

# East Midlands

# RSN NEWS

Issue 11 (Dec 2013) from the East Midlands Research Support Network

Welcome to the 11<sup>th</sup> edition of East Midlands RSN News.

Since our Research Forum in September, 4 important events have taken place and your Steering Group members have been busy attending these. This issue is therefore filled with reports on the first 3 of these events, namely the World Parkinson Congress in Montreal, an Open Afternoon at the Oxford Parkinson's Disease Centre and a Research meeting in Manchester. The Parkinson's UK Research Day took place in Birmingham on 23<sup>rd</sup> November and the report on this will appear in our January edition. Grateful thanks are due to all who have contributed articles to this edition.

Our next edition will be circulated in January and will include an introduction to a new feature to first appear in the February edition, "Has this been researched?" Watch this space!

At the Parkinson's UK Research Day in Birmingham, we learned that all the speakers are 'increasingly optimistic' that a cure, or a treatment that will halt the advancement of the condition, will be found in the not-too-distant future. On that positive note all that remains is for me to wish you, on behalf of the Steering Group, a very Happy Christmas and a 'Better' 2014.

Ian Billcliff, Editor



## The World Parkinson Congress 2013

Montreal, 1<sup>st</sup> to 4<sup>th</sup> October 2013

The World Parkinson Congress (WPC) was attended by our Chairman, John Telford, who reports on this unique event. Some members from the Parkinson's team at the Derby Hospitals also attended and we have reports from two members of that team on what they found to be the highlights of the Congress.

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... and much more!



(Meeting Room, by watiporn:  
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)*

# Reflections on the Congress

**John Telford, Chair, EMRSN Steering Group**

The World Parkinson Congress – which takes place every three years – is a clear demonstration that health care, research and simply just coping with the condition all belong together. The WPC has proved itself to be the biggest and most representative gathering of the Parkinson's community in the world. Between 1<sup>st</sup> and 4<sup>th</sup> October this year 3,300 people gathered at the Palais des Congres in Montreal to meet with each other and to engage with every conceivable aspect of Parkinson's. People living with Parkinson's (i.e. patients and carers), medical and social care professionals of all kinds and leading Parkinson's researchers were all present. Information, experiences and views were exchanged in an open, friendly and inspirational atmosphere. Participants came from all over the world, making this a truly international occasion.

The involvement of patients and carers was an important theme. 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 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.

Each day started with the whole congress getting together for presentations on important topics, ranging from new research perspectives through therapy issues and the challenges of living with Parkinson's to notable feats by individuals to rise above the condition. Many prominent researchers, neurologists and other movers and shakers in the Parkinson's world were present and spoke about the latest progress and achievements, with plenty of time being given over to incisive questions from the audience.

For much of the rest of the time there was a programme of numerous talks and workshops running in parallel, so that there was always something of interest for everyone – from dense academic research lectures to discussions of everyday problems like avoiding falls, keeping active and speaking loudly enough. In between times there were also practical activities, like performance, dance and singing – so it was not just talking and listening. There was a 'wrap up' panel discussion at the end of each day which identified the highlights. The whole WPC was an amazing experience.

A good number of the sessions were video recorded. So you too can get a feel for the occasion by going to <http://www.worldpdcongress.org/> and following the link to the webcasts.

## **EAST MIDLANDS RSN STEERING GROUP**

CHAIR:

**John Telford**, Leicester  
[jntelford@ntlworld.com](mailto:jntelford@ntlworld.com)

SECRETARY:

**Lionel Paulo**, Leicester  
[ljpaulostk@talktalk.net](mailto:ljpaulostk@talktalk.net)

MEMBERS:

**Richard Brown**, Sleaford, Lincolnshire

**Chris Johnson**, Derby

**Caroline Maxwell**, Daventry, Northants

**Maria Rice**, Nottingham

**Ian Billcliff**, Derby

**Graham Thorp**, Shepshed, Leics

**Tyna Brych**, Parkinson's UK East  
Midlands

Parkinson's UK had a team there of about a dozen including Steve Ford, the Chief Executive, Kieran Breen, the Research Director, several staff and a number of volunteers

and there was a stall in the exhibition area where participants could learn about the charity. There were also a number of participants from the East Midlands, including the 'Derby Team' of Rob Skelly, Lisa Brown, Fiona Lindop and Clare Johnson (Lisa and Fiona spoke at our Derby Forum in September – see EMRSN News 10).



*Richard Windle, Janice Russell-Taylor and Emily Hughes (RSN Manager) standing by one of the Parkinson's UK posters at the World Parkinson Congress (photo: J Telford)*

## Themes

From the wide range of topics covered at the congress, I think the following themes are worthy of particular mention. As this is the East Midlands **Research** Support Network newsletter, you will notice the research emphasis.

### **The nature of the beast - pathogenesis**

The first presentation was about what is really going on at the level of the nerve cells when someone has Parkinson's. What is the biochemical mechanism that causes brain cells to die progressively? It has been known for a long time that the formation of aggregates of aberrant forms of the protein called alpha-synuclein was at the heart of this process. Work over the last couple of years now gives more evidence that, once started, abnormal alpha-synuclein moves through the nerves 'infecting' or 'seeding' the normal protein so that it too becomes abnormal. In this way the adjacent nerves are affected and the disease gradually spreads from one part of the brain to another in a prion-like fashion. What's more, the team led by Prof Virginia Lee found that there were different varieties or 'strains' of the abnormal alpha-synuclein which could be part of the explanation for the variation in the way Parkinson's manifests itself in different individuals. The different 'strains' could account for and provide a common mechanism that unifies the range of related neurological conditions such as Lewy body dementia, PSP and MSA.

The work of this team has also come up with a better mouse model for Parkinson's (i.e. with a way of producing for experimentation a condition in mice which more genuinely mimics the condition in humans). Up to now a 'Parkinsonian' mouse has either shown Parkinson's symptoms but hasn't had the Lewy bodies typical of the disease, or has had the Lewy pathology but hasn't displayed the symptoms. By 'seeding' non-genetically modified (or 'wild-type') mice with abnormal alpha-synuclein aggregates, they have produced more genuinely Parkinsonian mice with both the symptoms and the pathology. This gives better hopes that treatments that are found to work in these mice will also work in human patients – which has, disappointingly, not been the case with existing animal models.

*(You can watch the web cast of Virginia Lee's excellent presentation at <http://www.icastpro.ca/events/wpc/2013/10/03/3rd-world-parkinson-congress/play/1688> )*

Other presentations at the WPC also dealt with research into other aspects of the disease process, such as mitochondrial dysfunction, the failure of the cell's garbage collection system, neuroinflammation and genetic factors, all of which have a bearing on why the disease process starts in the first place and why the body can't stop it.

### **Non-motor symptoms**

Prof Ray Chaudhuri has championed the recognition and better understanding of non-motor symptoms for many years. Constipation, bladder problems, sleep abnormalities, speech and swallowing problems, depression and cognitive impairment and so on tend to be neglected due to the focus on tremor, stiffness and slowness of movement. But non-motor symptoms are the root of serious distress and often appear before the motor symptoms. Prof Chaudhuri gave, as usual, a superb talk on this topic and you can watch it at <http://www.icastpro.ca/events/wpc/2013/10/03/3rd-world-parkinson-congress/play/1689> . It is not easy for a patient to raise this sort of symptom with their neurologist and this problem ties in with another theme of the congress - patient empowerment.

### **Patient involvement and empowerment**

It came up time and time again that it's a partnership. When it comes to treatment, therapy, research strategy and clinical trials, Patients and carers are as vital as the professionals. Not just as 'subjects' but as essential partners if the best outcomes are to be achieved. There was no disagreement that a Parkinson patient needs to be treated as a whole person. Everyone has different symptoms and needs therapy tailored to them, giving due consideration to social and lifestyle concerns. As emphasised above, Non-motor symptoms must not be overlooked. Encouragingly, the professionals were as enthusiastic for this holistic approach as the patients and carers.



*Dave deBronkart calling for patient empowerment*

There was equal enthusiasm for the involvement of patients with research. Not only was there a real need for more people with Parkinson's to put themselves forward as participants in clinical trials – some trials are failing because of a lack of subjects – but tangible benefits can be achieved by involving patients in the design of new trials. Less was said about the involvement of lay people in research strategy but it is notable that at least two organisations, Parkinson's UK and the Parkinson's Disease Foundation (USA), are asking their members to identify where they think there are gaps in research.

### **Exercising and falling**

Surprising very little was reported on research into whether exercise can actually modify the disease process and slow it down. There was quite a lot on this at the last congress three years ago in Glasgow and so one might have expected there to be further results reported. Nothing was reported on what sorts of exercise might have an effect on disease progression although one speaker said that for exercise to be effective you had to 'break a sweat!' Yet without question, everyone was convinced that plenty of exercise was an essential component of Parkinson's therapy. Martin Munneke reported on research in the Netherlands which was ambiguous on whether systematically encouraging patients to be more active actually had any effect on their formal UPDRS scores, but it was incontrovertible that patients felt subjectively in better condition, both physically and mentally, if they regularly engaged in physical activity.



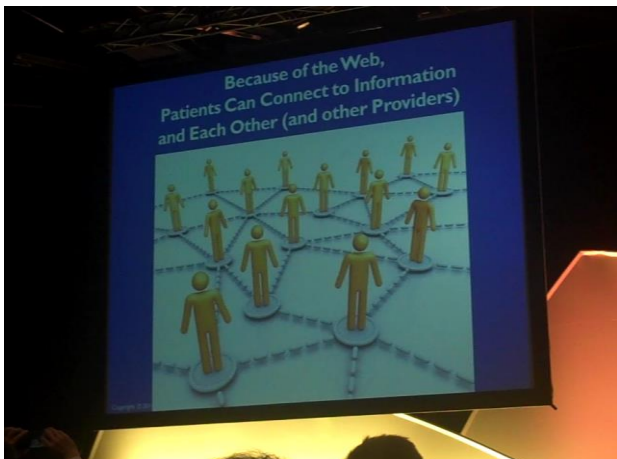
Freezing and falling were the topic of a set of talks (which unfortunately I missed because they clashed with others that I chose to go to instead). One of these talks was on the benefits of exercise in reducing falling. It was given by Victoria Goodwin who had previously spoken at the Parkinson's UK/SPRING workshop on exercise in 2009. It is a small world: many researchers keep turning up who have been active in the Parkinson's field for many years and we must be grateful to them for their lasting dedication to the condition that is central to all our lives.

### **Biomarkers**

A biomarker is a biological characteristic that can be detected or measured to indicate whether someone has Parkinson's before the symptoms have developed, or to give a measure of how far the disease has progressed, or how fast it is progressing. The importance of finding good biomarkers was mentioned in many talks. This is not only because it is likely that new treatments will be more effective if they are given as soon as possible after diagnosis but also because the currently available methods of determining the degree and rate of progression are hardly adequate for determining how effective any new drug is in changing the course of the disease.

### **Other therapies**

A theme which perhaps received less emphasis than previous years encompasses stem cell and neural implantation, the use of growth factors and gene therapy. But Roger Barker (Cambridge) gave an outstanding presentation covering all three which described work that is being done now that could yield positive results in the future. You should eventually be able to watch this at <http://www.icastpro.ca/events/wpc/2013/10/04/3rd-world-parkinson-congress/play/1694>, but unfortunately the WPC has to wait until some of the work he covered is formally published before they can put the webcast up.



*(photo: J Telford)*

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

## **Highlights from WPC2013**

### **Fiona Lindop, Specialist Physiotherapist**

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.

For me, one of the highlights was a session on posture which included the diagnosis and management of camptocormia – when the posture is flexed 45degrees or more in the trunk. This session also covered neck posture problems. It gave me further inspiration for how I might be able to help people experiencing these problems and I have already started introducing some of the exercises.

Another highlight was a session that covered freezing, falls and the benefits of exercise to reduce falling in Parkinson's. The first speaker, Alice Nieubower, discussed freezing and understanding why this might occur in Parkinson's, giving 4 different possible models. The second presenter, Fay Horak, looked at why people with Parkinson's fall and whether intervention can prevent this. The third speaker, Vicky Goodwin summarised the latest research into whether exercise can prevent falls. The evidence shows that exercise should include strengthening aspects and be progressive to be effective, and that some forms of exercise, such as Tai Chi, can reduce falls. In a different session, a new outcome measure

was introduced that could be useful in determining balance between people who freeze and non-freezers.



*(Treadmill The Exercise Tool, by John Kasawa; freedigitalphotos.net)*

On day 2, lunchtime was spent standing beside the poster of the work I had been doing with music and gait and this led to some very interesting discussions, both with professionals and people with Parkinson's. The next day I also had to present this work to a small group of people who had booked a poster-tour (touring about 5 similar posters and led by a facilitator) the next day. I am hoping to begin some research into the effect of music on gait in the near future.

While at WPC, I had the opportunity to attend a networking meeting for physiotherapists with an interest in Parkinson's from around the world. It was very interesting to hear about the different health system structures that impacted the way that physiotherapists could offer assessment and rehabilitation to people with Parkinson's.

On the last morning, it was a proud moment for the team as we sat in the main auditorium listening to Dr Skelly presenting the research recently undertaken into whether patients with Parkinson's admitted to a ward where all staff have been trained in management of Parkinson's have better outcomes and shorter stays.

## **Key points from WPC 2013, Montreal**

### **Clare Johnson, Occupational Therapist, SpARC**

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

The main theme for me that came from Montreal was the theme of TEAM work, the centre point of this team being the person with Parkinson's. The team included the families and carers, as well as the professionals and external agencies. The key emphasis was on getting patient involvement, not only in their individual treatment plan, but maybe also in service development.

Emphasis was put on the importance of MDT working. Early intervention with therapies is vital and medical staff need to be encouraged to make these referrals soon after diagnosis. As physical activity has been proved to maintain function, it is really essential that we as Therapists get involved to provide a holistic approach and promote a healthy lifestyle. This



should include mental activity and advice on sleep, reduction of stress and techniques to manage the condition to their best potential. I also heard at the conference, although I had previously been made aware of this, that laughter is an effective form of treatment.

Specifically from an OT point of view, the emphasis was put on functional goals, i.e. ensuring that all patients have something to work to that is purposeful to them. I learned of a few more standardised assessments that we could use in practice. There were some variations in opinion about the role of the OTs, but we were all mainly in agreement.

*(Hands of Teamwork, by Kittikun Atsawintarangkul; freedigitalphotos.net)*

There were specific tutorials on particular symptoms, which were all very informative about the severity of the symptoms and the management of them. I was interested in the Anxiety and Fatigue sessions and attended a really useful talk on sleep and fatigue; it concluded that fatigue is a subjective experience, not really related to feeling sleepy, but that exercise is again the best treatment for battling fatigue. I also attended the sessions on anxiety and depression and found I was able to consolidate my knowledge on this. It was helpful to be assured the treatment I was using and the advice I give is appropriate.

On the Thursday there was an Occupational Therapy Network meeting, in which I was one of four speakers from around the world who presented an update from their region. I was able to present the guidelines and policies we use in the UK, describing some of the drivers that affect our service provision. The other presenters were from Australia, The Netherlands and America. It was a brilliant opportunity to speak to other OTs around the world, mainly from Canada and Europe, and it was good to hear that we are all doing similar things and our treatment approaches were consistent. There is to be a global OT network; something we have already started in the UK, and I will add our list to the global one. Hopefully the network will grow as a link for knowledge and advice.

The conference gave me many ideas to take our service forward. I have specific thoughts on different intervention to include in my practice, Sexual Dysfunction being one of the areas which as a team we do not discuss with patients as often as we perhaps should. Not only is it a symptom of the condition which obviously affects relationships and mood, but there are also side effects from particular medications that need to be monitored.

Other forward thoughts include running a mini WPC for the patients in our region. We learnt such a lot, and our Patients who also attended gained such a lot from the conference, that we felt we wanted to share that with others when we got home. However, this may not be as easy a task as thought and will take some organising. We are also starting to network with other therapists with a special interest in our geographical locality.

I thoroughly enjoyed the conference and Montreal itself. I am very grateful for the opportunity to attend and will be able to use a lot of what I have learned in clinical and service development.

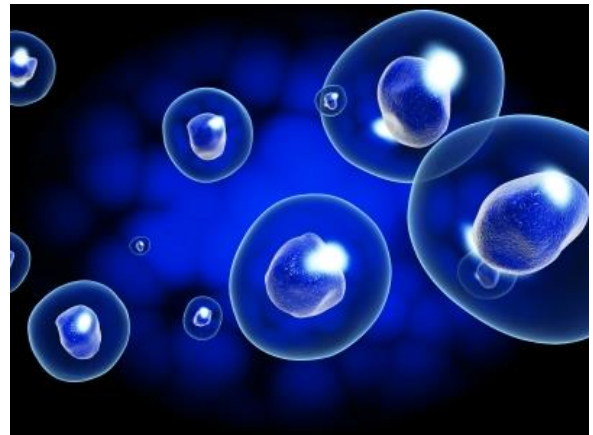
## Oxford Parkinson's Disease Centre Open Afternoon

The afternoon predominantly covered work being performed under the umbrella of The Monument Discovery Award, a £5m grant from The Monument Trust, a Sainsbury Family Trust which was set up by the late Simon Sainsbury, who had Parkinson's.

The Award brings together a world-class team of researchers at the University of Oxford, working on 3 key research challenges to accelerate progress towards a cure for Parkinson's:

1. Earlier diagnosis of Parkinson's
2. What happens inside the nerve cells that die in Parkinson's
3. Producing better animal models that truly reflect Parkinson's

There were 4 presentations and the summaries follow.



(Cell, by jscreationzs; freedigitalphotos.net)

## Early Diagnosis of Parkinson's

### Dr Michelle Hu, Consultant Neurologist

Dr Hu's presentation was on the work being done to achieve earlier diagnosis of Parkinson's, which should lead to more effective treatment. It is known that symptoms of Parkinson's appear a long time before clinical diagnosis is made, as much as 15 years before diagnosis. The aim of this work is to understand the biology of pre-motor and early Parkinson's.

The points were made that 90% of people with Parkinson's (PwP) have been diagnosed; the 10% not diagnosed are probably more elderly and in care homes. Also 25% of PwP have a relative with the condition, 75% not having a relative with it.

By the end of 2012, Dr Hu had recruited 940 participants in her study, 682 with Parkinson's, 202 controls and 56 siblings (the total figure is now up to 1121), research being conducted across 11 sites in the Thames Valley area. Preliminary findings are as follows:-

- analyzing data from the first 500 participants has shown that deterioration in hand dexterity, balance, ability to smell and anxiety predict memory symptoms and may be important early markers in identifying people at greater risk of future problems - mentioned by Prof Peter Jenner at our Research Forum (see EMRSN News 10)



- MRI scans have shown changes in the brain which reflect improvements in brain function following use of Parkinson's medication
- Several important proteins have been identified in the blood of Parkinson's patients, which are now being tested for accuracy in early diagnosis
- data from 250 PwP is being examined to better understand the role of genetics in the development of Parkinson's.

New developments in this study are:-

A Voice Initiative – the vocal chords are subject to tremor in Parkinson's and voice recording could be a quick and powerful tool in the diagnosis of the condition

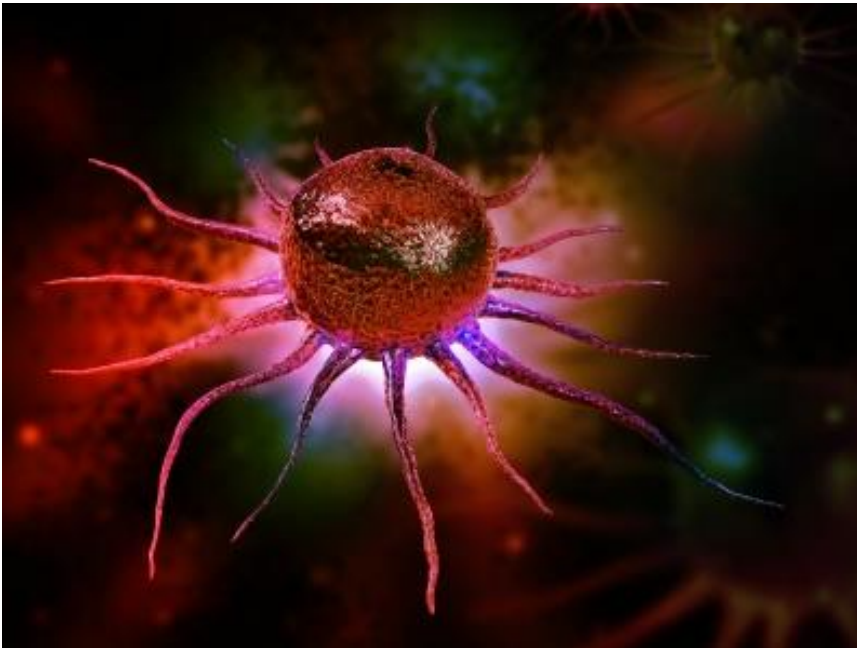
Colonic biomarkers – colonoscopy finds aggregation of alpha-synuclein in the gut several years before clinical diagnosis and this could be used as a diagnostic biomarker.

## Stem Cells in Parkinson's Research

**Dr Elizabeth Hatfield, Career Development Fellow, OPDC**

This project is concentrating on generating 'pluripotent' stem cells from skin cells and using them to develop new drug treatments for several disorders, including Parkinson's. Pluripotent stem cells are similar to embryonic stem cells and can be matured into any kind of stem cell, which can then be converted into dopaminergic cells.

The work is highly technical, involving the production of these stem cells outside the body, in Petri dishes. Each cell then has to be vigorously tested for any abnormalities and for its



*(Stem cell, by dream designs; freedigitalphotos.net)*

ability to turn into different cells. 1,000 people, both with and without Parkinson's, will be involved in the study.

It takes 56 days to convert the stem cells into dopamine nerve cells. After this it is necessary to check that the dopamine nerve cells behave the same way in Petri dishes as they do in the brain. It has been found that the cells produced in this way do actually 'fire' and their activity increases with time. A graph showing the rate of increase over a period of up to 10 weeks was shown. It is hoped that this

work will lead to a better understanding of Parkinson's and the team will be looking at what causes cells to cease functioning.

## Controlling the Striatal Dopamine Function

Dr Stephanie Cragg, University of Oxford

Dr Cragg's presentation concentrated on the interaction between acetylcholine receptors in the brain and dopamine-producing cells, but also mentioned the potential of nicotine in treating Parkinson's, both of which are the subject of Parkinson's UK grants.

We first saw a slide of a mouse brain, showing billions of synapses. In the brain, acetylcholine (ACh) is a gatekeeper to dopamine signals, so it is important to know which ACh receptors are involved and how the ACh circuit can be activated specifically. Electrical stimulation activates all circuits, but 'optogenetics' is a new technology which involves genetically engineering nerve cells to respond to flashes of light, which can then be used like a switch to control the activity of specific groups of neurons. In 2012, Dr Cragg's team showed that optogenetic targeting of ACh neurons was enough to trigger dopamine release in the mouse brain.

Therefore, there are dual drivers of dopamine signals: activity in dopamine neurons and also activity in ACh neurons. More circuits might control dopamine function than previously realised. Fundamental questions to be addressed are whether turning the ACh circuits on or off is the best strategy in controlling dopamine release and what actually happens in Parkinson's.

It has also been found that too much Ca<sup>++</sup> ion affects the death of dopamine neurons in Parkinson's, and through a Parkinson's UK studentship Dr Cragg's team have identified Ca<sup>++</sup> channels that operate on vulnerable neurons but not neurons that are spared in Parkinson's. So it could be that control of dopamine function is patchy, and that these regionally-specific mechanisms contribute to cell death.

Many research studies have shown that smokers are less likely to develop Parkinson's. It has been found that nicotine changes the way dopamine is used by nerve cells in the region of the brain affected by Parkinson's. In a typical healthy brain, nicotine can boost the amount of dopamine that nerve cells use to communicate but we don't know yet whether it has the same effect in the brain of a person with Parkinson's.

Work in this area is continuing in the following directions:

- Understanding the dopamine signals triggered by the ACh circuits and the timing of these, which is the subject of an MRC grant covering the period 2013 – 2016  
and

**PARKINSON'S<sup>UK</sup>**  
**CHANGE ATTITUDES.**

### **GENE BASED THERAPY or STEM CELL THERAPY?**

Latest news on the search for causes and cures

**Professor Roger Barker of  
Cambridge University**

2nd talk hosted by the Newark Branch  
Monday 17th February at 2pm

**Holy Trinity Community Centre  
Boundary Road Newark NG24 4RU**

**PARKINSON'S<sup>UK</sup>**  
**FIND A CURE.**

**refreshments, parking, a warm welcome.**

Contact Trisha 01636 821479 or Peta 01636 821985  
by 17<sup>th</sup> January

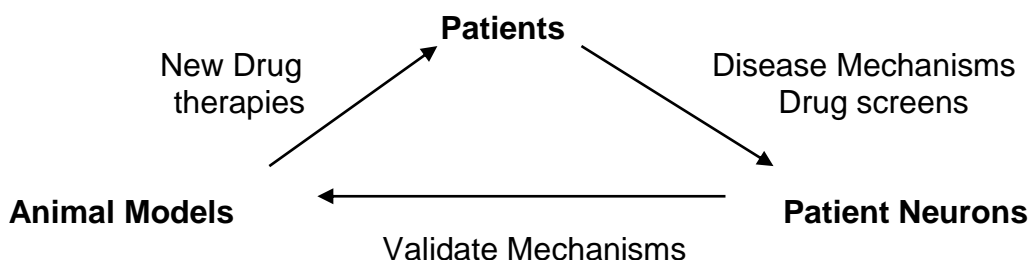
- Understanding how nicotinic receptors really work in affecting the 'on – off' dynamics of dopamine release and the function of a specific type known as alpha5. The outcome of a research grant application is pending on this work.

## Studying Animal Models of Parkinson's

### Dr Richard Wade-Martins

Dr Wade-Martins started by commenting that this work fits in with Dr Matthew Wood's project on delivering RNAi to the brain to reduce the amount of alpha-synuclein in the brain.

His first slide showed the relationship between patients and animal models:



In these studies the whole brain context is vital. It is much quicker to perform the studies on mice, as a mouse at 18 months old is equivalent to a human at 70 years old. It is first necessary to identify the genetic variants that increase the risk of Parkinson's and then deliver these to the rodents. Researchers then have to ensure they are seeing the correct gene expression patterns in the rodents, monitor the disease expression over time and then scale up the studies.

Having generated mice with genetic variations to give them human alpha-synuclein, mice were eventually obtained with twice the normal level of alpha-synuclein. With these mice it is found that a large amount of the dopamine neurons have been lost by the time they reach the age of 18 months, compared to the level present at age 3 months.

Measurements were made using a 'Rotorod' and fore-paw stride length and we were shown a short video of mice exhibiting Parkinson's symptoms. Also measured was the reduction of dopamine level with an increasing level of alpha-synuclein. At age 18 months compared to 3 months, there was also a reduced 'firing' rate of dopamine neurons.

This work is the subject of a paper appearing in the Proceedings of the National Academy of Sciences of the USA - [www.pnas.org/cgi/doi/10.1073/pnas.1309143110](http://www.pnas.org/cgi/doi/10.1073/pnas.1309143110)

Ian Billcliff

#### In the next issue:

- [National RSN Conference in Birmingham](#)
  - [Has this been researched?](#)
- [... and much more!](#)

## Manchester Metropolitan University Science Festival

The Manchester Metropolitan University (MMU) held a Science Festival at the end of October. There was an interesting workshop about Parkinson's disease in among the scientific activities, given by Dr Matthew Sullivan and entitled:

### Parkinson's disease: Discover what research matters

This seemed just what we needed to know. So I decided to attend this workshop.

MMU is a modern University with fine new buildings not the easiest to find one's way about but fortunately we met a helper of Dr Sullivan whom we followed to the lecture room. Once there we were given hand outs for the lecture.

Matthew gave a presentation which aimed to pass on some skills of finding and reading the scientific literature on Parkinson's for ourselves. It began by thinking about the process of doing science and then how studies get published. Researchers take into account a hierarchy of journal prestige when deciding what journal to ask to publish their research, and we should be aware of that too when we judge the quality of a study. Peer review is the gold standard of quality assurance in the scientific literature and this is only used in science journals, not in newspapers, so this is another indicator of reliability. After a welcome break Matthew moved on to the thorny topic of the statistical analyses used in scientific papers. Elements such as 'p-values' and 'confidence Intervals' were described. The overall punch line of the statistical analyses in a paper is that the authors are trying to see if their data are simply random numbers or there is something interesting going on in their data. The talk concluded by encouraging people to have a bit more confidence to look at this 'primary literature'.

This was a very interesting workshop if somewhat difficult to follow if you had little knowledge of statistics. But it did illustrate why it is important for researchers to publish all their results so that doctors could assess for themselves the likely outcomes for their patients.

Dr Matthew Sullivan and Maria Rice

## Research Consultation Meeting in Derby

Dr Rob Skelly has been leading research in Derby funded by Parkinson's UK on: 'Would specialist units improve hospital care for people with Parkinson's?' (please see report on presentation at our Research Forum in EMRSN News 10, p 4). The results of this pilot study are promising but evidence from a bigger randomised trial is needed to convince NHS commissioners that Specialist Parkinson's Units should be adopted by the NHS.

As a step towards this larger trial the researchers held a consultation meeting with members of the sQuad Working Age Group in Derby on 7 December. Lisa Brown and Apostolos Fakis explained the bigger study and led a discussion with the 17 participants on what is most important to people with Parkinson's with regard to hospital care and specialist units compared to general wards. The direct dialogue provided better understanding for the researchers and for people with Parkinson's and links will be maintained as the research progresses.

Chris Johnson



# COMING UP...

17<sup>th</sup> February 2014:

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

*1.30 for 2.00 pm. Contact Trisha 01636 821479 or Peta 01636 821985 by 17<sup>th</sup> January*

22<sup>nd</sup> 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 **Friday 10 January**. Please send us a copy of your newsletter and event notices.

Editor: Ian Billcliff ( [imb248@outlook.com](mailto:imb248@outlook.com) )

Editorial Group: Lionel Paulo, John Telford, Chris Johnson

We look forward to hearing from you!