

# East Midlands

# RSN NEWS

Issue 9 (Sept 2013) from the East Midlands Research Support Network

Welcome to the 9<sup>th</sup> edition of East Midlands RSN News.

In this issue we start with a brief report on the newly constituted Steering Group which met on 2 September. As we have all been enjoying some nice summer weather since the last edition, there is not a lot to report under 'News and Events', apart from two very important events. Firstly, Parkinson's UK annual conference took place during the first weekend in September and we have a report on the Research Workshop held at the Conference. Secondly, our second Research Forum, held in Derby on 14 September; this was a great success and a brief report of the proceedings is included. A more detailed report, with summaries of presentations, will be in the next edition.



(Neuron, dream designs: freedigitalphotos.net)

Apart from the forthcoming events listed under 'Coming Up', the rest of this issue is devoted to Deep Brain Stimulation (DBS), with an excellent summary of the procedure by Lionel Paulo in his 3<sup>rd</sup> Lesson and two articles describing the experiences of two people who have undergone the procedure. Our grateful thanks to Don Pearce and Karen Gavin for their openness in providing candid opinions about the operation and its results.

The whole purpose of East Midlands RSN News is to disseminate information about what is happening in areas of research into Parkinson's and encourage interest and participation in these activities. However, we cannot say how successfully we are achieving these aims without feedback from those who receive it. We really would be delighted to receive any comments on the content and timing of EMRSN News, so please email me at the address given on the last page.

Ian Billcliff, Acting Editor

## Inside this issue:

- **The Steering Group**
- **News & Events:**
  - Top 10 questions
  - More Support
  - Research Forum
- **Coming Up**
- **You might like to know:**
  - Lionel's DBS lesson
- **Personal perspectives:**
  - 2 People share their experience of DBS
  - ... and much more!



(Question Mark Dice Background Showing Confusion, 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)

## The East Midlands RSN Steering Group

The first meeting of the newly constituted Steering Group was held on 2 September 2013. The Group will operate under the framework of the newly drafted Terms of Reference (see below). John Telford was re-elected as Chair of the Group and Lionel Paulo as Secretary, other members being as listed on the right.

The basic aims of the Steering Group are to maintain an awareness of research activities for people affected by Parkinson's and encourage these people to participate in such activities. Without the participation of volunteers, particularly people with Parkinson's, some research projects will never get off the ground, with the result that new information on that project will never be obtained and a potential new treatment for Parkinson's may be lost.

It was agreed that the Steering Group would proceed very much in the way it has up to now, but in order to further its work, there is a pressing need for new members. The volunteer members of the Group plan to make presentations to Branch meetings, involving Branch Research Support Officers, in order to attract new members. Should anyone out there be interested in joining the Steering Group and help in shaping the future of the Research Support Network in the East Midlands, please email either Lionel Paulo or John Telford (for email addresses see frame on right).

The full Terms of Reference of the Steering Group are at: [http://www.em-rsn.info/docs/TOR\\_NEW\\_New.pdf](http://www.em-rsn.info/docs/TOR_NEW_New.pdf)

### The Annual Review

The Steering Group was formed in June 2011, the initial objective being to get the East Midlands RSN up and running. The Group came up with 8 areas of activity that they and the RSN should be involved with:

- **Fundraising** – the foundation stone on which all other activities are built
- **Research Meetings & Forums** – co-ordinating and advertising these events and organising particular events
- **Brain Bank** – encouraging PwPs to bequeath their brains to the Parkinson's tissue bank
- **Clinical trials** – participating in and encouraging others to participate in trials. Several SG members have done so and their experiences been reported in EMRSN News
- **Presentations** to Branches and groups – a template presentation has been designed for this purpose
- Involvement in **Lay Review Panel** – a number of SG members are lay review panellists, enabling them to have influence on the direction research projects are taking.
- **Visiting Research Laboratories** – one laboratory has been visited this year, but it is hoped that many more visits will be arranged.

### STEERING GROUP MEMBERS

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

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

- Disseminating **research information** – EMRSN News has been used to look at some promising developments. We endeavour to put the information out in terminology that can be readily understood by a layperson.

The role of the newly constituted Steering Group is to develop the work of the RSN in the East Midlands.

Even if you do not wish to become a formal member of the EMRSN Steering Group but feel you may be able to help with one of the 8 activities listed, please do not hesitate to contact Lionel ([ljpaulostk@talktalk.net](mailto:ljpaulostk@talktalk.net) or 0116 282 7340) or John ([jntelford@ntlworld.com](mailto:jntelford@ntlworld.com) or 0116 283 4447).

## News & Events

### The Top 10 Unanswered Questions

Parkinson's UK is launching an initiative to identify the 10 most important unanswered questions in Parkinson's research.

This is being done in association with the James Lind Alliance (JLA), a non-profit organisation that brings together patients, carers and healthcare professionals to identify and prioritise the most pressing research questions for their condition. It has already done this for conditions such as asthma, prostate cancer, schizophrenia and dementia. The project is being guided by the National RSN and Richard Windle (a speaker at our Research Forum, see [page 4](#)) is helping to plan the project.

The whole purpose of the study is to give people affected by Parkinson's a voice in the research process – a 'bottom up' approach, rather than 'top down'. As Dr Kieran Breen, Parkinson's UK's Director of Research and Innovation, puts it: "Without the input of people who have direct and personal experience of Parkinson's, it's impossible to be sure we're addressing the right research questions." The results of this massive study will be shared with the international Parkinson's research community with a view to shaping the direction of research all over the world.



*(Question Mark, by digitalart: freedigitalphotos.net)*

**However, this will only be possible if thousands of people get involved and complete the survey.**

The survey will be launched in October and will be available to complete on the Parkinson's UK website. Paper copies will also be sent out to all members in the autumn issue of 'The Parkinson'. The survey will run for 3 months and the results will be available sometime in 2014.

Please don't miss this opportunity to have your say.

## All change for one research project we have reported on!

If you are a regular reader of our newsletter you will know that Dr Victoria Haunton of the Leicester Royal Infirmary has been testing cerebral blood flow to the brains of Parkinson's and non-Parkinson's people for the last year.

With thanks from us for her work on the project Victoria has gone back to the wards (at least for the time being), but that does not mean the end of this research study; the baton has been passed to Dr Martha Hanby and the race goes on!

Martha's contact details are below. If you haven't been on this research project yet, now would be a great time to get in touch with Martha and arrange something. Martha's phone number is 0116 258 7253 and her email address is [MH378@le.ac.uk](mailto:MH378@le.ac.uk) - Thanks.



*(Flowing blood cells, by Victor Habbick: freedigitalphotos.net)*

## More Support for Research Support

The East Midlands Research Support Network (RSN) featured prominently at the Parkinson's UK 'Shaping our Future Conference' & AGM on 6 and 7 September 2013. On the background of a strong profile for RSN work, listed both among past achievements and future priorities, there were two special workshops on local involvement in research. Over 50 participants, many of them already active but looking to link up with like-minded people, heard about the East Midlands RSN and discussed ways to work locally and link regionally and nationally.

## Derby Research Forum

Our 2<sup>nd</sup> Annual Research Forum, held in Derby on 14 September, was a great success. There were 95 people in attendance and respondents to the Evaluation Form gave it an overall score of 8.8 out of 10 for the value of the information and knowledge gained.

We were welcomed to the Forum by Liz Greaves, Chair of Derby branch, who introduced John Telford as Chair of the Forum. The first presentation was by Professor Peter Jenner of King's College, London, who gave a very informative and entertaining talk on the position of Parkinson's research today, subtitled 'The Windmills of your Mind', based on the precept that research tends to go round in circles.



*(Prof Peter Jenner; photo: D Worthy)*

The remainder of the morning session started with a presentation by Dr Nin Bajaj from the National Parkinson Foundation Centre of Excellence in Derby//Nottingham, on the latest findings on high-field MRI scanning of the substantia nigra of people with Parkinson's, including the tracking of Parkinson's.

There followed a talk by Lisa Brown, Parkinson's Disease Specialist Nurse in Derby, giving an update on the value of specialist Parkinson's wards in hospitals and the session concluded with a very interesting presentation on the effect of music on the movement of people with Parkinson's, given by Fiona Lindop, Specialist Parkinson's Physiotherapist at the National Centre of Excellence for Parkinson's in Derby; it included a short video showing the remarkable transformation in mobility of a lady with Parkinson's, when listening to music on her i-Pod / MP3 player.

Richard Windle, of the Cure Parkinson's Group and the RSN Development Team, started the afternoon session discussing the need for faster and better drug screening and the last presentation was by Professor Ian Stanford on the potential use of drugs that have already been approved for the treatment of other conditions in the treatment of Parkinson's. He concentrated on two particular drugs, one used for the treatment of Type-2 diabetes and the other being used as a sleeping tablet.



(Prof Ian Stanford; photo: D Worthy)

The day concluded with a short panel discussion chaired by Dr Lucy Annett from the University of Hertfordshire.

*This is merely intended to be a brief report on the Forum. A fuller report, with summaries of the presentations, will appear in the next issue of EMRSN News.*

# COMING UP...

## **World Parkinson's Congress** (Mon 1 - Fri 4 October):

To be held in Montreal, Canada. This is being attended by our Chair John Telford, and also by Liz & Brian Greaves of the Derby branch. We look forward to hearing all about it on their return. Go to: <http://www.parkinsons.org.uk/default.aspx?page=11022>

## **Project visit to the University of Sheffield** (Tue 15 October, 14.00 – 16.00h)

'A new fruit fly model of Parkinson's' - Dr Whitworth and his team are investigating how changes in the VPS35 gene cause Parkinson's, using genetically modified fruit flies. Book through the research team at [researchevents@parkinsons.org.uk](mailto:researchevents@parkinsons.org.uk) or 020 7963 9352 / 9313. Plain English summary at: [http://www.parkinsons.org.uk/sites/default/files/g-1201\\_whitworth\\_plain-english-summary.pdf](http://www.parkinsons.org.uk/sites/default/files/g-1201_whitworth_plain-english-summary.pdf)

## **Oxford Parkinson's disease Centre Open Afternoon** (Thu 17 October, 14.00 – 16.30h)

To be held at the University of Oxford, Wellington Square, Oxford, OX1 2JD - Contact [researchevents@parkinsons.org.uk](mailto:researchevents@parkinsons.org.uk) or 020 7963 9352

## **Leicester Branch Meeting** (Wed 23 October, 14.00 – 16.30h)

To be held at Park House, Stamford Street, Glenfield LE3 8DL. The speaker will be Dr George Gveric, Manager of the MS & Parkinson's Brain Tissue Bank. Hear an overview of Parkinson's research and the Brain Bank.

## **National RSN Research Conference** (Sat 23 November, 11.00 – 16.00h)

To be held at the Crowne Plaza Hotel, Holliday Street, Birmingham B1 1HH. Further information to be issued soon.

## 2014 East Midlands Researchers' Meeting

To be held in Leicester in the second half of March 2014. More details as they become available.

*For details of other events outside our area, visit the Research Events page on the Parkinsons.org.uk website*

## You might like to know

### **Lionel's lessons**

A series of plain English explanations of aspects of Parkinson's research

\*\*\*\*\*

#### **Lesson 3 - *The ABC of DBS (Deep Brain Stimulation):***

*A Plain-ish English description of what it is and how it works*

Please bear with me on this one; Deep Brain Stimulation (DBS) jargon sounds complicated but some of the words have to be used to describe it. However, to put it in a nutshell we could say that DBS is a system built in to patients that uses electrical impulses to block the faulty signals that cause the symptoms of Parkinson's disease or other neurological ailments.

Aside from being effective for more than 70% of patients DBS does not destroy any parts of the brain, so if new treatments appear that make DBS obsolete DBS patients will still be able to take advantage of the newer technology.

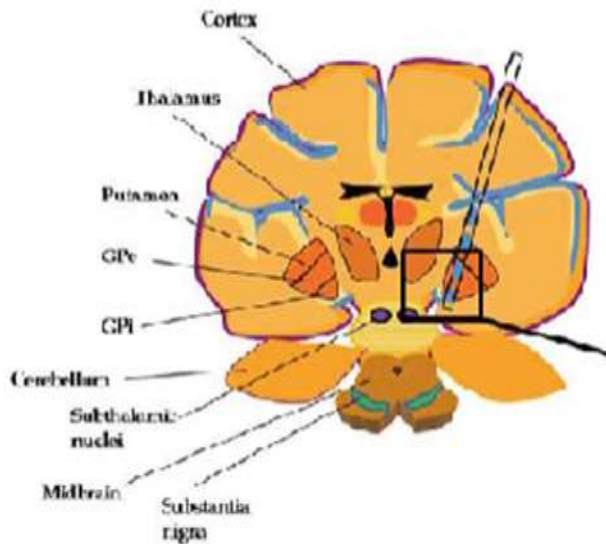
Three different areas of the brain are usually the targets for DBS surgery – each area gives different results and generally the first procedure below is not used for Parkinson's treatment, but I have listed it in case you hear of it and wonder what it does. Your surgeon will determine which area to work on depending on your symptoms. Listed below are some details on the three different procedures:

- A. Thalamic DBS; electrodes are placed in the Thalamus to block out the signals from that area. This works to help control tremor and rigidity and is the DBS of choice for Essential Tremor and Multiple Sclerosis but does not help with other problems that Parkinson's brings, so it is not usually used for Parkinson's treatment.
- B. Globus pallidus interna DBS (or pallidal stimulation) is effective for a wide range of symptoms and may have the edge when it comes to language and cognition. However, it seems to be less effective at improving walking and balance issues. Also there is less scope for reducing medication intake than there is with the third type of DBS described below.
- C. Subthalamic nucleus DBS (or subthalamic stimulation) is also effective for the symptoms of Parkinson's and recent research studies seem to show it is more effective at allowing the patient to reduce medication intake. This helps reduce dyskinesias (involuntary movements of the limbs) in patients that were being caused by higher medication intake. The research also showed that when a patient goes off (i.e. when the medication wears off suddenly) the ability to function stays at a higher level than for globus pallidus patients. Another advantage of subthalamic DBS is that

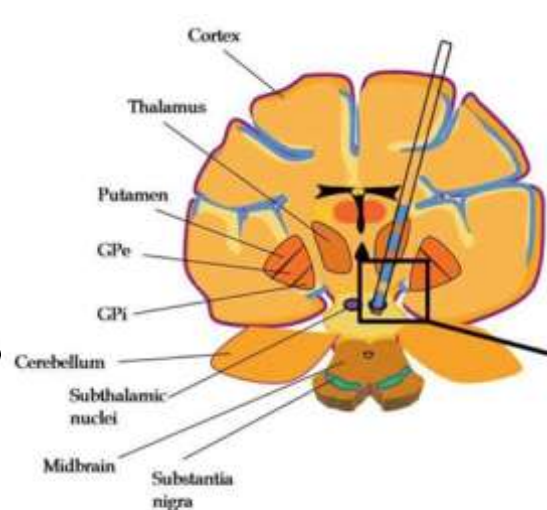
the surgery, to implant the electrodes in the brain is easier to carry out than globus pallidus or thalamic surgery.

The diagrams below show where these different areas are in the brain and where the electrodes would be placed – Gpi-DBS is the globus pallidus DBS and STN-DBS is the subthalamic nucleus DBS.

Gpi-DBS



STN-DBS



The diagrams above show only one side of the brain with an implant but generally both sides need to be treated and both would require electrodes to be implanted. The electrical impulses that emanate from the electrodes to block out the faulty signals in the brain are generated by a neurostimulator (also called an impulse generator), which has been implanted under the skin of the chest just below the collarbone. This device is about the size of a very flat stopwatch and is powered either by rechargeable batteries or more often a fixed battery that requires the whole unit to be replaced when it runs down. Depending on the voltage and frequency of impulses selected the power supply should last anywhere between 3 and 6 years, and this of course will be different for every individual, but it does mean periodic surgeries will have to be endured when the neurostimulator needs to be replaced.

The surgeon identifies where to place the electrodes by using magnetic resonance imaging (MRI) or computed tomography (CT) scan before the operation begins. All the parts of the system may be implanted in one operation but sometimes the neurostimulator is implanted in a separate operation to the electrodes.

Actually, once the operation to implant all these bits and the connecting wires has been done a period of around a month is needed to allow everything to heal before the neurostimulator is switched on, at which time your surgeon will use a wireless computer to program the initial settings and usually will want to see you 6 weeks, 3 months, 6 months and 12 months after the operation. The surgeon will adjust power settings, medication etc. at these visits, gradually working towards the best result possible. A programmer resembling a TV remote control will be given to the patients who can then tweak the settings of the neurostimulator themselves, adjusting them over time until the best results have been achieved.

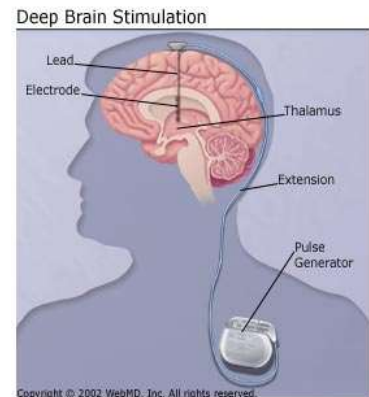
Risks and side effects: There is a 1% - 3% chance of infection, cranial bleeding, stroke, headaches, insomnia and temporary pain and swelling when the surgery has been

performed. When healed and the electrical stimulation is operational side effects can include numbness and tingling sensations, tightness of the face or arms, light-headedness, unwanted mood changes and speech problems (read Karen's interview on page 9 for her experience of these problems). Careful assessment by your consultant to determine whether you are suitable for DBS should be undertaken first.

If you have DBS you can still use phones, computers etc. but keep your programmer away from TVs, credit cards and computer discs as its magnetic field can damage them. Also note that airport metal detectors can cause your neurotransmitter to switch off, so take your programmer with you when you travel and a medical identification card explaining your DBS.

Diathermy is the use of a high frequency electronic current to produce heat and is often used to relax muscles. It should not be used on someone who has had DBS. Sports such as football, rugby and martial arts should also be avoided as the risk of damage to the implants is too high. A frequent cause of DBS system failure is the wire between the electrodes and the neurostimulator breaking.

Finally, to sum up, remember that although DBS can be beneficial in most instances, it is not a cure – as with all other treatments at the moment, it helps to mask and control the symptoms of Parkinson's, but it cannot stop the disease progressing, so please help to support research as the search for a cure goes on.



## Personal Perspectives

### One Person's Experience of Deep Brain Stimulation

*By Don Pearce*

In April and May 2013 there were a series of programmes on BBC 2 about the NHS. Having had an operation to set up Deep Brain Stimulation (DBS) to treat Parkinson's in January on the NHS, I was naturally interested in the series, particularly when the TV guide told me that the next programme would show a DBS operation. Did you watch it? I did and it left me feeling cross and upset, hence this article.

What was shown bore very little resemblance to my experience and so, in my view, was a biased view. On TV the operation was done under local anaesthetic with the patient able to comment on what she felt as the operation proceeded. It took place in 2 parts, separated by several months. They showed that they were able to switch the patient's tremor "off" almost immediately once DBS was switched on (good television, poor medical procedure).

For me the operation at Queen Elizabeth Hospital, Birmingham, was under general anaesthetic and took about 8 hours, during which electrodes were implanted in my brain and the stimulation programmer inserted under the skin of the chest. I was allowed home 2 days later. The stimulator was not switched on for another 4 weeks, during which time I noticed some slight reduction in some symptoms, but nothing dramatic. Once switched on the stimulator was set to deliver 1 volt. I was given a remote control to step up the stimulation by 0.1 volt each week. After 20 weeks I reached the maximum level of 3 volts. There was no feeling of pain or discomfort from the stimulation. There has been a notable



and significant improvement in a number of my Parkinson's symptoms – reduced stiffness, greater flexibility (I can now reach my feet to put socks on), better bladder control, sleeping longer, less dribbling, improved coordination, better balance, greater strength, quicker responsiveness in conversation. On a recent visit to my consultants they were pleased with my progress and indicated that I should expect further progress over the next few months. Unsolicited comments from a number of people confirm the obvious improvements.

At the same time as the stimulation has been raised, my medication has been reduced (down to 3 pills a day from 12). It is not easy to tell which improvement is due to stimulation and which to reduced medication, with the removal of unpleasant side-effects, but the combined effect of DBS has been dramatic. I thank the medical staff at Birmingham for their care and help, which has improved my life so positively.

One point the TV programme did make, with which I agree and would emphasise: “Yes, DBS is expensive, but when the savings in drugs, the reduced costs of care and the improved quality of life are taken into account it is probably very cost-effective, although not suitable for everyone.”

## **DBS: My personal experience**

An interview with Karen Gavin by Lionel Paulo

Have you ever wondered what DBS would be like? Would it be better than a drug-only protocol? Of course we are all different, but I think the best way to find out about any medical procedure is to ask someone who has been there, done that and got the T-shirt, to use the old cliché!

Karen Gavin is a name known to many of you – Secretary of the Leicester branch and the driving force behind the Leicester PD choir. Karen graciously consented to tell me all about her own experience of DBS, and we met on Thursday 22 August and recorded the following interview.

*Lionel:* Karen, how long after your diagnosis of PD was it before DBS was suggested to you, and what criteria were used to assess your readiness for it?

*Karen:* It was suggested 9 Years after I was diagnosed. The 3 criteria that qualified you for DBS were first you had tried various medications and none of them were satisfactory, second you had to be mentally alert and third you had to be physically fit. Unlike today you had to run out of all other options first before you could be considered for DBS (but as far as I know the criteria remain the same today).

*Lionel:* When did you have the operation and who was it that performed it?

*Karen:* It was done September 2007 by a female surgeon in Birmingham. Her name was Mrs Mitchell. I remember that she was one of a very few female neurosurgeons performing surgery in the country at that time.

*Lionel:* Why was the procedure deemed to be necessary at that particular time?



*(Karen Gavin, with Lionel Paulo; photo: D Worthy)*

*Karen:* Because by that time I could not plan to do anything as my PD was totally unpredictable. I did not know how I was going to be from day to day or even from hour to hour. A lot of the time my medication was like taking Smarties, it just didn't work at all.

*Lionel:* When you were informed about DBS did they give you an honest appraisal of what to expect or did they mention only the pros and not the cons, in effect making a sales pitch for it?

*Karen:* The information given to me was all positive. The link to the surgeon in Birmingham was Jean Martey (PD specialist nurse). She suggested that I think about having it done. When I finally saw the surgeon I was allowed to ask only a few questions. I had to find out more about it by myself.

*Lionel:* There are 2 main types of DBS procedure; Pallidal DBS and Subthalamic DBS – which type did you have and what is the difference between them?

*Karen:* I had the subthalamic procedure. As far as I know it is better for tremor.

*Lionel:* So maybe the pallidal type is better for rigidity?

*Karen:* Possibly. Pallidotomy was performed widely in the early days of treatment. It involves killing off cells in the pallidus, an area of the brain responsible for movement.

*Lionel:* Okay, now, can you describe what it was like before, during and after the operation?

*Karen:* Okay. Well, in the beginning it was quite daunting. I was in the hospital in Birmingham in the Wellcome ward where they put cancer patients who were on drug trials. As the operation approached I grew less worried as I knew it was my only option for some control over my PD, but mulling over holes being drilled in my head to fit the 'halo' frame was certainly thought-provoking. I had the operation under general anaesthetic and, from the time when I had the pre-op injection in the back of my hand until I woke up 8 hours later, I don't remember anything at all!



*(Surgery light, by renjith krishnan: freedigitalphotos.net)*

While I was out cold they put the electrodes and the stimulator in, all in the one operation – it's my understanding that sometimes they insert them in 2 separate operations. Of course, the stimulator was not switched on yet. My head felt as though it had grown in size. I wasn't to use soap on my head for a few days. Remnants of the operation clung to my hair, so that was difficult!

*Lionel:* That was going to be my next question – how long did you have to wait before it was switched on? By the way, I was surprised you had a general anaesthetic as I have read accounts of people who did not have a general as they had to be awake when the electrodes were being put in.

*Karen:* It took about a month before it was switched on – my brain had to settle down after the operation – but I was very glad that I was not awake while they did the operation. Birmingham at the time was one of the few places that did the whole operation under general anaesthetic.

*Lionel:* Did you experience the benefits, and drawbacks (if any), as soon as the stimulator was turned on, or did they take some time to become apparent?

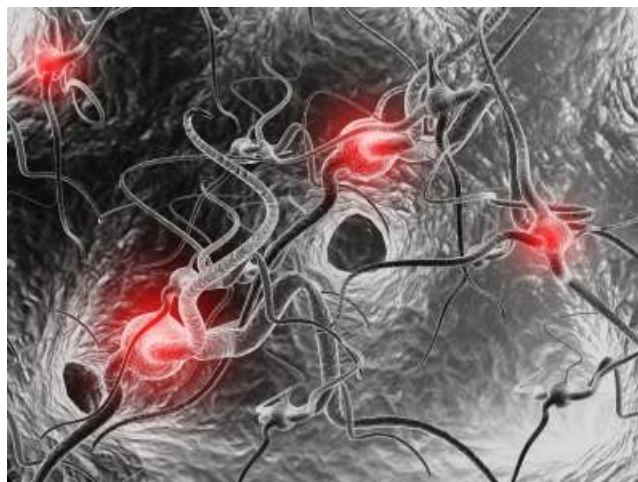
*Karen:* More or less as soon as it was turned on I could feel the difference. Straight after the op the biggest difference was in my voice, not in my movement. It had lost volume and clarity.

*Lionel:* It would seem that everyone is different. John Telford told me about a friend of his who recently had DBS and his voice was improved by it. Maybe the surgeons use more advanced techniques these days, who knows?

*Karen:* When you have subthalamic DBS some of the work in the brain goes near the speech centres. I don't know but perhaps they accidentally touched a part they should not have in my brain and that damaged my speech centre.

*Lionel:* Once the stimulator was turned on and you had settled down I expect that your medication intake would have been changed considerably – was that the case?

*Karen:* Yes, very much so. For 2 years I maintained the same drug therapy but my intake was half what it had been before DBS. I had been on 24 tablets a day and this was reduced to 12 per day. After 2 years had gone by I was readmitted to the hospital with mobility and voice problems, and my surgeon thought I was overdosing on Sinemet so they cut out all of my medication, leaving me completely immobile. Then they gradually introduced it again, aiming to find a minimal effective level, which they did.



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

*Karen:* I went on Stalevo and Pramipexole (Mirapexin). I don't remember the amount but am sure it was quite a bit less than before.

*Lionel:* Okay. Now, adapting; how long did it take to adapt to the 'new you.' Did you feel like a new person and get to the point where you felt completely stable?

*Karen:* It took 3 Years, as it was another year after the second hospital visit before I finally got down to the regime I am still taking, which are 2 amantadine and 1 mirapexin per day. I always felt... different. In my mind I have 4 versions of myself; pre-PD and post-PD me, and pre and post DBS personas. They are each very, very different.

*Lionel:* So we feel the same, because when I remember things from my pre-PD past I remember moving around completely freely but I don't remember what it felt like. It's like watching a movie of somebody else in my mind.

*Karen:* Yes, and sometimes I felt resentment towards other people who could walk around normally. DBS improved a lot of my symptoms. About 5 years ago I found out how different DBS made me feel, as Nic accidentally turned off my machine, and I experienced what Jean said I would have been like without DBS. I had a total body tremor... it was frightening.

*Lionel:* Have you seen the guy from New Zealand on Youtube talking about his DBS? He looks and sounds normal but when he turns his stimulator off to demonstrate the difference he becomes a mass of tremors. Then he switches back on and immediately is tremor-free again (click on the link to see this: <http://www.youtube.com/watch?v=uBh2LxTW0s0> ).

*Karen:* No I have not seen that, but it was exactly like that for me, so yes; I do feel like a new person.

*Lionel:* Okay, next question: We are 6 years on from the operation now. Have any unforeseen benefits or side effects appeared after all this time?

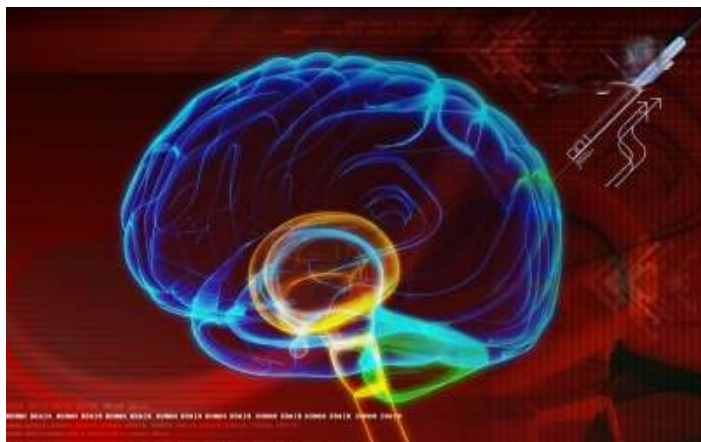
*Karen:* My kind of PD was a bit of a maverick; at one point or another before DBS I experienced every symptom you could think of. I had slight dyskinesia but the main problem was bradykinesia and dystonia – DBS worked very well and sorted them out. Most of the changes came early on but as I have said it took 3 years to settle completely. On a good day now people don't think I have PD at all! Compare that with before where some people guessed that I had Polio!

*Lionel:* So it has worked very well for you. That's good, so it makes the answer obvious to this next question but I will ask anyway; if you could turn back time but be able to use today's drugs would you still opt for DBS, or would you stick with the drugs?

*Karen:* Definitely have the DBS.

*Lionel:* Many of today's doctors are recommending DBS much sooner after diagnosis – they say it works better when done earlier, and waiting means you miss out on a better life for longer. Would you think they have got a point?

*Karen:* Well, 10 years ago at our AGM Doctor Aziz suggested that, so it's not a new idea. Would I agree with that? I don't know why I am saying this but I am not sure. I suppose the quality of life argument makes sense and you can probably cope with it better when you're younger.



*(Human brain, by dream designs: freedigitalphotos.net)*

*Lionel:* There is not much else to say about DBS – either it works or it doesn't – and it obviously did for you, but maybe I could ask; are there any negatives as a result of the operation that you regret but have to live with?

*Karen:* My voice. I used to be a good speaker, but I don't say much these days because my voice is not very good.

*Lionel:* You used to be a teacher didn't you? So your voice made your profession possible. You must have been a good speaker.

*Karen:* That's right. I did a lot of speaking but now I cannot do that. I did do one public appearance at the March Regional Meeting and found it very difficult – it nearly killed me! - So I really miss my voice.

*Lionel:* Karen, thank you for sharing your experience with all of us. It has given us something to think about.

Following the end of the interview I looked through a file Karen had kept that was like a journal of her experiences, containing her personal notes on a day-to-day basis. In reading these notes it was clear to see that even with DBS it had not been an easy ride, but ultimately it had proved to be beneficial.

*Please be aware that this article was about Karen's personal experience of DBS and there was no intent to present it as either an endorsement or criticism of DBS.*

EMRSN News is published bi-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 in this newsletter 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 6 November**. Please send us a copy of your newsletter and event notices.

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

Editorial Group: Lionel Paulo, John Telford, Chris Johnson

*(Return to [top](#))*