I move, you move, he-she-it moves. We move, you move, they move. We are all ON THE MOVE.
Editorial

by Peggy Willocks

Thematically, this issue of ON THE MOVE is about “Measurement and Monitoring.” If one had to choose the dominating cause contributing to the success (or failure) of clinical trials, it would be finding the right measurement. Trial designs and protocol must be carefully selected before the pre-trial testing ever begins. Inclusion and exclusion criteria are highly important as are outcome measurements. But, setting the endpoints and how you will measure the data objectively has the greatest influence on finding a statistical difference. In other words, what assessment tools will be used clearly must show that the intervening therapy or treatment made a statistical difference in a particular clinical trial.

ON THE MOVE was created by individuals at the grassroots level. There is no suggestion or indication from administration as to what content will be used. Neither are there assigned persons for topics. We just utilize our grassroots’ networking system, and it all comes together. The beauty of it all is that it’s free—it doesn’t cost a thing except for volunteers giving their time. And yet, some of the best ideas and outcomes are realized using this “shared” methodology.

Read the historical account of the GDNF story, masterfully put together by Linda Herman from Buffalo, NY. And it’s very accurate, because she was there, sitting with the original glial cell line-derived neurotrophic factor (GDNF) trial researchers and a handful of patient advocates from the Parkinson Pipeline Project in the USA. In fact, the Cure Parkinson Trust was born when its founder, Tom Isaacs, came to the Michael J. Fox Foundation to meet with other patient advocates to hear about Neurturin, another growth factor that lost to the approval battle over a decade ago.

So why is it important to support publications like ON THE MOVE? Because of all of the knowledge, experiences and people who want to have ownership in finding a cure. Next question?
<table>
<thead>
<tr>
<th>Title</th>
<th>Author</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Editorial</td>
<td>Peggy Willocks</td>
<td>2</td>
</tr>
<tr>
<td>The Oscars</td>
<td>Jon Stamford</td>
<td>4</td>
</tr>
<tr>
<td>GDNF Saga 2004 – 2014: A Personal Account</td>
<td>Linda Herman</td>
<td>5</td>
</tr>
<tr>
<td>Rallying, Freezing, Mobbing and Challenging: Two days in Grand Rapids, Michigan</td>
<td>Shelli Bell</td>
<td>10</td>
</tr>
<tr>
<td>Self-Tracking in PD</td>
<td>Sara Riggare</td>
<td>13</td>
</tr>
<tr>
<td>Robin Williams</td>
<td>John Dean</td>
<td>15</td>
</tr>
<tr>
<td>Need More Clinical Trial Participants?</td>
<td>Jean Burns</td>
<td>16</td>
</tr>
<tr>
<td>Happy Snappy</td>
<td>Jon Stamford</td>
<td>18</td>
</tr>
<tr>
<td>Help Unlock Information with Health Unlocked</td>
<td>Leslie Davidson</td>
<td>22</td>
</tr>
<tr>
<td>Cultivating the Mind as Medication</td>
<td>Pamela Quinn</td>
<td>24</td>
</tr>
<tr>
<td>PD Me</td>
<td>John Dean</td>
<td>26</td>
</tr>
<tr>
<td>A Quiet revolution in research</td>
<td>Jon Stamford</td>
<td>27</td>
</tr>
<tr>
<td>Questions of Judgement: Results from the Research Club</td>
<td>Jon Stamford</td>
<td>29</td>
</tr>
<tr>
<td>Swapping Notes</td>
<td>Jon Stamford &amp; Ray Chaudhuri</td>
<td>31</td>
</tr>
<tr>
<td>Keeping a Clinical Trial Journal</td>
<td>Jean Burns</td>
<td>35</td>
</tr>
<tr>
<td>How I Became Bionic</td>
<td>Catherine Oas</td>
<td>37</td>
</tr>
<tr>
<td>Raising Lazarus</td>
<td>Jon Stamford</td>
<td>39</td>
</tr>
<tr>
<td>OTM8 Comments</td>
<td></td>
<td>41</td>
</tr>
<tr>
<td>Epilog</td>
<td>Peggy Willocks</td>
<td>42</td>
</tr>
</tbody>
</table>
The Oscars
by Jon Stamford

It’s always nice to be able to report successes and recognition where it’s deserved. And I’m delighted to report that two senior members of Parkinson’s Movement have received significant awards in the last few weeks.

Anne Martin

Anne Martin, a Parkinson’s Disease Nurse Specialist (PDNS) working at King’s College Hospital was recently honoured by the PDNSA with the nurse of the year award for services with younger people with Parkinson’s and the development of nursing services in this field. This was at least partially in recognition of her work on the PM webinar series but also for the services she helped develop by email and meeting nurses at conferences for younger people with Parkinson’s. Two thirds of Anne’s workload is younger onset Parkinson’s under the age of 55 starting at the age of around 25 years old. Young onset people with Parkinson’s are often complex at diagnosis and need time. They need early education and to be empowered with knowledge of Parkinson’s. KCH has nurse-led all-day clinics with flexible appointments to fit around people and their work and families and evening clinics every 3 months for those who find it hard to come to clinics in the day time.

Israel Robledo

Israel Robledo will be familiar to everyone reading this, I’m sure. One of the brightest lights in Parkinson’s advocacy, a man of honesty, compassion and energy, I think of him as a brother. Israel recently received the Milly Kondrake Award For Outstanding Advocacy from PAN, the Parkinson’s Action Network. For those who know Israel well, this award is well deserved. Israel is a deep, philosophical and above all human person who thinks profoundly on so many issues. But more than that, Israel is a doer. If he says he will do something, he will. His word is his bond. And Israel’s influence in the relatively short time that he has been an active advocate is enormous. He inspires those around him and accepts no limitations to what he can achieve. But above all, Israel is the same man whether talking to an old crumpled man in a wheelchair or a senator in Washington. He tells it like it is, and I count myself privileged to have him as a friend and blessed to have him talk with me as a brother.
GDNF Saga 2004 – 2014: A Personal Account

By Linda Herman

In September 2004, Amgen terminated their clinical trial of GDNF (glial cell line-derived neurotrophic factor) for Parkinson’s and banned its further use in humans. The GDNF protein was delivered to the brain through a catheter and was powered by a pump implanted into the abdomen. GDNF was considered one of the most promising treatments in the PD drug development pipeline and was expected to reach clinical use in a few years (2007 was mentioned). Patients from a Phase I open label trial reported great improvements, and they desperately wanted to continue their treatment. Other people with Parkinson’s (PWP), especially those in advanced stages, considered GDNF to be their best hope to stop the disease’s progression and to restore destroyed neurons. Our hopes were shattered when Amgen pulled the plug (and the pumps).

But looking back over the last ten years, I realize there also was a positive result. Although we didn’t know it at the time, on that day, a “parkinson’s movement” was born.

Part 1 of the “GDNF Saga” appeared in the April 2014 issue of ON THE MOVE—as part of a book review for “Monkeys in the Middle” (see issue 8 no.2, p. 39), and it related the many controversies swirling around the Phase II clinical trial, labeled as a failure. This article, Part 2, reviews the years from 2004-2014. How did GDNF advance from sitting unused in Amgen’s lab to currently being tested in two ongoing clinical trials, in the U.S. and the U.K?

Many PWP had been hopeful about GDNF being “the cure” or at least able to provide more effective and reliable treatment for PD symptoms. And perhaps it might even be neurotrophic and neuro-regenerative. Many of us remember seeing Dr. Jeffrey Kordower’s videos of MPTP induced monkeys who received the GDNF infusions and appeared to be normal again. We met with trial participants who said they had gotten their lives and their smiles back with GDNF. Both of the earlier Phase I trials had positive results (1), and most of the Phase II patients also were beginning to experience improvements, after about 6 months. But this fact could not be included in statistical analysis and based on the numbers, the Phase II trial did not meet its principle endpoints at 6 months, and was labeled a “failure.”

When questions about the possible presence of antibodies to GDNF and other safety issues were announced, many neuroscientists and biotechs lost interest in continuing GDNF research. Most of the trial participants were very willing to continue the treatment while research continued. The FDA approved of this plan, but Amgen refused to provide the GDNF. “It doesn’t work and it might be dangerous” they claimed. At the same time, they refused to release their patent for GDNF to other researchers and institutions even though offers were made.

But PWP, doctors and scientists, who still believed in the promise of GDNF didn’t let the issue die; it was too crucial for all of us. An advocacy group, “GDNF 4 Parkinson’s,” formed to uncover more information about the study, and the decision to halt clinical trials. For the first time, trial participants joined with PD grassroots advocates, trial doctors, researchers, and PD organizations (mainly the Parkinson’s Disease Foundation) to convince Amgen to release its hold on GDNF, and reinstate treatments for the current participants. The company refused to discuss GDNF with anyone until the study was published in a medical journal. That finally happened in March 2006—18 months after the trial halt. The toxicology report was not available until August 2007—3 years after the halt. There was very little opportunity to have a dialogue about these opposing view-
points, and most people just moved on. But a small group kept the GDNF saga alive.

The long-awaited article in the *Annals of Neurology* stated that the Phase II clinical trial study failed to meet its primary endpoints, and there were possible safety issues—antibodies had formed in a few individuals. And there was evidence of cerebellum lesions in a few of the lab monkeys that had received the same kind of GDNF infusion. No adverse events were seen in the 100 people who had received GDNF in prior studies. When the tox report for the primate study was finally published, it offered little new information. The authors did advise the primate study sample was too small and they could not definitely conclude that GDNF caused lesions in the monkeys. They recommended additional primate studies. In response, Dr. Michael Hutchinson, one of the Phase II trial doctors, reanalyzed the data and concluded that out of the 4 monkeys that had cerebellum lesions, all had received very high doses of GDNF which were then abruptly withdrawn. The antibodies turned out not to be a problem. They occurred only in patients whose catheters became dislodged and subsided with no complications when the treatment ended.

Why were there such differing results between Phases I and II? Among those opposed to terminating the trial and benching GDNF, the main criticism was that there were too many differences in trial designs, such as the size of the dose, the pump/catheter systems, and the infusion methods, to allow meaningful comparison. The statistical analysis was also challenged—especially that the very small number of subjects may have caused the study to be underpowered and “thus incapable of ruling out a large effect of GDNF on Parkinson disease.” So the GDNF did not fail, but the trial design and delivery methods did. The outcome of the study should be considered inconclusive, not negative.

To Amgen’s credit, over the past decade, they did supply GDNF for pre-clinical research, to address the safety issues and determine the best target area in the brain and the best way to deliver the right amount of the GDNF. I wasn’t expecting to find as much research as I did, but it is limited to animal studies. They did set the stage for a renewal of clinical testing on humans.

The consensus now is that the putamen needs to be adequately covered for the GDNF to be successful. The delivery of the gene should be very precise and targeted. A number of methods of delivery are currently being studied and two are recruiting for clinical trials (see Clinical Trials below). Both trials will be using convection enhanced delivery (CED)—the use of pressurized infusions for safe, targeted, and homogeneous delivery of agents into small and large tissue. CED bypasses the blood–brain barrier, which has made it so difficult to deliver therapeutic agents into the brain right on target.

**GDNF Clinical Trials**

Ever since GDNF was banned in 2004, the return to clinical trials is something that many PWP have been reading about, talking about, planning for, working for, and always hoping that the trials will start soon. Currently there are two trials underway, and both are recruiting.

At the University of California, San Francisco, Dr. K. Bankiewicz has perfected surgical techniques for implanting genes precisely using “a novel interventional magnetic resonance imaging (MRI) targeting system to achieve precise, real time convection enhanced delivery.” The Clinical
trial is being housed at the NIH, and they are recruiting for the Phase I trial that started in May 2013.

Here are some of the comments about the NIH trial by 4 participants.

“Advocates have to practice what we preach and step up to the plate to volunteer. This is the one we have been waiting for nearly a decade so whatever the outcome it warrants the risk in this trial.”

“NIH wonderful facilities and excellent staff. It’s a shame that they haven’t attempted to draw on the experience of the trial participants about what in addition to GDNF is needed to heal from PD.”

“It’s a privilege to participate in a trial run by NIH. We all waited so long for some form of GDNF to be made available to patients in the form of a trial. I just consider myself to be lucky to qualify and participate at this time.”

“As a PWP who was a supporter of GDNF 4 Parkinson’s many years ago, I find myself wondering, where is the excitement in the PD community? Where are the volunteers for the trial?”

To learn more see: AAV2-GDNF for Advanced Parkinson’s Disease:
clinicaltrials.gov/ct2/show/NCT01621581?term=gdnf&rank=1

Across the pond in Bristol, UK, Dr. Steven Gill, funded by the Cure Parkinson’s Trust, developed a smaller and improved device that fits behind the ear where tiny plastic tubes are connected to a port in the brain. GDNF is infused through the port once a month, instead of the continuous delivery used in the earlier trials.

The Phase I has been completed and recruitment is underway for Phase II, which will be a placebo controlled double blind study. (8)

To learn more about the trial see:

http://www.parkinsons.org.uk/content/clinical-trial-test-gdnf-parkinsonsuitment

http://www.cureparkinsons.org.uk/News/gdnf-study-in-bristol-now-recruiting

Business Matters

We don’t know the reason, but in 2008, (4 years after the trial halt) Amgen quietly transferred its license for the GDNF gene to Amsterdam Molecular Therapeutics (AMT), a small biotech company in the Netherlands, to be used for development of a gene therapy treatment for PD. The gene would be combined with AMT’s proprietary adeno-associated virus (AAV2) gene therapy platform.

In Jan. 2012, AMT was informed that the European Commission’s Standing Committee would not grant marketing authorization for Glybera, a therapy for treating lipoprotein lipase deficiency. More data was required. This was the company’s lead project, and AMT was running out of money.

More bad news for AMT. In Feb. 2012, Amsterdam Molecular Therapeutics “announced today that its board of directors is recommending a substantial corporate restructuring and financing transaction which, if approved by shareholders, will result in the assets and certain liabilities being acquired by a newly formed private company uniQure BV, also based in the Netherlands” (press release).

In March 2012, AMT was dissolved, and their business and operations went to uniQure.

See:
uniQure BV is a private company, also in the Netherlands created specifically for the Transaction. uniQure will act as the new holding company for the gene therapy business (press release).

In June 2012, uniQure signed an agreement to partner with UCSF and the NIH on GDNF gene therapy for Parkinson’s.

In July 2013, Dr. Krystof Bankiewicz, UCSF, was appointed chair of uniQure’s CNS Scientific Advisory Board.

The gene therapy developed by researchers at the University of California, San Francisco (UCSF), uses the GDNF gene, which uniQure (formerly Amsterdam Molecular Therapeutics) licensed from Amgen.

So the GDNF gene is now housed in uniQure. It seems like a good home. Hopefully, data and access to GDNF will be made available to other researchers. This is almost a model collaboration between an academic research center, a biotech and the NIH to cure Parkinson’s. All that is missing now is the voice of the patient.

Another surprise was the out licensing of Amgen’s GDNF protein to MedGenesis, a biotech in Canada. In January 2010, Medgenesis announced “that it has successfully entered into an agreement with Amgen granting MedGenesis an exclusive, worldwide license for glial cell line-derived neurotrophic factor (GDNF) protein in CNS and non-CNS indications…” subject to the rights of a co-exclusive licensee for CNS indications in certain countries...“As part of the license agreement, Amgen now holds a small equity stake in MedGenesis…”

“MedGenesis also granted BioVail, another Canadian biotech, license to its Convection Enhanced Delivery (CED) platform for use with GDNF in CNS indications. MedGenesis and Biovail will initially focus on the development of GDNF for Parkinson’s disease,…” (press release). In 2010 the Michael J Fox foundation awarded a grant of $2.1 million to MedGenesis Therapeutix Inc., and Biovail Laboratories International SRL to further their collaboration in the development of GDNF, referred to as “a first in class disease modifying agent.”

See:
https://www.michaeljfox.org/files/accelerate/participants/MedGenesis%201.pdf

Conclusion

This article is both a history of the GDNF clinical trials and a personal account of a grassroots campaign to reinstate GDNF clinical trials and research. I have been following the development of GDNF since the trial halt in 2004. GDNF 4 Parkinson, was formed very soon after to uncover more information about the study, and the decision to halt clinical trials. For the first time, trial participants joined with PD grassroots advocates, trial doctors, researchers and PD organizations (mainly the Parkinson’s Disease Foundation) to convince Amgen to release its hold on GDNF, and reinstate treatments for the current participants. Patients, doctors and scientists from all over joined together both in person and online to support the trial participants’ appeal for compassionate use to reinstate their treatments.

The lives of every PWP would be affected by Amgen’s decision. If it had been allowed research to continue, who knows where we would be today? The animal research that was allowed during this period surely perfected the delivery methods that are now being used, but it took four years before Amgen granted license to another biotech. It took 8 years for the first new GDNF trials to start up. That’s a long time for a PWP.

GDNF 4 Parkinson’s failed to achieve a change in Amgen’s policy, but if not for our advocacy, GDNF probably would not been given another chance.
What we learned

Research should be patient-centered.

Patients should be a part of the research team at every level.

We need objective measures of symptoms that will consider the variability of symptoms between individuals and within each individual depending on the time of day, activity level and emotional state. Incorporate these into trial design and evaluation of statistical data.

Researchers should share data with other scientists. Completed studies should be available on the web immediately, before the journal article appears in print.

The informed consent should include an understandable explanation of why or why not trial participants will have access to the experimental treatments that work well for them. Patients in a Phase 2 or 3 trial who were in the control group, should be offered treatment at the end of the trial, if they want it.

Benefit/risk decisions should be made by the patients.

If everyone in the Parkinson’s community works together to fight PD, we might really see the cure in 5 years.

CITATIONS


3. Hovland DN. Et. al. Six-month continuous intraputaminal infusion toxicity study of recombinant methionyl human glial cell line-derived neurotrophic factor (r-methHuGDNF in rhesus monkeys.. Toxicol Pathol. 2007 Dec;35(7):1013-29.


Available online at: http://www.parkinsons.org.uk/sites/default/files/gdnftrial_patientinfosheet.pdf
Rallying, Freezing, Mobbing and Challenging: Two days in Grand Rapids, Michigan

Shelli Bell

Whenever the Parkinson’s community comes together there is an energy. A jolly atmosphere of people who believe in the possible. The Van Andel Institute in Grand Rapids, MI was no exception as it hosted the latest electric gathering of Parkinson’s rock stars in September. This was another event where friends and colleagues joined not only to learn and discuss the newest in research and ideas, but to be a family. I have no idea if other diseases spawn such a strong culture and community identity as PD, but I am continually in awe of the global network and skills of people with Parkinson’s (PWP’s). It seems that everyone knows everyone else and at times starts to feel a bit like an Appalachian wedding without the inbreeding. Forget Kevin Bacon, the PD community has one degree of global separation thanks to technology. Those networks have networks. For a newbie this is impressive as well as comforting.

This particular PD show was kicked off by Professor Andrew Lees’ acceptance of the Jay Van Andel Award for Outstanding Achievement in Parkinson’s Research. The future of PD research has a solid foundation in a man who channels the likes of beat movement icon William S. Burroughs and Sherlock Holmes. He confidently informed us that he is trying to start a revolution. Hallelujah. His revolution, if I followed him correctly through my haze of creeping akathisia, commands that we use more than evidence based medicine and research to make decisions. By channeling Burroughs, he urged us to embrace a restructuring of research environments to once again allow serendipity as part of the design for a new way forward, urged us to find a way to escape the stranglehold of escalating overregulation, and urged us to learn from history—many of the leaps of the last century were due to “sticking to instinct” and “flying crooked.” In short, Dr. Lees feels that bureaucratic overregulation is delaying or even stopping research to the tune of lost billions in research funds every year. He did have something in the bottom of his Pandora’s box, however. He reminded us that chance favors those in motion and that happy accidents stem from a willingness to experiment in life. Wise words.
So then if chance favors those in motion, it only seems fitting that what was arguably the most meaningful part of this gathering was put together by people who are constantly in motion: The Rallying To The Challenge Meeting courtesy of the VAI and Parkinson’s Movement. To borrow words of PM’s Tom Isaacs, it appeared to be a huge leap forward in addressing the need for a “paradigm shift in language, attitude and culture” in Parkinson’s research. The VAI’s press release for RTTC called it a “one of a kind patient centered meeting which will highlight the many ways people with PD can impact the clinical trial process and accelerate access to new PD treatments.” In its concept, the RTTC meeting was to be a discussion and brainstorming of how clinical trials can be improved and how patients can influence their success in positive ways. Prior analysis of a survey, generated and distributed in large part by Jean Burns (Hi Jean!) identified perceptions, practicalities and teamwork as key areas for making this happen. This was clearly the big ticket show and wasn’t on the obvious agenda to someone who registered late and was too chicken to crash something that she wasn’t registered for. Ultimately, had the coffee break offerings not been so distracting (OMG VAI! Nice work on the peanut butter flapjacks***) and new friends not so fun to chat with, I would have realized I could have taken my stash of flapjacks and tea to listen in on the RTTC breakout group discussions without hindrance. Not the end of the world, it turns out. My love for pb flapjacks has been rekindled and I made a couple of new friends who were not only charming but full of helpful information about self tracking, ways to get involved and who to avoid at recess.

The next day the PM executive lineup (Steve DeWitte, Tom Isaacs, Israel Robledo and Jon Stamford) reported the RTTC collective findings to the whole meeting cohort—scientists, patients and clinicians. Intensive discussions over the previous 24 hours had identified several aspects of clinical trial management, recruitment, execution and communication where significant improve-
ments could be made. But this was no talking shop -- each of these points was linked to an action and the weight of these should become apparent over the next many months as PM seeks to establish a charter of good practice.

If the RTTC discussion and report was the most meaningful part of the conference, then Wednesday evening’s synchronized freeze mob in downtown Grand Rapids was the most memorable. From a patient perspective, cognitive changes, target validation and fly/ primate/non-human research models are enlightening (depressing) but the real money is on the people. A busload of frozen Parkies and Parkie groupies made a powerful statement that nailed the claim on our t-shirts. Still Life (A triple entendre that some neurodegenerative catchphrase genius no doubt invented in the bath). Freezing as performance art with people who are continually in motion. It was an event second only to singing Wonderwall at 2 a.m. with a pub full of Parkies (and you all know who you are) in Montreal at the WPC a year ago. These things give us hope. They bring a touch of levity to our purpose beyond making dopamine agonist jokes. They help us do more than endure. They set the tone for gatherings to come and remind us all that these people are why we keep going, why we keep talking and fighting, why it is worth searching for a cure, and looking forward to seeing you all next time.
Self-Tracking in PD

by Sara Riggare

If you’re reading this, I assume that you know what PD is, or Parkinson’s disease, as the unabbreviated form reads. I assume that you are familiar with the symptoms and signs of Parkinson’s, either because you, like me, have been diagnosed with it yourself, or because you care for someone with Parkinson’s, in a professional capacity or as a family member or friend.

The other part of the title: “self-tracking” is probably less familiar, even though I am sure that some of you readers have some sort of perception of what “self-tracking” might entail. I am guessing that most of you then think of gadgets and devices, cool-looking technology, often used by ultra-runners, long-distance cyclists and other people seldom associated with Parkinson’s or other chronic conditions (yes, Alex Flynn, I know there are exceptions to that rule :) ). I will not pretend that I don’t appreciate technology, anyone who knows me even slightly would immediately call my bluff. I’ll be honest: I LOVE gadgets, devices, technology in every form! But, to me, self-tracking is so much more than technology!

Self-tracking is, in my opinion, the most powerful weapon I can wish for in my battle against Parkinson’s and I will explain why.

I see my neurologist once or twice a year, about half-an-hour every time. That is one hour per year, and the rest of the year’s 8,765 hours, I spend in selfcare. I am sure it is the same way for a lot of you out there as well. This means that I am directly in contact with healthcare’s practises and clinical guidelines for my Parkinson’s during no more than one hour per year. And it is only during this one hour that my neurologist can assess my symptoms, observe how my condition progresses and evaluate my status. It is also during this one hour per year that my treatment is being prescribed, different medications and other interventions. But it is during the rest of the year’s 8,765 hours, that I implement the treatment. Because, let’s be honest, my neurologist doesn’t even know if I take the medications he prescribes. But, probably most important, it is during the 8,765 hours in selfcare that I can observe the effects of the treatment. And this is where self-tracking comes in.

In my opinion, self-tracking is a very wide concept. It involves any and all activities where you observe yourself and any effect you might or might not have from any activity, treatment or similar. For example if you find that something you eat doesn’t quite agree with you, you are likely to make a mental note and the next time you are offered the same food, you will probably decline. Self-tracking can also be done using technology, such as a scale. Yes, of course weighing yourself can be regarded as self-tracking.

The U.S. based organisation The Pew Research Center’s Internet & American Life Project did a study in 2012 called “Tracking for Health” (http://www.pewinternet.org/2013/01/28/tracking-for-health/). They found that 69% of adults in the U.S. kept track of at least one health indicator, for example weight, diet, exercise routine or symptom. The study also shows that most people do not use any technology to self-track, most people track in their head and if a tool is used, the most common is actually using pen and paper. Not very high-tech, right?

So, why do people self-track? Why go through the trouble? Again, Pew Research found in their study that 63% of the trackers stated that self-tracking in some way had helped them with health issues.
The same is true for the trackers living with one or more chronic conditions, but to a higher degree, as many as 76% of the trackers with chronic conditions claim that the tracking has done at least one of the following: affected their overall approach to maintaining their health, led them to ask a doctor new questions or seek a second opinion, or affected a decision on how to treat an illness or a condition.

I didn’t know all this when I started to self-track. In fact, I didn’t even know that there was a word for what I did. With my engineering background, I just thought it seemed to make sense to try to understand the in- and out-going parameters of the dynamic bioreactor that is me. But where to start? Which of the gazillion charming and appealing symptoms or side effects of PD should I try to track first? Well, that is the million dollar question, isn’t it? And since PD is a very individual disease, the answer might be different for all of us. Also our individual situations is probably very different. I am sensitive to Levodopa, so I take a very low dose and still get a good effect.

That’s why they call it self-tracking, it’s about finding your own best way to deal with your situation, condition, what-ever-ition!

Please let me know what you track! Comment on the tab “Sara’s Self-tracking” on www.riggare.se!

Take home messages:

⭐ Self-tracking is my most powerful weapon against PD!
⭐ Find your way!
⭐ Don’t track too much!
I was on a vacation this summer when the reports about Robin Williams’ suicide first appeared. Like so many others, I was truly sad to hear the news and surprised to learn that he was coping with a recent Parkinson disease diagnosis. However, as the media began to report, I became concerned as they highlighted the correlation between his diagnosis and his suicide. From my perspective, it seemed that they were ignoring all of the other risk factors that Robin Williams presented with: history of depression, his very public struggle with substance abuse, even heart disease, which are correlated with an increased risk of suicide.

From the perspective of the Parkinson’s community, I think the most potentially damaging element of this narrative is that the general population could equate Parkinson’s with some kind of death sentence or that suicide might some type of appropriate response to the disease, particularly in the earliest stages. To be sure, it is normal to experience situational depression when receiving a life-changing diagnosis such as Parkinson’s disease. However, it’s critical to recognize that the disease process itself will usually amplify symptoms of depression and other psychological conditions (including apathy as well as anxiety). Most importantly, I want to highlight the fact that there are treatment options, particularly because the link with Parkinson disease is so intertwined with the neurochemistry of the brain.

At the very basic level, Parkinson’s is a dopamine problem. There’s not enough dopamine being produced in the brain and as a result, there is a reduction of movement, energy and activity. And that is going to have systemic effects at all levels, including mental health. To be sure, this description is a significant oversimplification and the influence of the lack of dopamine is complex. However, neurons work closely together in a complex system and when the dopamine cells stop “firing” as frequently (due to loss of the dopaminergic cells), it has an impact on other cells in the vicinity. To quote one of my favorite doctors, Dr. Avi Kurtz, if you have a dopamine firing problem, you have a serotonin firing problem and a norepinephrine firing problem and a whole cascade of other neurotransmitters that are affected (not to mention the influence of hormones and fatigue and pain and changes in cognition etc...).

I think this is an opportunity to bring awareness to the Parkinson’s community that depression is often a biochemical fact of life with the disease and we should be helping to get people with Parkinson’s past the societal stigma of pharmacological treatment (and showing them how incorporating high intensity physical activity in conjunction with medications is likely what is going to provide the best outcomes). To the general population, it’s an opportunity to educate them about the link between depression and Parkinson disease. However, the most important opportunity here is to highlight the fact that the bulk of the people that we see with a diagnosis today have been or will be living with the disease for decades. And the vast majority of them are able to live full, happy and productive lives. I don’t say this to minimize the terrible nature of the disease but just to be certain that everyone recognizes that Parkinson’s disease isn’t some kind of death sentence. To be sure, it is a difficult disease but in my little corner of Colorado, we have a whole community of people living well with the disease and I’ve got to believe that is the case for most of the other Parkinson’s communities around the world.
Need More Clinical Trial Participants?
by Jean Burns

I have long been a proponent of clinical trials, having joined my first trial as a “de novo” person with PD (PWP) eleven years ago. And for nearly as long, I have been a patient advocate who believes that the US has an imperfect system where in general, its human clinical trial participants do not receive the respect or treatment that they deserve.

Why does the scientific community have such difficulty finding subjects for clinical trials?

The system is difficult and confusing to navigate.*

Interested participants call and ask about enrollment, but no one calls us back.*

We take part in studies, but we never hear the outcome of the trial.*

Many of us have advanced PD. We may not drive any more, and the study center doesn’t provide transportation.**

Many of us are on disability, and the study center doesn’t reimburse all of our costs.*

If we are injured as a result of a clinical trial, most trials do not provide care for our injuries.**

Our opinions are not valued.*

It is important to remember that EVERYONE in the drug development chain: companies, researchers, doctors, nurses. admin staff, cleaning teams, everyone, EXCEPT human participants are paid. Human trial participants donate their time and their health. How can it be considered unreasonable for us to request that all of our expenses be paid? Or that we be able to provide input about the trial?

What do patients want? What do patients deserve? How can the system change so more people are willing to participate in research?

If you expect us to be on time, we expect the same of you.

Make participation enjoyable. It is possible.

When planning tests and activities, consider our health and well being first. How will different times or combinations of requirements affect us physically or psychologically?

Make all travel arrangements, and prepay for them as well.

Make and prepay for any required hotel reservations.

Pick us up at the airport.

Give us vouchers or a reasonable per diem for meals at local restaurants.

Provide care for us (including long term care) if we are injured as a result of the trial.

All of this is possible. When I went to the Institute for Neurodegenerative Disorders (INDD) for every other year SPECT scans, the folks at INDD made all arrangements, including air travel, limo pick up from a
NY airport, hotel room, plus prepaid and vouchers for meals. My cousin from Chicago once met me there, and we had a delightful time sightseeing in New Haven in between my tests. All of the people to whom I told my experiences wanted to know “how could they do the same? How could they join that trial?” Believe me, if researchers treat us well and make the experience as enjoyable as possible, the word will spread, and there will be little trouble recruiting participants.

So when I hear the common lament that “we can’t afford to do that,” I would like to remind the research community that 85% of clinical trials are delayed, and 30% never get off the ground due to lack of participation. And although 60% of PWP say they are willing to participate in a clinical trial, fewer than 10% do.**

The original requests for reimbursement for travel and for greater patient involvement are nearly a decade old. Do researchers really have the time and the money to waste by not making changes now that will provide better treatment to the volunteers?

Treat us as if we were a precious commodity. We are.

*2014 Survey about Clinical Trial Participation - pwp experiences
#CiSCRPs Perceptions & Insights
**MichaelJFox.org website 2014

Jean Burns is Co-chair of the World Parkinson Congress (WPC) Advocates for Parkinson Committee. She is human participant #3 in the US National Institutes of Health (NIH) Phase I GDNF Gene Therapy Clinical Trial. In February 2015 she will take part in an NIH Ethics Grand Round discussion about caring for (or not caring for) human trial participants who may be injured during clinical trials involving brain surgery.
the reduction in physical abilities is somehow compensated by an improved imagination and sense of the aesthetic.

With that in mind, we founded the Parkinson’s Movement Photography Club (PMPC) in early February this year. I saw it primarily as
an opportunity to show one’s photographs to other interested parties, to learn from each other and to be stimulated and engaged.

The rules of membership were about as simple as it could be. Members had to have Parkinson’s and an interest in photography. That’s all. Oh and a willingness to share their pictures online. After eight months, the club is thriving. We currently have 41 members, mostly amateur but with the occasional professional. And we use a range of equipment -- some of the best photos have been taken on mobile phones!

If you are interested in joining PMPC, you can find us at https://www.facebook.com/groups/520958248018992/
Help Unlock Information with HealthUnlocked

by Leslie Davidson

Until the last few months, my night-life went something like this—the insomnia gremlins would start partying in my brain, setting me to tossing and turning, pacing the house, picking up and putting down whatever book I was trying to read, and finally landing me on the sofa, pulling my laptop onto my lap. Out of habit, the first thing I checked was my email and often, so often, because of the time difference between western Canada and the UK, the only new message would be from HealthUnlocked, the patient question and answer page for the Parkinson’s Movement.

When I was first diagnosed I resisted visiting such social media sites, especially the patient-driven ones. The stories from those who struggled made me sad. The upbeat messages from those who had found a way to carry the Parkinson’s load with practical acceptance and humour made me feel inadequate. I stuck to the “big name” sites, Michael J Fox Foundation, Parkinson’s Society of Canada, National Parkinson’s Foundation. What I found there was a wealth of information. I was grateful but overwhelmed by what I was learning and what I had yet to learn.

Then one day, on the Parkinson’s Society of British Columbia Facebook page, I read a post by Jill Carson. It was a passionate call to action, a challenge to PWP’s to engage in the fight for recognition, for treatment, for quality of life, a cri de coeur that spoke to my frustration with the casual nature of the medical treatment I had been receiving and to my latent, child of the 1960’s, “gimme a cause”-ness.

I wrote to Jill and she responded. I told her what her piece had meant to me and that I wanted to help but didn’t know how. She responded with her great heart and enthusiasm (those of you who know Jill will know what I mean) and with a bit of a challenge.

It went something like this: So, you’re telling me you haven’t had to do the depression piece of the disease. It seems like you have some skill as a writer. Those of us who have a voice need to use it.

And she shared the video she had made for the WPC 2013. Her story inspired me and shook me. Her challenges seemed so much greater than mine and yet, there she was, refusing to accept the status quo, and networking like crazy in order to engage others in the fight for better...better understanding, better therapies, better meds, better research, better communication within the Parkinson’s community, and with the doctors and scientists engaged in our cause. Through her I became connected to my other Parkinson’s sisters of the heart, eloquent Donna, my brave Terrie, the mother of re-invention, and beautiful Peggy, the reason I am sitting here writing for ON THE MOVE.

On the last night I was able to manage a midnight read of HealthUnlocked, I found myself in tears over the plight of an American first-grade teacher with 32 years experience.

She wrote: I tried to qualify for social security disability but have been turned down twice “because my symptoms don’t prevent me from teaching.” I am preparing for my final appeal through a hearing...I loved teaching but getting up at 5am to have time to get dressed (it is a process since I can’t lift my leg up high enough to put on pants). By 9:00 it is all I can do to stay alert and not curl up under the read-
I wish the people that are voting for me to return to the classroom had known me before PD.”

I responded to her with little to offer but sympathy. However, I knew where to turn and that was to Peggy, Peggy Willock, an American educator and respected Parkinson’s advocate. Peggy responded immediately to my email and sent me the link to an article she had written on the social security disability system. I passed it on via HealthUnlocked. I don’t know at this time how it has gone for this teacher, but I do know that her post prompted an outpouring of empathy and advice. I felt empowered simply because I knew someone who might help. Others had obviously fought the same battle and their successes empowered us all.

I haven’t been sitting on the sofa in the middle of the night much lately. My husband lives with rapidly progressing, early onset dementia. His primary diagnosis just two short years ago was Alzheimer’s Disease and now the doctor has added probable Lewy-Body Dementia to the mix. This past summer he went from sleeping through the night to waking and in need of support 5, 6, 7 times. I snatched sleep in between changing the sheets and incontinence underwear, wiping up the floor, calming his fears and trying to control my own. Almost overnight he developed later stage Parkinsonisms, muscle rigidity, curved spine, inaudible speech, balance impairment, a shuffling walk. Now he is in care. Kind, skilled people surround him, but I am heartbroken by my inability to continue to be his primary caregiver. And in this first week of separation my nights are plagued by dreams of loss. Our friends surround us both, and among them are my Parkinson’s sisters, sending love and concern by Facebook message, email, phone and Skype. Perhaps one day I will tell my story on HealthUnlocked. I will tell about how lack of exercise and stress exacerbated my Parkinson’s and what a positive difference just three days back on the treadmill has made. Maybe I will share how it feels to be a caretaker and how it feels to lose that role to one’s own limitations. I anticipate that there will be empathy and advice. I already know that I am not alone.

Something of Interest

On the ballot for November 4, 2014 election, the state of Arizona, in southwestern U.S., has a referendum for the state’s citizens to decide if they want terminally ill patients the right to access any drug or treatment that has passed Phase 1 (safety) clinical trials.

“Arizona terminal patients’ right to try referendum, Proposition 303”

The measure, if approved, would allow investigational drugs, biological products or devices to be made available to eligible terminally ill patients. The term “investigational” refers to medical treatments that have completed phase 1 of a clinical trial but have not yet been approved for general use by the Food and Drug Administration and remain under investigation in clinical trial.

Any drug that passes a Phase 1 (safety) clinical trial may soon be available to terminally ill patients in the state of Arizona.
Cultivating the Mind as Medication

by Pamela Quinn

I’ve been thinking about how to harness the placebo effect. Can one even consciously do that or does the belief and expectation required have to be totally real, not premeditated? I’m not sure. And then I think: does rational thought greatly diminish the possibility of placebo because placebo is about belief, not understanding. Does my intellectual curiosity deprive me of this possible benefit?

So where does that leave me? Then I ask myself, “What is the closest feeling I experience to placebo? When do I feel at my best and completely forget my disease?” (I have Parkinson’s.) The answer is that it’s while I’m exercising outside. I love to move, and I love nature. Most often these disease-free periods occur when I’m medicated. But on occasion, they have occurred when I’m not. And that’s usually been an instance when I’ve been really eager to do something. My suspicion is that my adrenal gland is adding its own dopamine. But placebo is not chemical-specific; it creates health, no matter what the condition. So that takes us back to the power of the mind.

Do these two mental states to which I referred, a wholehearted belief in a positive outcome and a total immersion in something other than what ails you and that you enjoy, have anything in common?

I think they do; they both are different ways of being that help to promote better health. The first method benefits from expecting a certain reality that in turn boosts one’s body chemistry in an underlying, unknown, complex, and positive way. The second involves the process of redirecting one’s attention away from a problem or disease while pursuing a joyful endeavor, giving you the support of happiness and an emotional vacation. This allows for health to work quietly on its own, unhampered by the daily struggle of coping and the underlying stress of anxiety, frustration and fear of what’s to come. The experience is kind of like learning something new, having a good night’s sleep, and understanding it fully the next morning. The body has a positive mind of its own. And in those moments of welcome diversion, are we just getting a vacation from disease, or is there any repairing or temporary halting of the degenerative process actually going on? And is this state something we can make into a habit?

Taking control of how we think or how we avoid negative thoughts and their impact on our health and love of life is an area where the arts and science intersect. The arts can allow for a total immersion into something else, as with painting a picture, throwing a pot, becoming a different character in a play or embodying the quality of a leaf falling in a dance class – all these things allow us to leave who we are for a moment and to exist in another reality. The power of being able to do that, to change ourselves, even if it’s ever-so-briefly, or to lose ourselves in another activity, can have broader implications concerning the control we have over our lives and how we become who we want to be. We don’t have to be the disease that lives inside us. There is much more to us than that represents, and we can simply make a conscious choice not to let it define us. The arts provide the possibility of enjoyable immersion and the power of transformation. And although those experiences are associated with the arts, they are by no means limited to them; creativity is an affirmation of the self, about producing something that expresses yourself.
The very act of making—whether it be a thought, an elegant solution to a problem, a way of dressing—counters depletion. It adds, not subtracts; it affirms, not negates. The doing, rather than the field in which it occurs, is of utmost importance. It reminds us who we are and that we are ALIVE!

I encourage planners of conferences to consider whom those functions are really for and to be sensitive to what psychological impact they are having on the participants. Patients need to leave motivated, inspired, encouraged, and even happy, even in the face of disease. In addition to helpful suggestions concerning practical difficulties, there need to be offerings that provide opportunity for change, for achieving something new, for adding to lives as distinct from dwelling on a disease that subtracts, for having hope. I'm not advocating denial...we have to be able to recognize what's going on with our bodies and to be able to plan for the future. But I also don't want to leave a conference with the predominant feeling being that what the future holds is only a downward trajectory. That promotes negative placebo—nocebo. I am in favor of making sure we find ways to nurture the spirit, because experiencing something transcendent, be it a poem, a painting, a baby, a concert, a sunset or a beautifully prepared meal is good medicine, even if its benefits are short-lived. (We then have to figure out how to integrate more of them into our lives to extend their positive impact.) The best moment I’ve ever experienced at a big conference (Southeastern PD conference in Atlanta organized by James Trussell) was a talk squeezed into lunch break by a couple—he had PD—who set out to walk the entire Appalachian Trail. Their enthusiasm, their desire to fulfill a life-long dream, their determination was very moving and motivating for me. That’s what I brought home.

As health providers, as doctors and teachers, we want to understand how we can set patients up for optimum possibility of mental and physical function in life, and to be conscious of the steps we take to achieve that. Do doctors explore with their patients, “What brings you the most satisfaction? When do you feel your best?” and conversely, “When are you at your worst?” These are simple questions but ones which need to be asked and addressed.

Sometimes I think the power of the placebo effect is small and big at the same time; it’s the stone that starts the avalanche. If we can make a small improvement that we didn’t previously think possible, that can lead to another and another and so on. In the book, “The Power of Habit,” author Charles Duhigg explains that changing one important habit, known as a keystone habit, can alter the circuitry of your brain and function as a catalyst for life-long change. How can we use this for health? How we think, how our bodies chemically respond to those thoughts, and how we escape in order to help heal are areas of practical medicine that we need to appreciate, understand and harness more effectively.

Pamela Quinn teaches movement therapy for people with Parkinson’s disease for the Brooklyn Parkinson Group, The Edmund J. Safra Parkinson Wellness program in collaboration with the JCC and for individual clients. She also lectures, writes, dances and choreographs. Her most recent presentations were featured at the third World Parkinson Congress in Montreal.
I’ve been working with a developer over the past year or so to develop PD Me™, a set of iPhone-based tools for assessing symptoms of Parkinson disease. The core design approach is to develop tests that readily makes use of the technology currently available in the iPhone without a lot of secondary sensors or other equipment. That presents some unique challenges but I think we have come up with an elegant solution.

PD Me™ allows you to assess memory, balance, reaction time and time perception in under two minutes. It offers a diary to track symptoms as well as data tools and a historical reporting system to track symptoms over time as well as in relationship to medication timing. All data is confidential and stays on your phone unless you choose to share it.

Please take a moment to look us up on the app store (sorry, only iOS only for now). We are currently working on other tools to incorporate into the basic app. We would welcome your feedback and as well as your ideas.

John M Dean MA CCC-SLP

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It may not have felt like it at the time but, at 10:30 AM on 18th June, Parkinson’s Movement began a quiet revolution in medical research when 16 people with Parkinson’s, some with their partners, met in a church hall in London’s East End. Six hours later, as the participants filed home by bus, train and car, the deed was done.

Revolution is a big word and it probably takes some explaining in this context. After all, what could 16 patients possibly do that would be revolutionary? And why in the East End of London? Indeed many of that 16 may have been unaware of just how far reaching their participation that day was.

The event was the inaugural meeting in the hall of St Botolph’s Church in Aldgate of the Parkinson’s Movement Research Club (PMRC), a group of patients with an interest not only in research per se but in taking an active role in research. It doesn’t sound much and, if that was it, there would be no revolution. Patients have taken part in research for many decades if not longer. Patients have been subjects in clinical trials for as long as there have been clinical trials. When scientists have called for volunteers, patients have stepped forward. Where’s the revolution?

The revolution lies in the detail. Because PMRC is different. PMRC does not involve scientists or clinicians. PMRC exists solely to conduct research that is of interest to patients. The research is designed by patients, conducted by patients on patients and analysed by patients. Patients design the experiments and patients analyse the data.

While the significance of that sinks in, let me say that, to the best of our knowledge, this is unique. The roles of patients on clinical trials have traditionally been very much subservient. Patients provide the data. Indeed patients are the data. Until recently that was the sum limit of their involvement. But with the increasing rise of patient advocacy, patient roles have expanded to the extent that many clinical trial committees now involve patients in some form or other. Patients are beginning to have a voice on the committees where trials are designed and conducted. A small voice perhaps, but a voice nonetheless. This increased involvement is a reflection of enlightened pragmatism on behalf of the clinical trial scientists -- the likelihood of enhanced recruitment -- as well as the ethical necessity of allowing patients to participate in their own long-term healthcare.

PMRC is, in many respects, the conceptual extension of that philosophy. It is the notion of patient involvement taken to its logical conclusion. For
instance there is nothing philosophically that dictates physician led research. Indeed the more one thinks about it, the more the conceit is apparent. Patients are the ultimate beneficiaries of research. Is it not logical then that they should determine its direction? And determination of direction is not achieved by patients being token representatives on medical and scientific committees. This is achieved by patients being those committees.

And at 10:30 AM on 18 June, we put that philosophy into practice. Over the course of the day, patients conducted research on patients that was designed by patients. No scientists were involved at any stage (except where they were also patients).

There are constraints of course. Experiments involving invasive procedures or drug administration are clearly non-starters. But those involving psychological assessments, sensory testing, as well as basic physiological function clearly fall within the remit of PMRC. And, as much as there are constraints, there are also openings. Experiments that are of little interest to pharmaceutical companies or too eclectic for academia find their natural home in PMRC.

There are other significant assets to the PMRC model. Not least is the timeframe. We obtain sufficient data in a day from our 16 participants to write a modest research paper. An academic institution, governed by statutes and ordinances, has constraints upon its ability to recruit patients for trials to the extent that such a study would probably take perhaps four months, longer if you include the impediments afforded by ethics committees, grant awarding authorities and local governance. If you factor in the need to get research funded externally, the timeframe could be more than a year. Not surprisingly, faced with such red tape, most academics simply give up. And who can blame them.

Patients on the other hand are ideally placed to design and execute such trials. Moreover, because the trials are designed by patients, one can be sure that they will be of interest to patients. It’s a win-win scenario. I don’t suggest for one minute that this sounds the death knell for current clinical research paradigms. However it does provide a clear model for patient-directed research sitting alongside physician-directed programs. And who knows—one day, we might even invite a physician or two to join our research panel...
In an entirely accidental way, our first 2 research club meetings have focused on the senses. The first meeting addressed the sense of smell whereas the second, in a slightly more circumspect way, involved the sense of hearing, albeit not as its primary focus.

It is well known that people with Parkinson’s often have an attenuated sense of smell. That alone is a striking finding, bearing in mind the possible role of the olfactory bulb in the development of Parkinson’s. So, in the first Research Club meeting on 18 June, we decided to examine the sense of smell in a group of patients and to see whether this correlated with factors such as age, medication or duration of illness. Although this work was done using the University of Pennsylvania Smell Identification Test (UPSIT), a more or less standard method for assessing the ability to distinguish smells, we also tried out a test of our own design based on the ability to distinguish between male and female fragrances, which we christened the ASAP test (AfterShave And Perfume).

The results are shortly to be submitted to the Journal of Parkinson’s Disease and subjected to peer review. With that in mind, I can only give the broadest outlines of the findings. Not surprisingly, we found that people with Parkinson’s felt that their sense of smell was impaired and this was reflected in both their UPSIT and ASAP scores. On the whole, people who had Parkinson’s for longer have lower scores on tests.

Although we were interested in the loss of sense of smell itself, we were also interested in how that matched confidence. In the controls, we generally found that high levels of confidence predicted high levels of accuracy. This is much less clear for the patients. Possibly this is the result of the drug regime. While most patients were taking L-dopa and dopamine agonists, a small number were taking either L-dopa or agonists. Patients on L-dopa were generally much less confident in their answers than those taking dopamine agonists. But although patients on agonists were more confident, they were not generally more accurate, suggesting that they are subconsciously gambling on the outcome. This has some far-reaching consequences of course and we want to look into the data a little bit more closely.
The second meeting of the Research Club, on 7 October, followed on thematically from the first. We began by presenting the results from the previous meeting, in particular the findings related to judgement. Because judgement of time formed the basis of the second meeting. We conducted three separate experiments, each very short and, at time of writing, as yet not analysed in detail. In the first, we looked at the ability of patients to assess time and how this has affected by noise distractions. In the second experiment, we looked at the ability of patients to gauge relative tempo in musical phrases. And in the third experiment, we looked at the ability of patients to assess time in the presence of musical distractions. The results are not yet available but it is possible to say immediately that there were substantial variability between individuals.

But why are these two research days important? Both in their separate ways examine judgement—the ability to not make rash decisions on the basis of overconfidence, and the ability to assess time and therefore speed, critical aspects in motoring for instance.

But more than this, the Research Club days are a potent demonstration of the power of patients. We have the capacity to fill a niche for research—experiments that are of interest to us, but too small or with too little financial benefits to be of interest to large-scale drug companies. And let’s face it, in the battle to find a cure for Parkinson’s, it’s a case of “all hands on deck!”
Swapping Notes
Jon Stamford and Ray Chaudhuri

Jon Stamford interviews Ray Chaudhuri, professor of neurology at King’s College London and guitarist with the rock band Brainstorm.

If you have yet to come across Brainstorm, a four piece rock band from south London, then I suggest that now is the time. Their first album, “Imaginations”, released a matter of months ago is an eclectic mix of influences -- Jethro Tull, Eric Clapton, Oasis and the Rolling Stones -- delivered with a West Coast harmony style. And they have some pretty high-powered guest musicians on the album -- Jon Hiseman, the drummer of Coliseum and Barbara Thompson, the world-famous jazz saxophonist!

These alone are pretty impressive credentials for the band and, on their own, would be reason enough to take a closer look. But what if I told you that this band has a strong link to Parkinson’s? Interested now?

Because Brainstorm are not your average four piece. These are not spotty youths with more attitude than substance. No sirree. These are educated people. And when I say educated, I don’t mean GCSE in art from a failing comprehensive. I’m talking Seriously Educated. This band contains three movement disorder specialists. Two of those -- David Brooks and Ray Chaudhuri -- are professors of neurology at London teaching hospitals. These are men equally at home with patient’s notes or notes on the stave. A full-time journalist and a neurology research fellow complete the quartet. Brainstorm are Alexandra Rizos (flute, guitar and drum programme), David Brooks (keyboards) Dipankar De-Sarkar (bass, guitar) and Ray Chaudhuri (guitars, bass). All four contribute vocals or harmony vocals.

Obviously a band like this doesn’t just happen. I put some questions to Ray Chaudhuri about Brainstorm.

Jon Stamford -- Ray, may I begin by asking you how did Brainstorm start? Or put another way, what persuaded 2 professors of neurology to form a rock band?

Ray Chaudhuri -- Music is a creative art and many of us in Movement Disorders are indeed creative in terms of original research ideas. David and I have both been interested in similar styles of music and I knew David has played keyboards at a professional level with bands in the 60s and 70s and had a keen interest in modern as well as retro-rock. I also had a keen interest in rock, folk-rock and country-rock music, being heavily influenced by the harmony sounds of the West Coast Bay area bands of the 60s and also Beatles and Dylan among others. I played guitar in several bands in India as well as some in the UK. Alex was also a member of a semi-professional acappella band playing in Germany. It therefore, was a fusion of ideas that brought us together, particularly, writing original music. Dipankar De-Sarkar, was an accomplished bass player as well a classical Indian musician whom I had known from my school rock days in India. Unfortunately he left in 2013, to pursue his new career as editor of a new paper in Delhi and we miss him badly. His bass playing added a new dimension to our sound. When we formed, there seemed to be a lack, in our minds, of music spanning different...
styles and we were keen on real “no frills” musicianship instead of gimmicks and effects as well as blending flute with rock as did Traffic and Jethro Tull. And combining these styles with vocal harmony.

Jon Stamford -- You have some pretty high-powered session musicians helping out on the album in the form of Jon Hiseman and Barbara Thomson. What's the connection?

Ray Chaudhuri -- This has been a privilege. I have always been a huge fan of Jon Hiseman and his drumming as well as his credentials stretching from the John Mayall and Graham Bond days to his seminal, generation-defining, work as leader of the Colosseum. Barabra Hiseman was known to us as one of the foremost female saxophonists in the world and since she had a diagnosis of Parkinson’s I got more involved in their music too, particularly Paraphernalia. This was further stoked during the making of the documentary, Playing Against Time, beautifully shot by Mike Dibb for BBC. It was however, Jon who helped us define a musical style by encouraging us to write original music rather than simply doing covers and the icing on the cake came when he agreed to play drums for our songs in our first album Imaginations. In addition, we are also privileged that Barbara took a saxophone solo in one of our tracks, “Coffee Stain on my Pillow”.

Jon Stamford -- Do you find the day job influences your songwriting or do you see the two as completely separate aspects?

Ray Chaudhuri -- Day job and the experiences, interpersonal and professional, influence our songwriting. However, the songs cover many other areas. Many of my songs are related to my travel experiences, the diversity of and the awesome power of nature. I like to try and fuse these with some medical aspects. Hypothermia is an example. David’s track, The River speaks of the river of life and travel for work for instance. While in Fireflies we visit soul searching issues and romance combined with the evenings in an South African national park! And then there is the wonderfully mystic ballad of Dipankar, Fields of Dreams, about a departed friend’s life and also Summer, a song which encapsulates the skeletal shadows of a failing relationship.

Jon Stamford -- I am intrigued by the range of influences on Brainstorm. So if I asked you to pick, at random, five albums from your own record collection, what would they be?

Ray Chaudhuri -- What a difficult question!! I will try! Here goes

1. Abbey Road: The Beatles
2. Led Zeppelin 1 and 2: Led Zeppelin
3. Deja Vu: Crosby Stills Nash and Young
4. Valentyne Suite: Colosseum
5. Dark Side of the Moon: Pink Floyd
Jon Stamford -- The first Brainstorm album is excellent. What are the plans for Brainstorm in the future? More songwriting? A second album? More gigs?

Ray Chaudhuri — Yes we are now writing a second album. This is also a period when we are experimenting with IT programmes such as Pro Tools (under the tutelage of Jon Hiseman) and Logic Pro as programmes to record our demo tracks. We hope to take a completed collection to Jon’s studio in early 2015 to record. The tracks are now a little different and hope they show we have developed as musicians and writers. We have been asked to play at the opening of the Parkinson’s UK network of excellence programme on February 3rd 2015. We are looking forward to this. We had a terrific experience opening the International Movement Disorders Congress in Stockholm in June 2013 with our biggest gig to date!! It however, went down well. We would also hope to play in mid 2015 to showcase our new album.

Jon Stamford -- Let me end with a cheeky question -- which gives you more pleasure -- an inspired unusual diagnosis or a killer guitar riff?

Ray Chaudhuri -- For me, a killer guitar riff!!
Keeping a Clinical Trial Journal
by Jean Burns

Sept 2014

Just back from 6 month checkup. I sure hate that 5 hour plane ride!

The Docs aren't sure that my "improvements aren't placebo effect. Doesn't matter to me. I'm just going to enjoy feeling better whenever it happens. But Linda H read an article where a scientist can identify people whom they think will be more likely affected by placebo. I hadn't thought that would be me because I wasn't in PRECEPT trial. But whatever! The topic is moot, I had the surgery. The tests should show something!

I didn't make it through the entire PET scan. My back was killing me. Too bad it isn't SPECT. That one is shorter and more tolerable.

There was a snafu in taking my blood. Everyone was in a panic. They were missing a vial with a red top. Did I remember them having a vial with a red top? That would be no... I remembered 4 green tops. sheesh

Then there was discussion about which red-top vial they needed. I was glad they took both vials rather than take a chance on having the wrong one.

3 inches of rain in one day - yikes
I need to insist that I only have a single "OFF-ON session per visit.★

The PET scan day I had no meds until noon when I had 200mg c@r;b#$d0p& and then I forgot to take meds after that. So it wasn't until 1630 when I finally took them. I was a wreck ★

I met with members of Ethics although I was late. They were great! Very sympathetic and understanding!

Woo hoo!

Next visit to the study center is in December. It won't be so bad - no MRI, no PET no Lumbar. anxious for cooler weather to ride my trike

and so it goes!
How I Became Bionic
by Catherine Oas

October 2008: Deep Brain Stimulation (DBS) is a surgical “therapy” that has been FDA-approved in the U.S. since 2002, but used worldwide for nearly 20 years, for people with Parkinson’s Disease, Essential Tremor, and dystonia. Its use is intended for patients for whom medications no longer work effectively. Nearly 80,000 of us in the world are walking around with neurotransmitter implants that allow us to function nearly normally, at least motorically. The surgery is often done in two stages: the first stage, implanting the electrodes into the brain, takes about 5 hours during which the patient must be awake, part of the time. The second surgery involves connecting wires from the anchored brain electrodes from the scalp down through the neck and into two battery packs in the chest.

The above sketch is the device manufacturer Medtronic’s of a patient with implants in place. Medtronic is the primary company to make the units, including a patient controller; they have no real competitors. Most people have bilateral battery implants.

There is a “halo” that is actually bolted into your head at six places with screws. This halo prevents your head from moving at all, during surgery or the MRI and CAT scan that the neurosurgeon uses to guide his tools to the specific magical “sweet spot” in your brain: the subthathmic region. Other regions studied for implantation include the thalamus and the Globis Pallidus Interna.

An intake study is done to determine eligibility. I was tested by an occupational, physical, and speech therapist, as well as a neuropsychologist. I was evaluated, including a video of me off meds. You must have a supportive home life, since you will do much of your healing at home. You must be psychically strong; it is not a fun morning and the surgery is intense. Even though you have to be awake for a good part of it, at other times, the anesthesiologist puts you in a state of “twilight sedation” which helps you to forget much of the surgery.

What do I remember? I remember the sound of the drill making holes in my skull. I remember the look on my neurologist’s face and hearing her “oh my god” exclamation as the head nurse turned on and up the electrical current. The tremor in my left arm, flopping like a fish with no medication, and my jaw instantly ceased. My left side completely...relaxed, for the first time in years. I felt my body stop fighting itself. I remember when they turned it up too far, I felt literally like I was on fire. “HOT” I yelled, and nurse Peggy immediately turned the current down. To test my right side, which had few symptoms, they made me write the sentence,“Today is a sunny day in Seattle.” I remember thinking, who could even care about the weather?? But my micrographia, or cramped handwriting was gone, replaced with large, loopy cursive on a legal pad somewhere left in a Seattle surgery suite. I remember my neurosurgeon telling me before closing me up what a good and brave patient I was. “Brave?” I thought...it must be worse than it feels. And indeed, I could not look at the Wikipedia photo for a long long time. This surgery was traumatic, emotionally. It required all of my faith and all of my prayers to the healing angels around me. I felt every one of them during the course of that five hours. The wire implantation happened a few days later, as a day surgery. Both surgeries caused much nausea, so now I ask for a presurgery consult with the anesthesiologist, to make sure I get anti nausea meds in my IV “cocktail.”
I temporarily fell in love with my anesthesiologist, who performed his job as though it were a well-rehearsed, perfectly choreographed ballet. He knew when to turn up the sedative and when to clear my head, just from his close watching of my face. Under sedation, I think I told him I loved him and owed him a few kisses. Smiling, his Asian eyes crinkling, gave me reason to believe he had heard this before.

I tell you all this now because it was not easy to undergo. I was in so much pain post both surgeries that at times I just got through each minute, each hour, and considered it progress. My partner Steve became my caretaker, making sure my environment was as clean as possible to prevent brain infection (a fairly common danger) and gently showering me each evening. I felt much worse before I got better.

But, here I am, today, sitting in bed on a Saturday morning in October, 2008, six years post diagnosis. My typing speed is nearly as fast as it was seven years ago, with much less medication. I am back to work full time at a very mentally and emotionally challenging job after being at home on disability for over a year. And I am happier than I have been in a long, long time. I feel so lucky for my job, my profession, and being able to work and get back my feeling of purpose.

And so I look different. I have two huge bumps on my chest, too big because they impinge on each other when I lie down and one rides up uncomfortably on my neck. I am easily fatigued, and spend a good deal of time after work horizontally, too tired to make dinner. My hair is short and I bleached it a platinum blonde. I have gained 15 pounds, in part due to Steve, who insists I take my vitamins and eat three meals a day.

Would I do it again? I am not sure. Would I recommend this procedure? I am not sure. My neurologist looks at me in awe now and says I am a text-book perfect example of a patient this DBS is designed for. This means little to me. But what does mean something is that I can work and make an income again. I can move without feeling self conscious about people watching me tremor. My pain is slowly easing, and I can breathe a bit easier. Does DBS work? It did for me. And when the next and improved gene therapy or stem cell procedure joins the treatment options for Parkinsons, I will be one of the first in line. This bionic wiring is completely reversible.

So there, you have it. More research is being done on DBS for untreatable depression, obsessive-compulsive disorders, and a few other conditions. I am bionic because I chose to be. The license plate on my brand new shiny red VW Rabbit reads:

**Postscript, June, 2014:**

I had the surgery done April, 2008, with revisions of the battery packs in 2009 and replaced in 2012. I was able to work and parent my daughters (my two reasons to have the surgery), until December, 2010. DBS allows me to function fairly normally (I rode my bike from Seattle to Portland two years in a row to raise awareness and funds for Parkinson’s Disease). DBS was not able to save me from finally, losing my job, then, my income (I’m currently on SSD and private long term disability from my former employer) which meant I could no longer afford the car. DBS is a good therapy for motor functioning such as tremor and dystonia. But it reaches the tip of the iceberg, only, and it makes the other, more impacting parts of the disease more obvious. Mood swings, feelings of apathy and fatigue, and speech difficulties are common side effects of the surgery itself.

*Thanks to Margaret Tuchman and the Parkinson Alliance for much of the statistical information. DBS4PG.org … or www.parkinsonalliance.org.*
Raising Lazarus

by Jon Stamford

I had the misfortune, earlier this year, to spend some time in hospital. I won’t bore you with all the gory details of my admission, but the gist of it was a blue flash dash at night to the nearest hospital, some 20 miles away, with acute pancreatitis. Of course, and this will be familiar territory to any of us who have experienced emergency admissions, I forgot to take my meds with me. In fact, I forgot to take anything except the clothes I was wearing.

For those of you who haven’t ever been in Casualty late on a Saturday night, try not to. For Casualty in a British hospital, and I imagine it is the same elsewhere, changes during the day. Mid-morning on Monday and the waiting room has a light sprinkling of sprains and cuts. On a Saturday night, by contrast, it is a Dantean vision of hell. Despite the pain and a fairly hefty slug of morphine, I was still aware of the quartet of drug addicts in the bay opposite me discussing the precise form of revenge they were going to inflict upon their dealer for spiking their heroin. Further along, a drunken scuffle was broken up by two police officers after one of the protagonists had punched a nurse. Not surprisingly, my primary concern was to be clerked and given a bed elsewhere.

The following morning, after a night’s sleep, my concerns were different. I realised at 6 a.m., the time at which I would normally take my first Parkinson’s Cocktail (rasagiline, benserazide, levodopa, propranolol and rotigotine) washed down with a little orange juice, that I had none of the necessary medications about my person. I was already beginning to stiffen up and shake badly. I summoned a nurse and explained that I had Parkinson’s and that I needed these medications now. “No problem” she replied “the drug trolley comes round at 10 a.m.” and breezed off to change some dressings before I could respond.

I pressed the call bell again. The nurse reappeared with a quizzical look. I explained, as clearly as I could, that I was not being deliberately difficult but this was not a matter of convenience but of necessity. I explained that the timing of my medication would have significant bearing on my health irrespective of the pancreatitis and that if more than an hour later than my normal time, my meds would be significantly less effective. She said she would speak to Sister.

An hour later, Sister had not visited me. It was nearly 7:30 a.m. and I was already shaky, and stiffening up. I called for Sister and, after a few minutes (this was a busy surgical ward) she came. I told her what I had said to the junior nurse. She reassured me that the drug trolley would be making its round at 10 a.m.

This time I was a little more assertive. Strident even. I explained that, by 10 a.m., some four hours after my normal medication time, I would be a dribbling, quivering, expressionless, voiceless ghost and not the suave, erudite and intelligent interlocutor she currently saw. Perhaps persuad-
ed by the power of my reasoning, or merely keen to be somewhere other than the bedside of an evidently difficult patient, she promised to look into it.

She returned, perhaps 30 minutes later, to say that nothing could be done as the hospital pharmacy did not open until 9:30 a.m. on a Sunday morning but that, nonetheless, she would be first in the queue when it did. I asked whether she could check some of the other wards to see if any of the necessary drugs were available. She could. And would.

Another half-hour passed and I was by now slumped in a chair beside my bed, expressionless and barely able to move. The junior medical students, buzzing like flies around the consultant, must have feared the worst. The clinical picture in front of them was not one of acute pancreatitis but of something akin to cerebral palsy. Or so it must have seemed.

By the time the drug trolley arrived (ransacking the other wards for medication had proven fruitless) I was practically immobile, apart from those limbs with tremor. My voice was so weak that I could barely be heard and I had to ask a nurse to prop me up in the chair.

More alarmingly, the drug trolley had none of the medication. Whispered conversations between staff seemed to indicate that the matter was now at least being taken seriously. A nurse was dispatched, and practically ran, to the pharmacy. The barely concealed look of alarm on her face when she returned confirmed my fear. Of the five medications I needed, they had two. The ward’s nursing station, now a hive of activity (in stark contrast to their patient) quickly established that an emergency delivery would be arranged for the other three.

I finally received my medication at midday, some six hours after my normal time. When the drugs arrived I was sufficiently weak that they had to help me count out the tablets and capsules. I was barely able to put them in my mouth, surrounded by a gaggle of anxious nurses. When I had swallowed the last tablet, I asked the nurses to return in 30 minutes. “Will you need more then?” one asked. “No” I replied “but I want you to see the effect the medication has on me and why I need it on time”.

In fairness to them, they returned as asked. Even if they had not read the story of Lazarus, they must have been astonished. Midday’s motionless statue was now sat in a chair, enjoying a strawberry mousse while finishing the Telegraph crossword. The transformation could hardly have been more eloquent. “Now do you understand?” I asked.

And the lesson was well-learnt. My medication arrived punctually every day thereafter. Indeed the nursing staff were often ready with my medication before I was.

But of course it shouldn’t have reached that stage. Parkinson’s UK’s “Get It on Time” campaign has been running for years. It should not have taken as much distress as it did to make sure that I “got it on time”. Sadly there is sometimes still a disconnect between the excellent aims and objectives of the campaign on the one side and the practicalities of modern ward-based nursing on the other. We have to find ways of bridging that gap.
OTM8 Comments
from our supporters

Peggy and Jon, this is such an accomplishment...multiple languages, such a great variety, from storytelling to the hard science. I am so grateful to have been allowed to be part of this. Multiple pats on the back to you both - LD

Jon, just read and shared "On the Move" and it is excellent.
Yes it is a team effort and a darned good one at that.
But whether recognized or anonymous there must be a driving force behind that team effort to keep that momentum going. You are that momentum (person of passion) that greases the skids and is moving us to the next level. Your finger prints are all over this effort. I see it and want to commend you for it, I look forward to seeing the next issue. - CE

Awesome job everyone!! It looks spectacular, reads even better! - JC

Looks superb.
Lindy's input is invaluable. - DP

Great magazine! Well done!
Posted on my blog! - KH

Simply a fantastic production. Here I am at 5:30 in the morning having just finished reading it. Thanks for all the effort you put in for the benefit of others. - RK

Another masterpiece, Jon. Congratulations to you and all others who contributed to this very successful PM issue!! - RT

Great job as usual with OTM. - IR
Epilog

by Peggy Willocks

ON THE MOVE proudly displays in this issue the talents of Jean Burns, USA, (pdplan4life.com) who has formatted a light-hearted and “fun” theme. Contributions from writers continue to amaze the editors and readership.

Sometimes the contributing authors write a serious, fact-filled article, but other times we have an emotional account of something personal we want to share. Such personal accounts would hopefully serve to drive PM members to bond on a more one-on-one level, which is a huge task when attempting to involve people globally. People are also requesting to write for OTM, and we encourage your requests to keep coming.

Thank you to everyone who reads OTM. We feel it contributes to a sense of one big family on a mission—to find a cure for the disease we all share. We hope to obliterate the name “Parkinson’s” from the science books. This is how we rally the troops to start.