist, I am very keen to introduce the benefits of research and forthcoming genetic treatments to the South West. I strongly believe that what we can achieve here can be applied successfully to the rest of the UK and in this respect we have the support of the Muscular Dystrophy Campaign.

I hope you enjoy reading this newsletter.

Dr Anirban Majumdar



## Website Launch



We are currently designing our new-look website, which will be a fantastic resource to find out more about the Network. Not only will there be a section keeping you up to date with news and activities happening in the Network, but also further details of the clinics we run in the South West and the staff you can expect to meet. We are designing the site to be a really valuable source of information so that patients, their families and carers, and the general public can learn more about Neuromuscular conditions and the support that is available. There will also be information on how to register with our Network Mailing List, and ways in which you can become more involved in our Network activities!

We are also planning a dedicated professional and clinical section, which will be very useful if your general practitioner or health workers would like to learn more about what we do and how you can be supported.

It's a very exciting project and we are really looking forward to sharing this with you.....Launch Date scheduled for November 2014!!

[www.swneuromuscularodn.nhs.uk](http://www.swneuromuscularodn.nhs.uk)



## Who's Who?

Our Network is committed to providing a world-class service for people with a neuromuscular condition living in the South West, and we have maintained a dedicated team of professionals to help support you whether you are in a Hospital Clinic, in the Community or in your own home. You may already have met some of the team, but there are also a few new faces to introduce:

### Neuromuscular Consultants

Dr Anirban Majumdar & Dr Kayal Vijayakumar - Consultant Paediatric Neurologists, Bristol Royal Hospital for Children

Dr Andria Merrison - Consultant Neurologist, Southmead Hospital Bristol

Dr Liz Househam - Consultant Neurologist, Derriford Hospital Plymouth

### Neuromuscular Advisors

Elaine Burrows & Ann Morgan - Neuromuscular Advisors, Southmead Hospital Bristol

*Neuromuscular Advisors for Devon and Cornwall will be in post very soon*

### Neuromuscular Physiotherapists

Nikki Doran - Neuromuscular Physiotherapist, Southmead Hospital Bristol

Bev Toms - Paediatric Neuromuscular Physiotherapist, Bristol Royal Hospital for Children

Claire Eddy - Paediatric Neuromuscular Physiotherapist, Royal Cornwall Hospital

Claire Frimpong-Ansah - Paediatric Neuromuscular Physiotherapist, Plymouth Child Development Centre

Vicky Farrell - Neuromuscular Physiotherapist, Peninsula Community Health

Geraldine Goldsmith - Neuromuscular Physiotherapist, Mardon Neuro-rehab Centre, Exeter

### Neuromuscular Psychologists

Sadie Thomas-Unsworth - Specialist Clinical Psychologist, Southmead Hospital Bristol

Craig Newman - Specialist Clinical Psychologist, Derriford Hospital Plymouth

### Neuromuscular Coordinators

Sharon Standen & Jane Kinney - Neuromuscular Coordinators, Southmead Hospital Bristol



## What next?

We are releasing two newsletters each year to keep you updated on our Network activities - one in January to welcome in the New Year, and a further mid-summer edition in July. These will include exciting news items that we think you'd like to hear about, as well as a couple of regular slots from our Network colleagues, for example:

### Focus On.....

Our Network staff work closely with a variety of different disciplines to help support you in all aspects of your care, including our Respiratory, Cardiac and Genetic colleagues. In each edition, we will focus on the latest developments in one of these areas, providing input and insight into what is happening in other services.

### Meet the Team.....

So, what sort of things do the Network team do? If you've ever asked that question, then you're in luck: we will be chatting to different staff members in our Newsletters to get an understanding of what working for the Network entails, getting a deeper insight into each staff role.



## Coming up.....

### In the Network

- **Transition** - the transfer from children's to adult services can be a daunting time for families. We are investigating ways to streamline this process as much as possible in our clinical teams.
- **Living with Muscle Disease** - It is often difficult to adapt to living with a long-term neuromuscular condition, or a new diagnosis. We are looking at methods of helping our patients adjust to the challenges they may face.
- **Patient and Family Events** - we have always had great feedback from our patient and public events, so over the coming months we will be planning future Neuromuscular Information Days and getting some dates in the calendar.

### National/Regional Events

- **MDC National Conference** - Run by the Muscular Dystrophy Campaign on 18 October in the Hilton Hotel, Coventry. Further information can be found on the website [www.muscular-dystrophy.org/how\\_we\\_help\\_you/care\\_events/7325](http://www.muscular-dystrophy.org/how_we_help_you/care_events/7325)

## Have Your Say

Here at the South West Neuromuscular Network we are striving to provide the best possible resource we can, involving members and their families in shaping the services they access.

We are always keen to hear your comments or suggestions for our Newsletter, so if you have an idea for a news story or event, or just want to share your experiences with us, we would love to hear from you.

Please email the team: [nbn-tr.neuromuscular-odn@nhs.net](mailto:nbn-tr.neuromuscular-odn@nhs.net)

or write to us at the address below:

South West Neuromuscular Operational Delivery Network  
Dept of Neurology  
Gate 10, Level 6 Brunel Building  
Southmead Hospital BRISTOL BS10 5NB



## Data Validation Form

We are obliged to make sure our contact details for you are regularly maintained and kept up to date. If any of your details have changed in the past year, we would be grateful if you could complete the form below and return to us at the Network. Alternatively, these details can be sent to our email address (details below).

*Please note that these details are kept secure, accessible only to Network staff for the purposes of informing you of Network activities and events, and improving the services we provide in the South West. We respect your privacy and will not share your information with any third party.*

TITLE:	SURNAME:	FIRST NAME(S):
If child, please provide parent/guardian details:		
DOB:	GENDER:	NHS NO (if known):
ADDRESS:  POSTCODE:		
TELEPHONE:	MOBILE:	EMAIL:
NAME OF CONDITION:		DATE OF DIAGNOSIS:
GP DETAILS (Name, Address, Tel):		

## Network Mailing List

You have received this Newsletter as you have had contact with the South West Neuromuscular Operational Delivery Network. If your preferences have changed, please tick the relevant box below and we will update our records.

I do not wish to receive further updates on the Network activities and events

I do not wish to receive information on Research Projects

I prefer to receive information: By email  By post

 0117 41 41185 / 0117 41 41184

 [nbn-tr.neuromuscular-odn@nhs.net](mailto:nbn-tr.neuromuscular-odn@nhs.net)



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