

## East Midlands Research Support Network

# Annual Review 2013 / 2014

### Introduction

The East Midlands Research Support Network (RSN) was launched in June 2011 when a Steering Group was set up to get it up and running. It was deemed that that had essentially been achieved so that in September 2013 a newly constituted Steering Group (with largely the same membership) took on the role of **developing** the work.

The membership of the group has changed a little over the year. In particular Tyna Brych, the Parkinson's UK Regional Manager for the East Midlands, took on a substantial role at National Office and delegated the EM RSN work to Harry Wade who began attending Steering Group meetings in order to continue to provide the invaluable support from the Regional Office.

Much of the Steering Group's work has continued to be done by email and telephone but there were 4 physical meetings during the year.



(Hope for Cure, by vitasamb2001; freedigitalphotos.net)

### East Midlands RSN News

Producing the newsletter monthly, or sometimes a little less frequently, has again been one of the main activities of the Steering Group. 10 editions were produced during the year. The year started with Ian Billcliff as editor. He had taken over from Caroline Maxwell while she was indisposed. Unfortunately Ian had to step down from this and also from the Steering Group itself because of other demands and, fortunately, Caroline was in a position by the summer to take over again. Much gratitude goes to Ian who helped us think through some important editorial decisions and keep the publication on its course of continual improvement. You only have to look at previous editions, which can be found on the EM RSN page of the Parkinson's UK web site, to see the wealth of high quality articles in EM RSN News ranging from reports of regional research-oriented events through research matters of regional interest to explanations of topics of global scope.

There is now a large emailed circulation for EM RSN News and it reaches well beyond the borders of the East Midlands region such is the reputation it has achieved. The editor is always looking for contributions from its readers both in the form of articles on topics related to research, comments on what has been published and general views on the RSN and its development. This year the newsletter has featured articles explaining research topics under the heading of 'Lionel's Lessons'

*It's been another busy year for the East Midlands RSN and, thanks to the hard work of the Steering Group, even more people are now informed about research activities and experiences through the newsletter and have had the opportunity to find out more detail at meetings and forums organised locally.*

*The clear and easy explanations of sometimes very complex subjects is a great help to the many of us who don't have a research background - myself included! - and the personal thoughts, experiences and explanations help to de-mystify and humanise some of the challenges that many people with Parkinson's face and questions that they have. Huge thanks to the steering group and to all contributors to the newsletter in particular.*

*Working collaboratively and thoughtfully has been the key to the Steering Group's significant, high quality output and I am really pleased to have been a small part of that again this year.*

Tyna Brych, Head of Local Group Network & Regional Manager - East Midlands, Parkinson's UK

and 'Has this been researched?' Effort has also been put into explaining in accessible language some of the more complex concepts of the science behind the research talked about in the Forums and meetings. We

believe there is an appetite for accounts that go beyond simplistic ones. In a sense EM RSN News is the mirror in which everything we do is reflected. It is the window onto all the other EM RSN activities which will now be described, starting with the activities which have consumed the most joint effort.

### **The Annual Research Forum:**

Derby, 14 September 2013 - 'Towards better Parkinson's Medication'

Reports on this Forum appeared in the November 2013 edition of EM RSN News which said "There were 95 participants and responses to a post-Forum survey were very positive, with an overall evaluation score of 8.8 out of 10 for the value of the information and knowledge gained." ([http://www.parkinsons.org.uk/sites/default/files/emrsn\\_newsletternovember2013.pdf](http://www.parkinsons.org.uk/sites/default/files/emrsn_newsletternovember2013.pdf))

The programme included an overview of Parkinson's research today, examples of current local research, and presentations and a panel discussion on research into better medication. The speakers were Prof Peter Jenner, Dr Nin Bajaj, Lisa Brown, Fiona Lindop, Richard Windle, Prof Ian Stanford and Dr Lucy Annett.

The Forum was made possible by generous funding from the Derby Branch of Parkinson's UK out of the legacy of Mrs Margaret Manester and from the national RSN. We are particularly grateful that the legacy will also cover some of the costs of future Forums.

### **The Researchers Meeting:**

22 March 2014, at Leicester University

This too is becoming an annual event. It is a short meeting – 3 hours – which aims to bring together all the Parkinson's-orientated researchers in the East Midlands so that they can tell each other in some detail about what they are doing and to compare notes and sometimes discuss potential collaborations. A small audience of RSN members who are able to cope with the technical language is invited to sit in. The interaction between researchers and members is one of the features that has been much appreciated. Since the first meeting in 2103, it has been discovered that almost double the number of Parkinson's research projects exist in the region than were previously identified. Some are Parkinson's UK funded and others not and they range from basic science, lab-based projects to applied and socially orientated trials and surveys which involve people as subjects. The report of the March 2014 meeting is in the May edition of EM RSN News at [https://www.parkinsons.org.uk/sites/default/files/emrsn\\_newslettermay2014.pdf](https://www.parkinsons.org.uk/sites/default/files/emrsn_newslettermay2014.pdf) .

In a packed programme, 9 researchers (out of about 13 in the region and maybe more by now) updated us on their projects. There was also a short session when RSN members were able to put their questions to the professionals.

### **Other activities of the Steering Group**

**Fundraising:** The Steering Group has not itself organised fundraising activities but has relied on its members to participate in fundraising activities organised by local branches and groups. Some members have participated in sponsored events notably abseiling (Roger Elkin) and a marathon (Chris Johnson).

**Research meetings:** As well as the first Research Forum that was held in October 2012 and a meeting in March for Parkinson's researchers in the East Midlands, Steering Group members and other research supporters attended the RSN supporters conference in Birmingham in May which gave an opportunity to tell others about what we have been doing in the East Midlands, to learn what has been going on elsewhere and to focus on the theme of the gathering which was 'Developing our Research Support Network'. Also in May was a 'UK together' meeting in Loughborough when Parkinson's UK new research strategy was aired. Earlier, in February, the Newark branch put on a research meeting at which Dr Roger Barker gave an excellent presentation on Parkinson's research and the prospects for efficacious cell transfer techniques.

**Clinical trials:** Several members of the Steering Group have continued to participate in clinical

*I have been to the last two Research Forums in the East Midlands. The value of these meetings is demonstrated by the large numbers attending and the high ratings given to the speakers. This is a great example of what volunteer-led activities, supported by Parkinson's UK staff, can achieve. This is largely down to the work of the small group of people listed at the end of this report. I hope we will be able to replicate these activities in other parts of the country. Meanwhile I'm looking forward to coming back next year.*

Richard Windle, Chair  
RSN Development Team

trials over the last year and others have joined new ones. The national office sends out notifications of trials and studies as they learn of them and we do our best to encourage members to link up with them and to report on their experiences. The Steering Group has also kept abreast of the developments of the AllTrials Campaign and has reported progress in EM RSN News.

**Presentation guidelines and talks on research to branches and groups:** This year we asked each branch and group in the region to request someone from the Steering Group to go to one of their meetings to talk about research and the RSN. We had such a good response that it has not always been possible to get someone along. Yet six such visits were covered. The PowerPoint template document on which the talks can be based has continued to be used and is available (free!!) for anyone to customise to meet their own background and experience and then use it to give presentations across our region. Meeting ordinary members in branches is always a valuable thing to do and we plan to continue the programme especially as it is a way of attracting others to be involved in the work of the RSN.

**Lay Review Panel:** This is at the heart of the charity's research project assessment and funding function. A number of Steering Group members are part of the Panel.

**Lab Visits:** The only project visit organised in the region this year was to the PaMIR project at Nottingham University. This was reported on in the July edition of EM RSN News: [https://www.parkinsons.org.uk/sites/default/files/emrsn\\_newsletterjuly2014.pdf](https://www.parkinsons.org.uk/sites/default/files/emrsn_newsletterjuly2014.pdf) . Visits like this help to strengthen our links with researchers who, in this case have participated in a number of the EM RSN events such as the annual Forum and the Researchers meeting.

**Following and disseminating research progress and new developments:** Again this year the Newsletter has been used to report on developments that have come to our attention. The



*(Neuron, by renjith krishnan: freedigitalphotos.net)*

Research Forum and other meetings provided much of the raw material for informative articles as did the World Parkinson Congress which was held in Montreal at the start of October 2013 which several members of the RSN attended. We are now establishing a convention that each annual Forum includes a presentation on current progress in Parkinson's research.

**Brain Bank:** There is clearly a role for the RSN to encourage people with Parkinson's and others to bequeath their brains to the Parkinson's tissue bank. We made negligible progress, however, in organising a visit to the Parkinson's/MS Brain Bank in Hammersmith. Maybe this coming year...

## Issues

**Finance:** The East Midlands RSN operates without any real budget, requesting financial support from Parkinson's UK and local groups to deliver specific activities. Fortunately the national RSN budget has covered running expenses but we can expect the situation to be more difficult if there is more RSN activity throughout the country. We have been immensely fortunate to have much of the cost of each Annual Forum covered by a generous legacy and it is pleasing that other local branches have been coming forward with offers to make financial contributions for specific events for which we are most grateful.

**The role of the research supporter:** Last year's Annual Report said: "What the Steering Group has achieved is amazing when you consider that the majority of its members have Parkinson's. But, in the long term we can't pretend that this is not a vulnerability." This is still an issue that we must face up to and so we must continue to be on the lookout for new people to work with the Steering Group and to be members of it. We have been fortunate in having a few new people join us during the year or to work on sub-groups organising specific events. It is essential that this is continued. We have endeavoured to create a welcoming atmosphere and to remove any obstacles to enthusiastic members to participate in our work. So if you want to help, do get in touch even if you think you have little to offer. The RSN will continue to thrive if the Steering Group



is refreshed with the help of new supporters even if this is only on a limited or short-term basis. Even if you don't want formally to be a member of the Group, you can help with one or more of the 8 (or more) activities. Email or Phone Lionel ([ljpaulostk@talktalk.net](mailto:ljpaulostk@talktalk.net) – 0116 282 7340) or John ([jntelford@ntlworld.com](mailto:jntelford@ntlworld.com) – 0116 283 4447) for a chat.

This review is a report of the EM RSN as a formal entity. But we must also recognise the efforts of individual RSN members. Many are enrolled in trials – one is involved in initiating a research project; are affiliated to the AllTrials Campaign; fundraise with their local group; do sponsorship feats; go to research open days around the country; attend international conferences; join and campaign with other Parkinson's organisations such as the MJFox Foundation and Parkinson's Movement; donate their brains to the Brain Bank; post items on the Parkinson's UK on-line research Forum; and engage others on the topic of research wherever they meet them. This is the groundswell that, although out of sight, can make a real difference.

### Development of the RSN

During this year the nationally-based RSN Development Team has been taking a more active look at the development of the RSN throughout the country. Also this year, Claire Stephenson has been confirmed as full-time RSN Manager which has provided a much more stable situation following Emily Hughes' having to share her time with being Volunteer Manager which she has now been appointed to do full-time. In addition, John, the EM RSN Steering Group Chair has become a member of the RSN Development Team. Following the successful RSN conference in May, the Development Team has set up three 'Task Groups' (called Steering Groups). We look forward to a lot of progress being made to invigorate research-focussed activities throughout the country as a result of this determined initiative. Gradually more people are being drawn in and we look forward to growing enthusiasm in support of the achievement of better treatments and of that elusive cure.



(Network Definition Magnifier, by Stuart Miles: freedigitalphotos.net)

### Plans for 2014 – 2015

More of the same, really. Without more members joining in the work of the Steering Group we cannot expect the range of EM RSN activities to increase. Nevertheless we are confident that the Newsletter and those events that have become features of the annual programme can continue. We look forward to plenty of support from national office and we look forward to linking with research supporters throughout the country as the RSN develops nationally.

As we contact more people in the region with a growing interest in research, we look forward to engaging them in activities and the organisation of activities. As some of us need to reduce our involvement we look forward to new people taking over and taking the EM RSN further.

### Appendix

The core membership of the Steering Group over the last year:

|  |                           |                         |                        |
|--|---------------------------|-------------------------|------------------------|
| John Telford                               | Chair                     | Maria Rice              |                        |
| Lionel Paulo                               | Secretary                 | Richard Brown           |                        |
| Chris Johnson                              | EM RSN News production    | Roger & Kath Elkin      |                        |
| Caroline Maxwell                           | EM RSN News Editor        | Lynn Bedford            | Forum Organising Group |
| Ian Billcliff                              | EM RSN News Editor (part) | Steve & Jenny Johns     | Forum Organising Group |
| Tyna Brych / Harry Wade                    |                           | Regional staff team     |                        |
| Claire Stephenson (replacing Emily Hughes) |                           | RSN Manager (national). |                        |

All have made important contributions to our activities listed above and to making the newsletter such an excellent publication. The members would not want to blow their own trumpets but working together they have achieved such a lot. Maybe this is through their friendliness and cooperative nature coupled with a commitment to the cause. This is all the more reason why others should have no hesitation in coming forward to join with us!

*This report has been jointly compiled by the Steering Group with final editing by the Chair.*

*John Telford, October 2014*