

## East Midlands

# RSN NEWS

Issue 10 (Nov 2013) from the East Midlands Research Support Network

### **\*\* Special Research Forum Edition \*\***

Welcome to the 10th edition of EMRSN News, which is dedicated to the recent Derby Research Forum. This was a great success and we are grateful to all who helped with the event and to Chris Johnson who oversaw the organisation of the day. His report and summaries of all presentations follow.

By now you will all have received the autumn edition of The Parkinson, with the insert entitled 'Tell Us'. Please, please respond to this, either online or by returning the insert, so that we can ensure research will be going in the direction that you, the members of Parkinson's UK, wish it to go.

Since our last issue, the World Parkinson's Congress has taken place in Montreal, attended by our Chair and other members of the East Midlands Network, together with several members of the Parkinson's team from SpARC. Articles on the highlights of the Congress will appear in our next issue, but a couple of 'Tasters' appear at the end of this edition.

Ian Billcliff, Editor

## Forum Overview

Following a successful first such event in Leicester in October 2012 (see EMRSN News 4), this 2nd Annual Research Forum was held on 14 September 2013 at The Roundhouse in Derby.



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

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.

### Inside this issue:

- [Steering Group](#)
- [Research Overview](#)
- [Latest MRI findings](#)
- [Specialist wards](#)
- [Walking with music](#)
- [Faster better drug screening](#)
- [Repositioning drugs](#)
- [World Parkinson Congress 2013](#)
- [Coming Up](#)

... and much more!



*(Forum key, by Stuart Miles; freedigitalphotos.net)*

Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. A charity registered in England and Wales (258197) and in Scotland (SCO37554)

Under the title 'Towards better Parkinson's Medication', the Forum was intended for people with Parkinson's, their partners and carers, and aimed to be easily understandable without a scientific background.

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. A big thankyou to 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 very grateful for all the support we received and look forward to next year's Forum.

Chris Johnson

## STEERING GROUP

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**Caroline Maxwell**, Daventry,  
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**Maria Rice**, Nottingham

**Ian Billcliff**, Derby

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East Midlands

## Parkinson's Research Today or 'The Windmills of Your Mind'

### Prof Peter Jenner

King's College, London

The presentation opened with two fundamental statements. First, Parkinson's research sometimes tends to be seen as going round in circles, with researchers re-visiting ground they have covered before, as demonstrated by the fact that, although levodopa (L-dopa) was discovered over 50 years ago, it is still the best drug available in the treatment of Parkinson's symptoms and all efforts to improve its effectiveness have proved unsuccessful.

Secondly, the non-motor symptoms of Parkinson's (i.e. those not associated with movement) are often neglected. Parkinson's is a syndrome, not a single condition, and often the non-motor symptoms are more important than the motor symptoms, affecting the quality of life to a greater extent. The whole picture is very complicated, but the main focus of research to date has been on the motor symptoms. The other symptoms need to be investigated as well.



(Prof Peter Jenner, photo: D. Worthy)

When L-dopa was first discovered it was given to Parkinson's patients in large doses, causing side effects in a very short time and leading its effectiveness to 'wear off' quickly. This led to dopamine agonists being used in the early treatment of the condition, but treatment has now reverted back to using L-dopa in low doses in the early treatment regime because dopamine agonists are less clinically effective and a number of clinical trials have shown that L-dopa is the best drug to treat Parkinson's, if used carefully and in low doses

initially – again going round in circles. New preparations of L-dopa are coming out that seem to give a longer period of benefit than those that have so far been available.

The brain is a network of chains and if one part of the chain is broken it has a knock-on effect on all other nerves further up the chain. So, if dopamine-producing cells are knocked out, it alters the activity of a number of other chemicals in the brain and if these chemicals are involved in the control of movement, it gives researchers an opportunity to manipulate another system in the brain, other than dopamine, to try to find a new class of drug to treat Parkinson's. Researchers are therefore very busy working on this at the moment, a non-dopaminergic approach to the treatment of Parkinson's.

The pathology of Parkinson's is widely diverse, affecting different people in different ways and researchers are now starting to identify different subsets of patients, each with a particular dominant symptom. Age is the most important factor for the onset of Parkinson's, but researchers are starting to understand that medical histories may be useful in determining groups of people who may be at risk of getting the condition. There is also a much more balanced approach being taken in the treatment of Parkinson's, looking at each patient as an individual and deciding which is the most appropriate treatment to use for that patient.

Looking at statements about different dietary factors affecting the onset of Parkinson's, Prof Jenner described this as rather 'soft science', but said that there is fairly hard evidence that exercise does affect the survival of dopamine producing neurons.

Ian Billcliff

## Latest findings on MRI of Substantia Nigra and New Study for Tracking Parkinson's

### Dr Nin Bajaj

National Parkinson Foundation Centre of Excellence, Derby & Nottingham

The aim of this work is to use recent advances in Magnetic Resonance Imaging (MRI) to provide biomarkers that are useful in the clinical assessment of Parkinson's and to use these biomarkers to track the progression of the condition in a small group of patients with early signs of the disease. This is an emerging field, with limited and sometimes controversial findings. To overcome this, the team working on the project plan to collect a large amount of MRI data from 300 people with early PD; these will be divided into 100 healthy controls, 150 with the condition and 50 who will be re-scanned after 18 months to assess progression.

Nigrosomes are parts of the substantia nigra that are highly vulnerable to dopaminergic cell loss in PD and 5 nigrosomes have been identified. In people with Parkinson's 98% of dopamine producing cells have been lost in nigrosome 1, the loss in each nigrosome successively reducing and being least in Nigrosome 5. Cell loss is extensive, even in early PD, with, for example 75% to 82% loss in someone with a 7-year duration of the disease, but although the nigrosomes shrink, they are not absent.



(Dr Nin Bajaj; photo: D. Worthy)

Dr Bajaj showed a number of slides demonstrating the difference in scans of particular parts of the substantia nigra between Parkinson's patients and controls and showing the differences in levels of nigrosome 1.

The conclusion from this work is that high resolution MRI can spot nigrosome 1 and that the absence of nigrosome 1 in a scan could prove useful in developing a neuroimaging diagnostic tool for Parkinson's.

Ian Billcliff

## The Value of Specialist Parkinson's Wards

### Lisa Brown

Parkinson's Nurse Specialist, Derby

In EMRSN News 7 we reported on Dr Robert Skelly's work in setting up a Parkinson's unit on one of the general wards in the Royal Derby Hospital. Lisa Brown's presentation covered the Prospective Study on the question of whether a specialist unit improves the outcome of patients with Parkinson's during and following a stay in hospital.

The study started with a focus group, which involved patients, carers, researchers and doctors in the design of the study. This helped to ensure that everyone involved was supportive of the idea and was in agreement about the objectives of the study and clinical measurements necessary to achieve these. It also ensured that the study reflected patients' needs and was 'patient friendly'.

The core features of a specialist unit were identified as being:

- mandatory staff training
- care to be led by a geriatrician with specialist training in Parkinson's
- an enhanced stock of Parkinson's drugs to be held on the ward
- ward staff to use Parkinson's management guidelines
- regular multidisciplinary meetings to be held
- enhanced access to specialist Parkinson's therapists, the specialist Parkinson's nurse and movement disorder neurologist
- self-medication to be encouraged where possible.



(Lisa Brown; photo: D. Worthy)

The clinical measurements included in the study centred on medication, length of hospital stay and patient experience / satisfaction and the basic stages of the study were:

- collect "before" data on patients over a 3 month period
- conduct thorough staff training in the care of Parkinson's patients
- collect "after" data on patients over a 7 month period.

Data was collected on 20 patients before the introduction of the specialist care and 24 patients afterwards, the median age of patients involved being 81 in both cases, although at differing stages of the condition in both cases. The first thing to note was an improvement in the receipt of medication by patients in the 'after' group, both in terms of accuracy and time of taking the medication, with a corresponding reduction in prescription errors. There was also an apparent reduction in the length of stay in hospital in the 'after' group and a significant improvement in patient 'experience' or satisfaction.



There were some difficulties getting Parkinson's patients admitted to the specialist ward, due to pressures on bed availability and some difficulties were experienced on occasion in conducting the necessary measurements. In addition, everyone involved was aware that the trial was in progress, so there was the potential for some bias in the results. However, the general outcome of the trial was positive. The reduction in length of stay in hospital was felt to be of borderline significance on this one trial, but if the results could be confirmed and replicated over other hospitals there is the potential for considerable cost savings.

It is proposed to conduct a larger trial to confirm the findings of this pilot trial, including an evaluation of the cost-effectiveness of such specialised wards. So, watch this space!

Ian Billcliff

## Walking with Music

### Fiona Lindop

Specialist Physiotherapist in Parkinson's, Derby

This was a very interesting presentation, discussing the possibility that walking to music could be very helpful in improving the mobility of patients with Parkinson's.

Fiona discussed the fact that mobility skills are not very good in a large number of Parkinson's patients, especially with regard to tripping and falling. It is well recognised that Parkinson's patients are affected in many ways, such as festination (taking only tiny steps), freezing and feeling as though the top half of the body is still going whilst the rest of the body has stopped. This is because the person's automatic pilot has been affected and can also result in tremor, rigidity and postural instability.

All these factors can affect a person's confidence in performing tasks and also leads them to not want to go out in case they fall. Multi-tasking is difficult and other effects are depression, fatigue and apathy, all making life difficult for the patient.

Cues and strategies can be used to counteract these effects; for example, it is known that the element of surprise by shouting "BIG STEPS" behind a person struggling to move is often all that is needed to help them get moving again. Patients are encouraged not to do more than one task at once if they are having difficulty and some patients need visual clues in the house to help them walk through doorways etc.



*(Fiona Lindop, photo: D. Worthy)*

In this project, Fiona is particularly looking at the use of music to help patients get moving more easily. One patient in a 'Time and Go' test reduced the time taken to perform the test from 92 seconds, when not listening to music, down to 34 seconds when listening to music. Also, when 2 patients were tested turning through 180 degrees, the number of steps taken was reduced by between 40% and 60% when the patients started listening to music.

A video was shown of one patient who had lost all confidence and was walking in a very slow and laboured manner; she found walking to the local shop very difficult as a result. However she had found that if she plays certain music through her ear phones her personality and mood changes and she is able to walk with confidence. The video showed

her doing this, turning around on the spot with no difficulty and even skipping to the beat. It was amazing to watch the transformation.

Fiona is proposing a Pilot Project to investigate this further and see if there is a way forward with music, when medication doesn't work, including testing whether a metronome will have a similar effect. She has already held a Focus Group on the subject and is about to apply for funding. This is a very interesting study and we look forward to learning of the results.

Liz Greaves

## Faster Better Drug Screening

### Richard Windle

RSN National Team & Cure Parkinson's Action Group

The after-lunch session at conferences is sometimes known as the 'graveyard slot' when participants slump in their chairs and doze while the unfortunate speaker endeavours to grab their attention. Richard Windle was clearly familiar with this syndrome and gave us no chance to doze. His well prepared and clearly delivered talk held all our attention and left me, for one, far better informed about the process of producing new drugs.

We have all heard the basic facts that it can, in fact usually does, take up to 15 years and vast sums of money to nurture a drug along the path from the laboratory where it is just a glimmer in a researcher's brain to the pharmacy where it can be dispensed to the public. Richard's presentation explained the factors which have to be taken into consideration at each stage and the regulatory and financial restrictions which must be negotiated. Initially, the scientists must understand what aspect of the disease they are targeting; for instance why brain cells die, or what causes a tremor, then they must choose one of possibly thousands of potential drugs for their research.



(Richard Windle; photo D Worthy)

They must consider the method of delivery – tablets, injections, patches or many others, the possible dosage and the stage in the disease progression at which it will be given. Drugs must first be tested on animals which is a highly regulated process. Then come different stages of human trials to gauge the safety of the treatment, its efficacy, the optimum dosage and possible side-effects. This stage is extremely lengthy, very expensive and subject to countless regulations which take little account of either the urgency to find a successful drug or the varied degrees of risk involved in different trials. In fact, it is likely that neither aspirin nor L-dopa would have survived this rigorous procedure if they were developed today.



Richard explained that to speed up this process, national and international bodies must learn to work together. They must agree to cut through some of the red tape and take a more relaxed view on sharing both their results and their data. Fortunately this is recognised and legislative changes are being proposed at both national and European level.

Parkinson's UK is monitoring the process and lobbying government where necessary. But fundamental to the success of developing any new treatment is the willingness of people with Parkinson's to volunteer for trials. Without our participation, data cannot be generated on the effectiveness of treatments, whether drugs, surgery or other therapies, so studies would have to be abandoned.

Richard was diagnosed with Parkinson's in 2009. His background in social research equipped him to give us an excellent overview of the journey of drugs from lab to pharmacy. Looking back, I realise he made very few judgemental statements and did not express overt criticisms of the process. He left his audience to draw their own conclusions. But, after telling us that gradually different bodies are beginning to share information, his final slide, a quotation from Henry Ford, expressed hope; it read:

*Coming together is a beginning, keeping together is progress, working together is success.*

Caroline Maxwell

## Repositioning of Drugs

### Prof Ian Stanford

Aston University, Birmingham

Revisiting a drug that is used to treat one condition and investigating its potential use in the treatment of another condition is becoming more and more common. Professor Stanford presented data on two potential drugs for the treatment of Parkinson's, Exenatide (or Exendin-4), used in the treatment of type 2 diabetes (studies undertaken at UCL Institute of Neurology) and Zolpidem, which is a common sleeping tablet (studies at Aston University).

As stated by Peter Jenner, there are no drugs available to treat the non-motor symptoms of Parkinson's and there is no drug that either slows or halts the progression of Parkinson's. The cause of Parkinson's is unknown and it is risky for a pharmaceutical company to risk ££ millions in research, with a slim chance of bringing a new drug from discovery to market. So, researchers are looking at new applications for clinically safe compounds, already developed for one condition and with the potential of use for other conditions.

There are 6 or 7 in clinical trials at the moment, one compound being investigated, Exenatide, is found in the saliva of a large reptile found in SW USA. Patients have been recruited who have had at least a period of treatment with L-dopa. Treatment over 12 months has shown a modest reduction in some symptoms and a full sustained improvement in finger tapping, hand clapping, foot tapping, tremor and rigidity. This study has led to a £1.98m investment from the Michael J Fox Foundation for further evaluation.



(Prof Ian Stanford; photo D Worthy)

Zolpidem, has also been investigated over the last 3 – 4 years at Aston University Brain Centre, which also has a Wellcome Trust Laboratory for studying brain waves in patients, a non-invasive technique. Brain waves result from the synchronous activity of a large number of neurons and occur at different frequencies.

- |  |                                       |
|--|---------------------------------------|
| Delta waves. 1-4 times per second      | - sleep waves                         |
| Alpha waves, about 10 times per second | - when one is sitting quietly         |
| Beta waves, about 20 times per sec     | - these involve moving about          |
| Gamma waves, 40–80 times per sec       | - associated with perception, memory. |

In Parkinson's patients there is an exaggerated Beta-wave activity, which acts as a functional block to movement.

Zolpidem, when used as a single dose of 10 - 20 mgs gives 8 hours sleep without a problem. However, at low sub-sedative doses Zolpidem appears to de-synchronise the beta brain waves and therefore has a potential for treating Parkinson's. Some tests have been done, administering a single 5mg dose of Zolpidem and in every case the exaggerated beta wave activity has been much reduced, which results in some recovery of cognitive and motor function.

In one Parkinson's patient, after dose was able to write his signature, having not been able to do so for 3 years. This is an example of a non-dopamine based therapy, referred to by Peter Jenner. Further trials are looking at 15 patients all with different symptoms, all on different medications.

Ian Billcliff



## The World Parkinson Congress 2013

**Montreal, 1 - 4 October 2013**

*The World Parkinson Congress – which takes place every three years – has proved itself to be the biggest and most representative gathering of the Parkinson's community in the world. It is a clear demonstration that health care, research and simply just coping with the condition all belong together. John Telford was among 3,300 who attended and he reports on the highlights of this unique event. Others from the East Midlands also say what inspired them.*



(John Telford, photo D Worthy)

There was excitement about recent research progress that gave hope that the complexities and variations of the disease are being better understood, giving the prospect of new therapies. There was recognition based on the experiences of people living with Parkinson's that dealing with non-motor symptoms (i.e. not just those relating to movement) were central to quality of life. And there was particularly strong endorsement that people affected by Parkinson's Parkinson's should be involved in everything – their own treatment options, the formulation of health care policy, the design of clinical trials, the development of research strategy and so on.

John says: "The next WPC will be in Portland, Oregon in 2016. If I could I would book my place now. Will you come too?"



**Fiona Lindop, Specialist Physiotherapist**, writes:

'WPC was a wonderful, exhausting and yet stimulating experience, and I am excited about the service developments that the Derby team have planned as a result of what we learned in Montreal. It was an excellent opportunity for professionals and people with Parkinson's to come together to share knowledge, enhance skills and network with people from around the world.'

**Clare Johnson, Specialist Occupational Therapist**, writes:

'The conference was inspiring, particularly as there were people with Parkinson's and their families attending too. The conference was intense, tiring but extremely interesting with lots of chances to learn new things, as well as network with the Parkinson's community globally. It was brilliant to get the chance to speak to Occupational Therapists from all over the world and share knowledge and experiences.'

**Read more ..... in our next issue**

## COMING UP..

23 November 2013:

### **Parkinson's UK National RSN Conference**

*at the Crowne Plaza Hotel, Holliday Street, Birmingham B1 1HH*

*The conference will run from 11.00 am to 4.00 pm, with registration and coffee from 10.00 am - Further information: [researchevents@parkinsons.org.uk](mailto:researchevents@parkinsons.org.uk)*

17 February 2014:

### **Newark Branch Research Meeting, with Roger Barker**

*1.30 for 2.00 pm*

22 March 2014:

### **Researchers' Meeting**

*at Leicester University, 10.00 am – 1.00 pm*

September / October 2014:

### **East Midlands RSN 3<sup>rd</sup> Annual Research Forum**

EMRSN News is published monthly by the Steering Group of the East Midlands Research Support Network (RSN). The RSN brings together people driven to help find a cure and better treatments for Parkinson's. Through our network, anyone can get involved in research and raise funds and awareness for Parkinson's research.

The views expressed EMRSN News are not necessarily those of the Editor, the Editorial Group, the EMRSN Steering Group or Parkinson's UK.

The next deadline for contributions is **Wednesday 27 November**. Please send us a copy of your newsletter and event notices.

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We look forward to hearing from you!