

## Newsletter of Greater Manchester Neurological Alliance

Volume 6 Winter 2011/12

GMNA's objective is the relief and support of people in Greater Manchester who have neurological conditions, and of their carers. It aims to be a representative and credible channel of communication between commissioners, providers and users, and to encourage users and carers to make their views known.

If you would like to get involved, please contact Yvonne (details overleaf)

**New faces in the office** In Spring we sadly said good bye to Helen Stapleton, our Admin Support worker, as her contract had ended. However, we have been pleased to welcome Sue Lowe and Sharon Simm to our ranks. Sue is the Chair of Manchester Ataxia Group and has volunteered her time once a week. She has special responsibility for our Facebook and Twitter accounts. Sharon is self employed and comes in twice a week to help out with general admin duties. During the summer we were grateful for the help of Chris Lynch (GMNA Trustee) and Rachel Hughes (student volunteer).



Seasons Greetings  
from GMNA



### Success!! PQASSO Award for GMNA

We are really pleased to announce that we have just achieved PQASSO Level 1 and will receive its Quality Mark which is valid for 3 years. We began implementing PQASSO (Practical Quality Assurance System for Small Organisations) two years ago by assessing ourselves against set indicators and we achieved this in July 2009. With the help of an award of £1000 from Salford CVS we were able to progress to the next stage which involved an external assessment. This award shows that our organisation is 'fit for purpose' and will hopefully enhance our credibility which is important when looking for future funding. Special thanks to Sarah Bawden from Salford CVS for all her support and advice.

### GMNA & NHS Reforms

Last year the coalition government launched a white paper detailing radical changes to the NHS. Along with our member organisations and the national Neurological Alliance, we have actively engaged in the subsequent consultations. Our main concerns are the ability of the Clinical Commissioning Groups (CCGs) to commission appropriately for neurology and particularly for rarer conditions and the threat to the continuity and sustainability of local services from the 'choice' and 'any qualified provider' policies. Throughout we have underlined the continued validity and importance of the 11 Quality Requirements of the National Service Framework for Long term Conditions. A further concern is the effectiveness of the proposed monitoring arrangements. Although we are still unsure about the commissioning arrangements for neurology across Greater Manchester, we are about to approach all potential commissioners and providers with information about GMNA's aims, activities and expertise. We hope to raise their awareness of our role and improve our chances of continued funding (which is currently a major concern). *If you have already have a good contact with any commissioner or provider, please ask us for a copy of our special leaflet addressed to them.*

### Trustee Changes



Sue Lowe



Liz Roberts

**Trustees play a vital role in charities since they have ultimate responsibility for the effective and efficient management of the organisation. This year we said good bye and thank you to Margaret Shaw for many years of service and commitment and welcomed two new Trustees. Sue Lowe, Chair of Manchester Ataxia Group, and Liz Roberts, North West Regional Information Officer for the Stroke Association. Both come with a wealth of knowledge and experience and we are very happy to have them on board. Details of all our Trustees can be found on our website.**

**Open meetings** We have held two Open Meetings this year. Our first was in May 2011 and was combined with our AGM. We used this opportunity to share information about the work we had been doing with Salford Royal Foundation Trust (SRFT) around our three wish list items. We presented updated information about the implementation of the 'What You Need To Know Passport' (*more details overleaf*), development of a Rare Conditions Service (details below) and progress towards improved Neuropsychology Services. We have just re-mapped the Neuropsychology services across Greater Manchester and we will continue to press for improvement. Our second meeting took place in Dec 2011 and focused on the NHS Reforms and on Rarer Neurological Conditions. Our main speaker was David Stockdale from NW Specialised Commissioning Team who gave a succinct overview of the proposed changes. We then were fortunate to have personal accounts from a service user with Guillain Barre and a carer/representative from The Encephalitis Society. In addition we were able to update people on the Rare Condition Service mentioned above. This involves some of the Specialist Nurses working on a rota system to support patients with Rare Conditions. This is still a pilot project but we are pleased that SRFT is taking steps to bridge this gap in service provision at the hospital. Presentations available from our website.

## Profile : Ataxia UK

The word "ataxia", comes from the Greek word, "a taxis" meaning "without order". Ataxia is the name given to a group of neurological disorders that affect balance, coordination, and speech. There are many different types of ataxia that can affect people in different ways. This condition unfortunately causes a loss of physical co-ordination due to underlying damage to the nervous system and brain, and can affect every part of the body. This means it can cause a wide range of symptoms such as: difficulty walking, speaking, swallowing (dysphagia), and performing tasks that require a high degree of physical control, such as writing and eating. There are two main types of ataxia; hereditary ataxia: where the symptoms develop slowly over many years and are caused by underlying problems with the genes. Acute ataxia is where the symptoms develop suddenly due to a related trauma, injury or health condition, such as a stroke

Around 10,000 adults in the UK have a type of ataxia. Ataxia UK is currently funding research to find out how many children have the condition – it's thought there are several thousand. Some forms of ataxia are treatable, but in most cases there is still no cure. Funding is ongoing towards a wide range of research projects to try to find treatments that can help ataxia, and ultimately to find a cure.

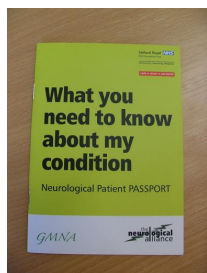
There is a Greater Manchester Ataxia Support Group which meet on the last Saturday of most months.

For more information contact Sue Lowe (Chair) on 0161 683 5538 or email [jaysuelaura390@sky.com](mailto:jaysuelaura390@sky.com) Please also visit [www.ataxia.org.uk](http://www.ataxia.org.uk)

### What You Need To Know Leaflet

#### (WYNTK)

The A6 WYNTK Neurological Passport has been used in Salford Royal Hospital for some time now and we hope that staff on all wards have become more aware of its presence. The Specialist Nurses are beginning to check if their patients have one (eventually an electronic flag system will assist them to do this) and if not are able to provide one. **If you are not offered one then please do ask.** It is hoped that this service will be extended into the A & E Department. Remember that the original A4 version of this leaflet is available for download from our website for all neurological service users. We will continue to work with District General Hospitals to implement a similar service.



### Mobility Issues

**Wheelchair Services in Salford** - GMNA has long standing concerns about the provision of Wheelchairs across Greater Manchester and is using an opportunity to work with the Commissioner at Salford PCT who is also focusing on this issue. There have recently been some improvements to this service and we would like to consult with service users to see if the improvements are working. In the new year we will have some questionnaires ready for individuals to complete. If you have used the Equipment and Wheelchair Service in Salford in the last 6 months and would like to participate in the survey, please contact Yvonne on 0161 743 3701.

**Patient Transport Service in Bury**—A survey of the impact of the changed criteria for access to Patient Transport Services has just started in Bury. Further details and a questionnaire is available on our website.

### Greater Manchester Neurosciences Network Board (GMNNB)

We continue to attend these meetings to ensure that the user voice is heard. We have responded to and commented on the draft documents re Neuro Rehab, participated in the on-going Epilepsy Review which aims to provide recommendations for best practice in Epilepsy care and contributed to discussions on Headache, Back Pain and Medicines Management issues.

#### New Technology

GMNA is trying to keep up with the times by adopting a range of technology to help us distribute our news and information on a larger scale. As well as checking our website for latest information, you can also visit our Facebook page or follow us on Twitter @GMNA1

**Please continue to feedback your views, comments and experiences.**

#### Local Neuro Support Groups

The **Bury, Rochdale & Oldham Neuro Support Group** has adopted a new format since January 2011. We now link with local branch groups across the three areas and ask them to host an occasional meeting for us. This is a really good way for voluntary sector groups to work more closely together as well as allowing us to share resources and information more effectively. The **Neuro Support 4 Salford, Manchester & Trafford** is hoping to adopt a similar format in the New Year. Keep an eye on our website, facebook and Twitter for details of the next meetings.

#### Welcome to our two newest Member Organisations!

**ROBES (Rochdale, Oldham & Bury Epilepsy Society)**  
contact Les O'Shea on 0161 761 7140.

**Bury & Bolton ME/CFS Support Group**—Contact Pam Turner on 01204 793846

We are grateful to

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