PARKINSON'S UK CHANGE ATTITUDES. FIND A CURE. JOIN US.

East Midlands RSN NEWS

from the East Midlands Research Support Network

*** January 2014 / No 12 ***

Welcome to our January 2014 edition and a Happy New Year to all.

The majority of this edition covers the Parkinson's UK Research Day in Birmingham, the last of the autumn Forums, but we also have a very interesting contribution from Angela Rushton on her experiences with Deep Brain Stimulation, a subject which was covered in the September 2013 edition - No. 9.

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

We're delighted that Angela is so positive about the outcome of the procedure, in spite of the difficulties she experienced.

It is good to know that work is being done to make the simple tasks easier for people with Parkinson's, as evidenced by the interview with Emily Lukes, a student at Loughborough. Keep up the good work, Emily.

The other important article is the introduction to our new feature, to start next month, "Has this been Researched?" This invites questions, comments or information from our readers and we look forward to a lively input, covering a varied assortment of topics. Many thanks to all our contributors to this edition.

Ian Billcliff, Editor

Inside this issue:

... and much more!

(News Word on Laptop, by Stuart Miles: freedigitalphotos.net)

News & Events

Parkinson's UK Research Day

Birmingham, 23rd November 2013

On a beautiful Saturday, 4 of us converged on the Crowne Plaza Hotel, along with about 120 others, for the 2nd Annual Research Day. The gathering included representatives from Parkinson's UK, researchers and people with Parkinson's and their carers.

We heard 4 very interesting presentations on different aspects of current research into Parkinson's and our reports on these follow in the order of presentation on the day.

What have we learnt about the causes of Parkinson's?

Prof Anthony Schapira

University College London

Professor Schapira began on a positive note by pointing out that the single most important priority for researchers was the search for a cure, and many areas of research are steadily increasing options for future treatment. This leads him to feel 'increasingly optimistic' that in the not-too-distant future a cure may be found, or, and perhaps more likely, treatments that would modify Parkinson's and control it, preventing the progression of the disease which is inevitable today.

(Human Brain, by dream designs: freedigitalphotos.net)

The incidence of Parkinson's disease increases dramatically as we age, particularly over the age of 60, making age the primary risk factor for Parkinson's. Changes in the brain over time may begin 10, 20 or more years before typical motor symptoms appear. During this period some non-motor symptoms such as loss of sense of smell, depression, or sleep problems may appear. The substantia nigra loses dopamine neurons, and protein blobs, called Lewy bodies, appear in the brain, containing 'mis-folded' clumps of a protein called alpha-synuclein. Alpha-synuclein is found in every brain but in Parkinson's it 'sticks' together (or aggregates) and gradually spreads, affecting many other functions of the brain. If the spread of Lewy bodies can be stopped, this would stop the development of Parkinson's and there have been encouraging results in the laboratory on this aspect.

For many years it was thought the environment was a major cause of Parkinson's, and a great deal of research has taken place over the last 40 years testing this hypothesis and searching for all causes and risk factors. So far no environmental factor has been shown to cause Parkinson's, although some factors may influence the risk of developing it. There is no single cause of Parkinson's but factors such as pesticides, herbicides, farming, solvent exposure, having red hair, low vitamin D levels and being a doctor or a teacher, all increase risk; however, these increases in risk are only very slight so they would probably increase your Parkinson's risk from 1 to 1.2, an increase of only 20%. The lifetime risk of getting Parkinson's in the UK is around 4%. Some of the factors mentioned e.g. red hair may indeed reflect genetic influences.

There is also a list of beneficial factors which slightly reduce risk including black hair, high urate levels, NSAIDS (Non-Steroidal Anti-Inflammatory Drugs), coffee, smoking and Isradipine. Unfortunately some of these bring other health problems with them.
All the above factors influence our genes; modifying their expression in our bodies either positively or negatively (for instance smoking has a big negative influence often leading to cancer).

(DNA, by dream designs: freedigitalphotos.net)

Only recently has it been recognised that genetic factors play a significant role – years ago it was thought that genetics had little to do with it – and these studies have made a dramatic impact on understanding genes and proteins such as parkin, DJ-1, PINK-1and LRRK2 which have been identified and are being studied as genetic factors in Parkinson's. The NHS Genome Sequencing Project aiming to catalogue thousands of people may prove useful in this respect.

The pathogenesis (or developing) of Parkinson's involves mitochondria – the cellular energy stations which power our systems. The mis-folding of alpha-synuclein protein in the cells causes aggregation of these faulty proteins until ultimately they become Lewy bodies and then accumulate in the brain. These faulty protein aggregates clog the cell and also can pass from cell to cell, spreading the damage. This was observed with stem cell transplantation experiments some time ago, the alpha-synuclein aggregates infiltrating the new cells. Finding a way to stop this protein sticking together and spreading would halt the progression of the disease.

Finally, the lysosomes found in each cell are the biological version of rubbish collection and recycling. They are powered by the mitochondria and remove old protein structures to make way for the new structures. The clogging of these systems leads to reduced function and ultimately failure of the cells. Finding ways to prevent this and restoring 'garbage removal' from the cells is also vitally important.

Professor Schapira concluded with the optimistic thought that today we understand better the pathology of Parkinson's, the causes and contributory factors, and the interactions between various treatments, so although there is no cure today, effective answers and treatments may be available in the not-so-distant future.

Lionel Paulo

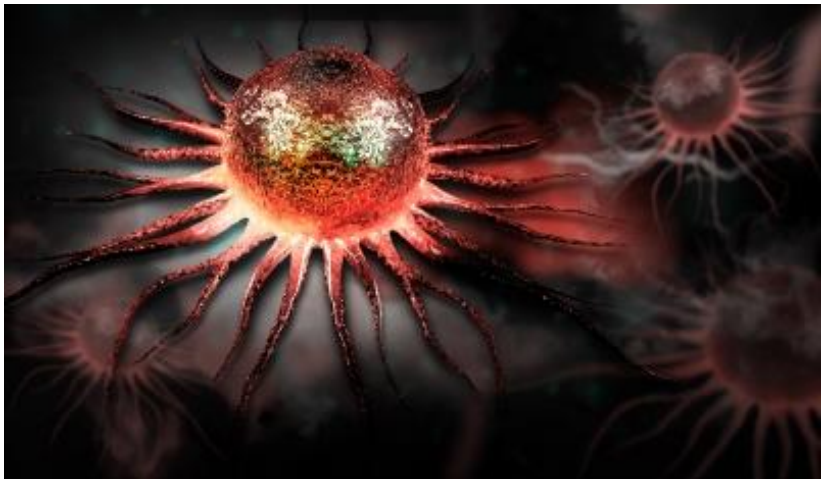
Stem Cell Research

Dr Emma Lane
Cardiff University

Dr Lane first talked about 'The Brain Repair Group' at Cardiff, its mission being to understand and develop new methods to repair brain damage caused by injury and disease. The strategy is a 3-pronged approach, investigating neural transplants, gene therapy and neuroprotection, using a multi-disciplinary team.

The present method of treating Parkinson's is to stimulate the amount of dopamine in the brain by taking dopamine agonists or L-dopa. An alternative is to transplant, or graft, embryonic cells into the brain. However, there are problems associated with this procedure:
- variable or unreliable efficacy of the procedure
- problems with foetal tissues in terms of the ethics, logistics and quality control
- possible side effects, particularly graft-induced dyskinesia (GID)

Side effects can emanate from either the tissue itself, which can be affected by factors such as the age of the embryo, the culture process used and the form of the tissue transplanted, or from the patient in factors such as age and severity of the condition. The number of cells transplanted, the location of the deposits and tissue distribution can also have an effect. This study has been going on for 4 years, creating a model for Parkinson's in humans and rodents, exploring GID and applying the findings to creating a better model.



(Stem Cell, by dream designs: freedigitalphotos.net)

Findings have been as follows:
- the size of the transplant is not a contributing factor, but gives best recovery. In the clinical trial therefore researchers could transplant a lot of cells to achieve the best outcome.
- other non-dopamine cells are not a problem as long as there are enough dopamine cells present. So researchers could limit the number of non-dopamine cells in the graft, but did not have to be overly concerned.
- pre-existing L-dopa induced dyskinesia may predispose to GID. Patients who had not yet developed severe L-dopa-induced dyskinesia were therefore primary candidates for transplantation.

100 patients have been recruited for a trial being conducted through Transeuro, a European research consortium with the main objective of developing a safe and efficacious treatment methodology for Parkinson's patients, using foetal cell based treatments. Surgeries are based in Cambridge and Lund, Sweden, and 20 patients are to be offered the opportunity for transplantation in a Phase 1 study and closely monitored.

A more sustainable alternative may be stem cells which can be used in the same way.

Questions to be asked of this treatment are: 'Is it consistent, reproducible, safe and effective'? Sources of such cells are early stage embryonic stem cells, adult stem cells from sources such as blood, bone marrow and fat and induced pluripotent stem cells, produced by turning other cells back into stem cells and then into brain cells. (See also the report on the OPDC Open Afternoon in EMRSN News 11).

The current situation with regard to this research can be summarised as: dopaminergic neurons can be made with high efficiency, from a variety of cell types, they are safe in animal models (they stop dividing) and moves are being made to enter clinical trials.

The questions remaining are: will side effects be a problem and will the ongoing use of Parkinson's medication be a problem for the new cells ??

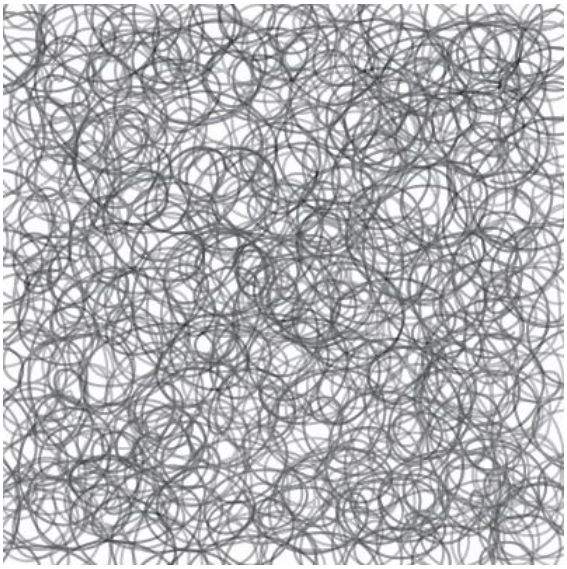
Stem cells are also valuable for Parkinson's research in cell models, to study their behaviour to understand the mechanisms of underlying Parkinson's, defining new therapies for Parkinson's and in understanding the genetic variance of Parkinson's.

Ian Billcliff

Non-motor symptoms of Parkinson's

Prof K Ray Chaudhuri
King's College London

Many people with Parkinson's have a number of non-motor symptoms including, for example, memory loss, anxiety, hallucinations, fatigue, mood changes and depression. These non-motor symptoms often do not receive the recognition they deserve, although they can be more bothersome than motor symptoms. It is highly significant that non-motor symptoms are more prevalent than motor symptoms and indeed, hospitalization of people with Parkinson's is often due to non-motor symptoms, rather than problems with movement. Professor Chaudhuri, a world-recognised expert on the subject, gave a fascinating outline of this often neglected aspect of Parkinson's, which had also been a key part of Prof Peter Jenner's presentation at the East Midlands RSN Research Forum in September (see EMRSN News 10, p 2)



(Disordered Background1, by gubgib: freedigitalphotos.net)

The key points Professor Chaudhuri made for individual people with Parkinson's is that non-motor symptoms precede the motor symptoms, can seriously adversely affect quality of life and can be measured independently, but are an integral part of Parkinson's and therefore need to be part of the treatment plan. It is essential that patients alert their doctors about the non-motor symptoms they experience, particularly those which they find most bothersome. He referred to the 'Non-motor symptoms questionnaire' which can be downloaded from the Parkinson's UK website at http://www.parkinsons.org.uk/content/non-motor-symptoms-questionnaire - Why not fill it in before your next visit to the consultant or specialist nurse, if only to remind yourself what issues you want to raise? The fact that the questionnaire lists 30 non-motor symptoms

speaks for itself. According to Prof Chaudhuri the average number of non-motor symptoms experienced by a patient is 6 – 8 but, very importantly, many of them are treatable.

Professor Chaudhuri emphasised that Parkinson's is a multi-system disorder, with 3 subtype groups of non-motor symptoms. It could be the case that two people, both exhibiting first stage motor symptoms, are affected very differently by non-motor symptoms, one being severely affected, the other only mildly affected. In this instance, each would require a very different treatment plan.

Other non-motor symptoms mentioned included pain, sleep disorders, bowel and bladder problems. Professor Chaudhuri noted that fluctuations in non-motor symptoms often only appear in the 'off-period' of the medication.

A summary of Professor Chaudhuri's presentation in Birmingham can be found at http://www.parkinsons.org.uk/forum/thread/57379 - together with a short interview on his main points at http://bit.ly/1fZ7du0 - A webcast which includes Prof Chaudhuri's presentation on non-motor symptoms to the 2013 World Parkinson Congress in Montreal is at http://www.icastpro.ca/events/wpc/2013/10/03/3rd-world-parkinson-congress/play/1689 (2'25" - 28'25").

Chris Johnson

Thoughts for the future

Dr Oliver Bandmann

University of Sheffield

'The future is looking bright', said Dr Bandmann as he concluded his address. This followed his clear and at times amusing run-through of some of the more recent developments in understanding and treating Parkinson's.

Dr Bandmann started with the question that all people with Parkinson's have: Why did I get it? For a particular individual this can rarely, if ever, be answered. And so the complexity of this condition, which has dogged progress over many years, is revealed. Yet the good news is that in the last five or ten years researchers have got a much better grip on the origin of those complications. We now understand that Parkinson's is different for different people, that it is more like a collection of diseases than a single disease with a single cause, that it starts long before the first movement problems begin and that it doesn't start in, nor is it confined to, the part of the brain that gives rise to the movement problems. Indeed it could start in the gut, triggered by a toxic reaction to an ingested substance. We also know much more about how the disease process progresses.

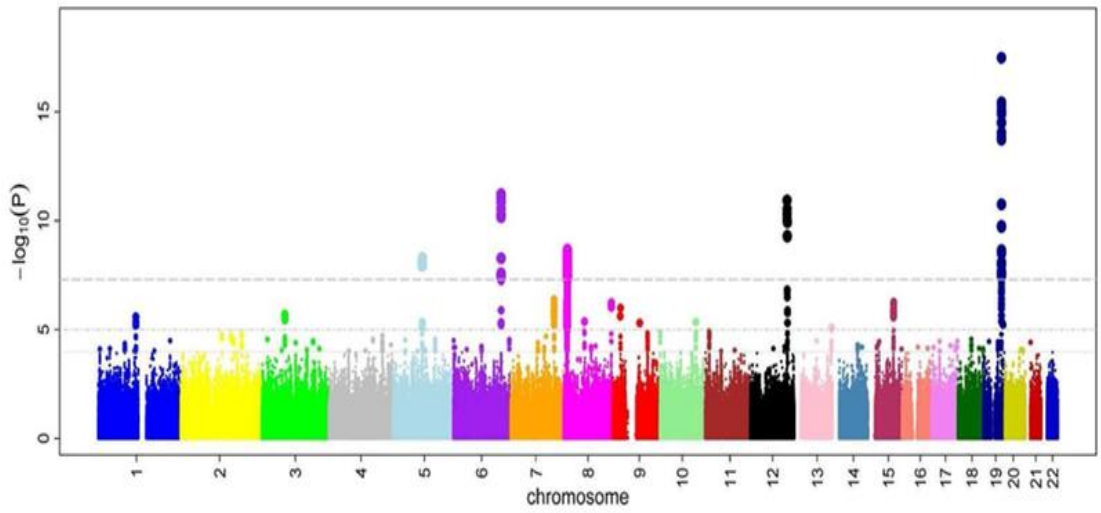
(Human Brain, by ddpavumba: freedigitalphotos.net)

He reiterated what Prof Chaudhuri said about non-motor symptoms, emphasising first that patients must alert their doctors about those non-motor symptoms which they find most bothersome; only then will they be able to get treatments which can be very effective – evidenced, he said by way of example, by the smiles on the faces of both partners on their next appointment following his prescription of Viagra. But similar positive outcomes –

smiles too - can be obtained for constipation, depression and sleep disorders amongst others.

He had his own personal take on brain cell transplantation and its limited potential, since it could not address all the areas of the brain where neurodegeneration occurred. Yet he pointed out a recent study that found some patients were still benefiting from foetal neural transplants – and still not needing Parkinson's medication - over 18 years following the operation.

Regarding genetics, Dr Bandmann said that the change over the last few years had been in understanding that there was not a 'single gene responsible for Parkinson's' but that it is a question of tiny variations in quite a large number of genes that can each increase the risk of developing the condition. The locations of these genes are being discovered by Genome Wide Association Studies (GWAS). A typical graphical output of this technique resembles the skyscrapers of the New York skyline and is known as a Manhattan plot. The tallest 'skyscrapers' represent the gene variations which are most strongly associated with Parkinson's as a result of genetic analysis of a very large number of patients.



File from the Wikimedia Commons. licensed under the Creative Commons Attribution 2.5 Generic license. Source: Ikram MK et al (2010) Four Novel Loci (19q13, 6q24, 12q24, and 5q14) Influence the Microcirculation In Vivo. PLoS Genet. 2010 Oct 28;6(10):e1001184. doi:10.1371/journal.pgen.1001184.g001

There is strong evidence for an interplay between environmental and genetic factors that modifies the risk of an individual contracting the disease itself. Once all such factors are teased out, Dr Bandmann foresaw that in the future a person could be offered a thorough multi-dimensional screening which would enable a treatment regime to be tailored to the characteristics of their particular variety of the condition. What's more, there could be a 'window of opportunity' in Parkinson's progression which would mean the earlier the treatment was given the better it would be for the outcome.

He only had time to mention briefly areas of active research relating to mitochondrial dysfunction, the impairment of the cells' garbage disposal systems and other pathways associated with Parkinson's. It was the sum total of all these efforts, however, that gave rise to his robust optimism.

John Telford

Obituary

It is with great sadness that we report the death on the 27th December of Jonny Stevens, who we met during the visit to Flaviano Giorgini's laboratories last year and who contributed a fascinating article about the visit to our July Newsletter (No. 8). Jonny was associated with the Northallerton Support Group, was a prolific blogger and contributed a lot to the Parkinson's UK online research forum.

Lionel remembers him in the following tribute.

Jonny Stevens

Some people make an impression on those around them because they appear to march to the sound of a different drum – Dr Jonathan Lee Stevens was one of these unique individuals. I remember a lab visit at Leicester University, meeting up with Jonny for the first and indeed only time. Here was a guy who was diagnosed in 2012 at the age of 33 and was struggling to cope with many unpleasant effects of Parkinson's but despite this he bravely tackled life head-on and was a prolific blogger, delving deep into his own unique philosophy and sharing it.

Jonny came up with a quirky, uniquely entertaining view of things in his writing - his article for our newsletter was unlike any we had ever seen, an original, amusing work that still stands out in my memory. But then, I don't think anyone who ever met Jonny will forget him.

See you later Jonny.

Lionel

Personal Perspectives

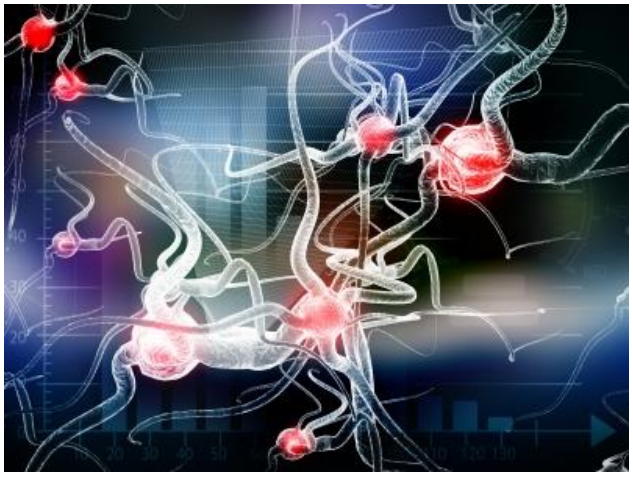
"Has anyone discussed the possibility of an operation called DBS or Deep Brain Stimulation to help you with your problems?"

This was the question which had a massive impact on my life. I was at an appointment with Lisa, my Parkinson's Disease Nurse Specialist, and I must admit that I knew very little about deep brain stimulation. I was on a large amount of drugs and had a pump fitted which delivered medication continuously throughout the day which gave very good results but the down side was that it made the injection sites swell and I had to go on a fairly regular basis to have my "lumps and bumps" treated. The other medication kept kicking out. My life was difficult as I was not sure what I would be like from one day to the next or more truthfully from one hour to the next. There were lots and lots of questions, which I had to ask and most of them were patiently answered by Lisa and the web access provided more information when I got home.

DBS is used for other conditions as well as Parkinson's and can have dramatic results. In a recent documentary programme on television, one lady was being treated for severe tremors by DBS and it was marvellous to watch as the shaking was virtually stilled in a short time as the stimulator started working, Wow! There are some brilliant people around who

have worked many such miracles over the last decade. There was a big 'but' here; my problem was not tremors but stiffness, especially if medication was wearing off. Lisa assured me that this op could help and afterwards the amount of medication should be decreased. It sounded great and I quickly made the decision to go ahead.

I was diagnosed with Parkinson's disease over twenty years ago. I was a schoolteacher and was having difficulty in rotating my wrist, which proved to be a problem as I taught a practical subject. I had not told anyone of my diagnosis at first, so I was desperately seeking ways of disguising my inability to do things which required speedy manual dexterity. Life was not easy, especially when I did inform my employers and they decided they could make me redundant.



(Neuron, by renjith krishnan: freedigitalphotos.net)

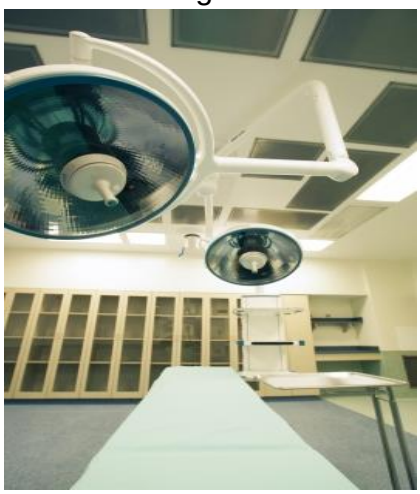
Now it was really exciting to find something which could make such a difference, if only I could have this operation. I know that there is no cure for Parkinson's but my life would be enhanced in so many ways. I was told of tests, which had to be done first to ensure I was fit for surgery and of course the subject of money is a big issue. The cost of the operation is over £30,000 and there would be further costs involved when the battery had to be changed; would the PCT fund this?

To my delight I was referred by my consultant to the neurological unit at Royal Hallamshire, Sheffield and I looked forward to the first appointment with a mixture of excitement and trepidation. I underwent a series of tests and assessments over the next months, some physical and some mental, the latter proving to be totally exhausting. The last hurdle was finally overcome when I heard that the PCT would fund the operation. I was all set to go and was admitted in August 2011.

Usually this type of operation is carried out in two consecutive stages with the patient being awake during the initial stages so that the effect of the positioning of the electrodes can be assessed; the anaesthetic is then administered for the rest of the procedure. In my case there was no need for me to be awake during the operation as I did not suffer tremors. I remember quite clearly arriving in the pre-op room and seeing all the people in their blue scrubs... and after that I really don't remember much except a few incidents.

Somewhere in the process something had gone wrong. Even now I do not know whether it was a problem which occurred during surgery or afterwards. Apparently one of the electrodes had moved. Why? I don't know. How? I don't know. When? I don't know. Did it occur during the operation or afterwards, as I was apparently bothered by the wires which trailed lose from the site of the op and I kept tugging at them? I remember none of this and have gleaned bits of information from my family and close friends who visited me. I was in a state of psychosis. I suffered all sorts of hallucinations. I was rude to members of staff and to my family when they would not do as I wanted them to do (and now I apologise to everyone as I really do not remember what happened). Time did not exist for me; I was unaware of minutes, hours, days. I did get up and walk around as I improved physically, and anyone who was taller than me was 'persuaded' to go for a walk with me around the ward. The staff were all very good (my family confirmed this), but I was a problem. The brilliant neurosurgeons have no idea what happened. The two concerned with my case have over three hundred of these procedures to their credit and I am the only one who has had this problem. No-one knows why. It is usually a very successful procedure.

My stay in hospital should have been about ten days but I stayed there for about six weeks and was then transferred to Nottingham where my neuroconsultant spent most of his working week. This was not a happy time for me as five years before this my husband had been very poorly, investigations were on-going and he was sent into Nottingham for further tests – only to discover he had an inoperable brain tumour. He was on the same ward as I was put in; in fact the bed was in the same position. When all this was realised it was not long before I was moved again to Derby.



(Operating Room, by digidreamgrafix: freedigialphotos.net)

I stayed in Derby until the beginning of December and much of my awareness of time came back to me, my general health improved and I was sent home, but had to return for a time after having a fall. After coming out for the second time I was in need of carers for some time, as I live on my own. Gradually I became much more independent and in August 2012 I returned to Sheffield to have my electrode put in its correct place, but after long negotiations with the team it was decided that the best thing would be to use one side only, which has had no detrimental effects – in fact I now have to think which side is 'on'.

Now am able to drive again, I can get in and out of bed myself, the stairs are no problem and I am up and down for most of the day. In short, I can do most of the usual things in life that anyone who is able bodied does without thinking – something for which I am eternally grateful to the team from Sheffield. All in all life is much improved. I still rely on my tablets and have the occasional "blip" and there are times when I need to rest more than usual. I know it will not go away but at present it is "tamed."

I must add another vote of thanks here. I would not have got through this without the support of my brother and sisters. They were fantastic and remain so. Family means everything.

Was it all worth it? A very definite yes!

Angela Rushton

(This article was written with the knowledge and consent of the neurosurgeon.)

Designing for dining with Parkinson's people

An interview with Emily Lukes

Wednesday 27th November 2013 found me attending the Leicester Branch meeting in Glenfield with our Steering Group Chairman John Telford. While there were a couple of other activities going on, our attention was drawn to some prototype samples of cutlery and crockery which were the first items made by Loughborough University student Emily Lukes for her degree project.

Emily's project aims to come up with designs for crockery and cutlery which would be easier for Parkinson's people to use, yet look stylish in their own right and also satisfy non-Parkinson's purchasers. Judging by my own look at these prototypes I think she has made an excellent start and will achieve these aims. Our interview follows:

Lionel: Emily, How long have you been working on this project?

Emily: I started this project in October with the school year and it will run for 8 months.

Lionel: What served as your motivation to start this project?

(Emily Lukes, photo: Lionel Paulo)

Emily: I am in my final year for my degree at Loughborough University and during the final year you have to pick a project to work on for 8 months for the end of year degree show. We were given the summer to decide which project we were going to do, and I was really stuck for ideas. Then, when I was visiting a friend we went round to visit her granny, and as soon as she heard I was a design student she said all the issues her husband had suffering with Parkinson's, and it just came out as the perfect project.

Lionel: Did you have any thoughts in mind as to how the cutlery should appear before any people with Parkinson's critiqued it?

Emily: The whole focus of this project is to make it inclusive, so although the cutlery and crockery at the end of this project will help people with Parkinson's to eat and drink and hold their knives and forks as long as possible before needing further care, the most important factor is that it must look good on the dining table and you must all be able to use it together as a family.

Lionel: Parkinson's people exhibit a wide variety of problems; is this equally true when they are eating, are there elements in common now you have talked to quite a few PD people? Did you find everybody saying they prefer the cutlery heavy or light, or did you get a wide variety of answers making it hard to pick something and nail it down?

(Mug, photo: Lionel Paulo)

Emily: I'm relieved that all my theory up to now is pretty much paying off. This is my first proper meeting with end users and it's been good to hear that my theory has come up really well, some of the things that I had put in that didn't have much meaning behind them other than they looked nice have come out really well. The lip on my mug has been really well reviewed for ease of carrying, so it's good to know my initial style has been well-received. I will be making some changes but it has been a very good start.

Lionel: Are you aiming to have these put into production and sold in the shops regionally or nationally or even internationally?

Emily: Well, although this is just a student project and it would not be expected to be put into production, I am planning to approach Denby in the next few weeks to talk to them for advice on developing my ideas further. They may just give some advice on manufacturing methods and I named this style, it's a very Denby style with the shapes I used and the material stoneware and it's made in England; hopefully Denby will really like this and want to produce it.

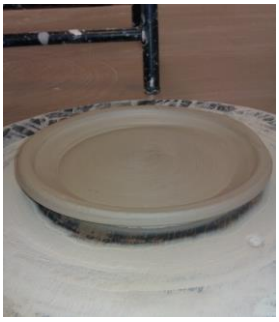
Lionel: Yes, if you can get Denby to back you that would be really good.

Emily: Yes, I'm trying to get it into the John Lewis range, and hopefully when it's finished you won't know it's for Parkinson's people, it will be able to be used by everyone, perhaps even scaled-down to suit children that have the same issues.

Lionel: Do you have any ambition to research Parkinson's disease further when you have completed this project?

Emily: I have been surprised how much I have found this project interesting, and I do wish to go into a career with inclusive design.

Lionel: Emily, have you got any advice to give to other people who would like to start a project of their own as to how they would go about it? Or would you say every project is different and it's a matter of having the initial thoughts and then acting on them?



(Plate inside, photo: Lionel Paulo)

Emily: You need a good idea in the first place and you must identify a real need, don't design rubbish just for the sake of designing something. Do your research and think outside the box, set your criteria you want to design for and be really stubborn about designing for them – use previous designs for inspiration but recognise the mistakes in them and keep designing until you find something that works in every way and answers the criteria that you want it to.

Lionel: One last thing, having talked to people with Parkinson's I don't know if you have seen any of us trying to eat, if so do you have any thoughts on what we can do to help ourselves when eating or drinking?

Emily: I only know what I have read on the internet, things like surrounding yourself with relaxing colours and music, not rushing and don't get stressed.

Lionel: Okay, thank you very much Emily, and good luck with your project.

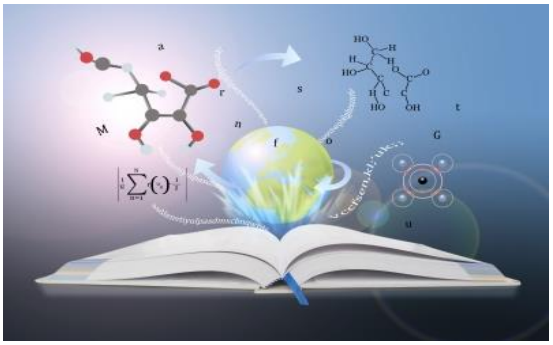
I am looking forward to the day when Emily's designs are on sale and will definitely be a customer – when it happens I will let you know through the pages of this newsletter, and you can benefit from her inventiveness yourself.

Lionel Paulo

"Has This Been Researched?"

A question and answer forum on Parkinson's research

This newsletter was recently renamed 'East Midlands RSN News' and we are now aiming to be more up to date with research news by switching to monthly publication. Our priority must be to provide information on research that you, dear reader, would want to know about. Whether you are an RSN member or not, we do know you are interested in research because you are subscribed. What we don't know is what specific areas of research you are keen to learn more about; or perhaps you have heard about or been involved in new research that we are not aware of.



(Book of Knowledge, by Natara: freedigitalphotos.net)

A new feature, to be introduced in February, will open up the newsletter to your input. You are invited to ask questions on any aspect of research, or tell us about new research you have heard about, or even tell us about your personal experiences with or concerns about anything to do with research. This can be done anonymously if you don't wish your name to be mentioned. We will then endeavour to find out answers about the topic that receives the most questions and these will appear in the same edition. We will invite readers' responses and further comments to be included in the following edition, along with answers to the next subject that has drawn a majority of questions.

As you can see, you, our readers, will be helping to steer the content of the newsletter in the direction you want it to go. We must start somewhere, so we have picked the first subject to

discuss, in the February edition, which will be 'Depression', a problem that many Parkinson's people live with. Following topics will be readers' choices.

In order to allow us enough time to research and prepare answers before publication, we request that you submit your questions for our March and subsequent editions as early as possible. Questions can be sent by e-mail to Ian Billcliff at imb248@outlook.com, or to Lionel Paulo or John Telford, whose e-mail addresses are found on page 2.

Ian Billcliff / Lionel Paulo

Coming Up ...

17 February 2014
1.30 for 2.00 pm

Newark Branch Meeting, Holy Trinity Community Centre, Boundary Road, Newark NG24 4RU

A talk by Professor Roger Barker of Cambridge University about Gene Based Therapy. In order to attend, you need to have contacted Trisha on 01636 821479 or Peta on 01636 821985 by 17th January.

22 March 2014
10.30 am to 1.00 pm

Researchers' Meeting at Leicester University

The main purpose of this is for researchers to exchange information on their work on Parkinson's amongst themselves and to discuss areas of mutual interest.
There will be a small audience of lay people, who will be present mainly to 'listen in' on the discussions. Because of time constraints, a basic understanding of Parkinson's biology by attendees will be assumed and some of the projects described will require some background knowledge to understand them fully. Time will be reserved for input from RSN members present.
If you wish to take up this open invitation to attend, please e-mail John Telford on jntelford@ntlworld.com or Ian Billcliff on imb248@outlook.com

September / October 2014:
East Midlands RSN 3rd Annual Conference

Return to top

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 **Monday 3 February**. Please send us a copy of your newsletter and event notices.

Editor: Ian Billcliff (imb248@outlook.com)

Editorial Group: Lionel Paulo, John Telford, Chris Johnson

We look forward to hearing from you!