

Reflections on 3rd World Parkinson Congress (WPC), Montreal October 2013

Edinburgh Branch sponsored three delegates to participate in the event: Werner Remmele (left), Mo Morgan and Simon Wilkinson



A Branch symposium was held on 30 November 2013 at which all three reported on their experiences and spoke of the highlights of the Congress for them. This report documents Werner, Mo and Simon's *personal reflections* on their attendance at WPC Montreal. There may be a little overlap in some of the things mentioned but we felt it important that the reports remained as close to the original submissions as possible.

While all three express their huge gratitude to the Branch for sponsoring them as delegates, we in turn should recognise and express our appreciation of their significant efforts – in preparing for the trip by meeting to discuss and agree how they could best allocate their time, travelling across the Pond and back, attending and participating in as many events as their bodies and minds allowed, preparing for the Branch Symposium *and* writing their reports.

As an addendum, page 8 provides useful links to more information about asterisked (*) items in this report, as well as to downloads of Werner, Mo and Simon's presentations at the November symposium.

WERNER REMMELE

Many friends had told me about the outstanding event which was the 2nd WPC, 2010 in Glasgow. Their enthusiasm and a glimpse at the programme for the 3rd Congress were the reasons for me applying for sponsored participation by the Edinburgh Branch.

Mo and Simon were the other two members of our small Edinburgh-based delegation. In preparation, we had co-ordinated our different interests with the objectives of the Branch and compiled a preliminary programme for each of us – not an easy task given the huge number of options and parallel events.

Unexpectedly, we faced some problems on the way to Montreal. We experienced flight delays in Edinburgh due to technical problems, which were then compounded by a fire close to Heathrow. This meant our connecting flight had already left by the time we arrived in London. BA finally solved our problem and we touched down in Montreal the same evening, albeit a few hours later than planned. Unfortunately, Simon's and my baggage did not make it on that flight. They were finally delivered just before my emergency ration of drugs was finished.

The WPC 2013 boasts impressive numbers: with more than 3,500 delegates, participants and speakers, this Congress was the largest of its kind so far. But despite the enormous area covered by the convention centre, the distances between the individual venues were kept short and manageable.

The day before the official start was taken up with three parallel pre-congress sessions. I chose to attend ***Interdisciplinary Care & Parkinson's Disease***. There was agreement amongst all the speakers that to deliver the best treatment for Parkinson's patients a multi-disciplinary, professionally managed team is required – a team in which *all* information is transparent and quickly available. Of particular importance is the single point of contact i.e. the key person responsible for contact with the patient. This ensures fast response and importantly keeps the focus on the patient.

These conclusions are now accepted world-wide and interestingly, it was encouraging to hear that *our UK approach with our use of Parkinson's Nurses was repeatedly cited as a positive example*.

In the following, I will focus on some personal highlights. A detailed description of individual sessions and lectures can be made available at a later date.

Two lectures during the Opening Ceremony touched me deeply:

- *Robert Kuhn*, a WPC 2013 Ambassador, is a highly successful lawyer and suffered for years from Parkinson's. He delivered a deeply philosophical view of how the disease changes the perspective of ego-centered to a more open behaviour: the **I** view becomes a **We** view.
- *Daniel Bissonnette* used his task to present the award for the winner of the video competition as a reflection on his relationship with PD. He met his future wife when she was already ill. In the succeeding 10 years the relationship between the partners changed with the progression of the condition and today is still dominated by love.

The session on the ***death of neurons*** offered two further highlights:

- *Christine Klein* spoke about interaction between genetics, environment and behaviour, with proof involving impressively clear statistical evidence, that they *are* connected.
- *Virginia Lee* showed the neurodegenerative process in Parkinson's. The lecture was later followed by an extended evening lecture, which can be discussed separately.

Of note regarding the session on ***non-motor manifestations*** of PD:

- The start of the session was delivered by *Ray Chaudhuri*, who gave a shortened version of his 2013 Edinburgh lecture.
- I was particularly impressed with *David Burn's* statements about dementia and psychiatric symptoms in Parkinson's.
- The roundtable discussion on non-motor symptoms was as excellent as the two talks mentioned above. *Ronald Pfeiffer* conducted this conversation, during which I realised for the first time how these symptoms arise, and thus have their causal reason in PD.

An evening event which was not part of the Congress was hosted by the Parkinson Society Canada. *Virginia Lee* was invited for the 10th *Donald Calne Lecture: **New Insights into the Mechanisms of Parkinson's Disease Progression***. Dr. Lee seems to have been successful with a breakthrough in research of the neurodegenerative process. Her results not only expand the understanding of the disease but can also bring advances in treatment in the long-term. I have acquired a DVD of this outstanding presentation and made it available to the Edinburgh Branch (*).

Roger Barker's lecture on ***Cell and Gene-based Technologies for Restorative and Neuroprotective Therapies*** was the highlight of the session on *Management of Parkinson's Disease*. The contents of the other lectures were mostly already known from the introduction day.

Less scientific but nevertheless remarkable for me were:

- The musical, *The Alan Parkinson's Project* (*), which represents disease progression.
- The movie, *The Astronaut's Secret* (*), about the astronaut Rich Clifford, who once flew into space after having been diagnosed with PD and completed the mission despite his illness. After the film, Rich was available for discussion.

My personal choice is only a tiny part of the congress offerings. At times up to eight events ran simultaneously and this does not take into account the large number of roundtable discussions with experts. There was little time to explore the more than 100 exhibits of the poster session or to visit all the booths of industrial and PD groups.

My final conclusion: it was an outstanding event with a variety of good and even excellent contributions. However, hard as we tried, as a team of three participants, we did not manage to exhaust the whole variety of possible information. Maybe, 2016 in Portland, Oregon

I want to thank the Edinburgh Branch and its representatives for the opportunity to have attended this great Congress and I hope that I can provide my contribution by passing further information on to the members.

SIMON WILKINSON

As a person diagnosed with Parkinson's some 8 years ago at the age of 38 my personal journey with PD will be a long one, as such I keep it on the "back burner" and try to lead as normal a life as a fulltime Police Officer and father of two active children will allow. As a member of Parkinson's UK, I was aware of WPC 2010 in Glasgow; so when I saw the second round of adverts from the Edinburgh Branch looking for volunteers to attend WPC 2013 I put my name forward and was delighted to be chosen.

After a somewhat longer than expected and frustrating journey, I and my new friends, Werner and Mo arrived in Montreal, despite our baggage being missing for two days.

I went to WPC Montreal with an open mind and with the task of recounting the event. However, there are numerous special moments I didn't anticipate encountering. My lasting memory is the overarching friendship of everyone I met and the collective goal we all shared – that of living with and beating Parkinson's.

One of the key messages of the Congress was that ***people with Parkinson's who stay mentally and physically active deal with the condition more successfully*** than those who do not. Therefore, the common thread that became apparent in a number of lectures and presentations I attended was ***self-efficacy*** and the benefits of becoming as involved and educated as possible in relation to your treatment. Building a good working relationship with your specialists and nurses, wherever possible, is vital.

Other highlights included the opening speeches by *Robert Kuhn* and *Bryn Williams* both ambassadors who gave heartfelt speeches at the ceremony. Of the 3 plenary sessions, the 3rd on the Friday, given by UK's *Roger Barker* was the most informative, along with his fellow speakers, especially those in the follow-up meeting that Professor Barker chaired.

Numerous parallel sessions and meetings were squeezed in amongst visits to poster talks, video presentations and meeting new-found friends. This included the *Commissioner of Montreal Police's Homicide Department*, Clément Rose and his daughter. Clément is of a similar age to myself and was diagnosed four years ago.

A number of quotes from speakers stand out, one of which was how the speaker described the state of "***treading water***" mentally i.e. people maintaining their previous rate of output but needing to work much harder to do so and therefore tiring more easily, to which I can relate.

To try and sum up the experience in a brief document does not do justice to the event or the contributors. In what was a hectic four days, despite a tiring experience and missing more than I had intended due to interference from my PD, I came away from WPC 2013 inspired and with a positive mind-set to not let Parkinson's win the battle.

Lastly, I would like to express my gratitude to members of the Edinburgh Branch for allowing me to attend the event on their behalf, and despite a somewhat limited feedback presentation by the three of us at the November symposium, I feel we have the material to further develop this for the Branch.

MO MORGAN

Having attended Glasgow in 2010 I had an idea of what to expect and suffice it to say that Congress in Montreal was both exhausting and exhilarating. By relating some of the highlights I'll attempt to illustrate why. Despite a 27-hour journey involving flight delays, therefore missed flight connections and lost luggage, Simon, Werner and I arrived 'à Montréal,' albeit tired. The luggage arrived safely within 36 hours just as Werners' reserve medication was running out.

Pre-Congress

With a couple of days to acclimatise, we set about exploring Montreal. With wonderful weather and despite the scale of the city we did remarkably well. We registered late afternoon on the Monday so were all set to join our choice of pre-congress courses the following day. Mine was *Science and Advocacy*. Before Congress, I had been invited to join Pam Quinn (winner of 2010 Congress video award) and other participants, many from the Brooklyn Parkinson Group for a 'Happening' performance at the Reception which was to follow the WPC Opening Ceremony on 'pre-Congress Tuesday.' This was also the day allocated to set up research posters, one of which I co-devised and organised: *Can Dance Improve Cognitive Functioning for People with Parkinson's?* So, with rehearsals, a dress rehearsal, performance, poster hanging and attending as many lectures as possible, pre-Congress day was busy! Some of the highlights were:

- Meeting fellow *abstract poster* presenter and neuroscientist *Professor Joseph de Souza* (Joe) from York University's Faculty of Health, Toronto (more later).
- Getting to know the Brooklyn Parkinson Group dancers who work with *David Leventhal* at the Mark Morris Dance Group's centre in Brooklyn, New York City and others during rehearsals for the Opening Reception 'Happening.'
- Hearing many brilliant speakers giving taster sessions about pretty difficult subjects which they covered in more depth during Congress. These included: ***The Role of Imaging in Diagnosis, and as a Window into the Progression and Pathogenesis of Parkinson's; Role of Deep Brain Stimulation in Management of Parkinson's; and Attempts to Obtain Neuroprotection in Parkinson's.*** The speakers included *Walkin Walkin* (yes, a real name!), *Ken Marek*, *Patrick Brundin*, and *Warren Olanow*, all eminent scientists and researchers in their fields.
- Experiencing the inspirational WPC Opening Ceremony, especially:
 - *Bob Kuhn* (see Werner's entry) who spoke about the difference between illness and wellness which is only the 'I'; when realising this he challenged himself to avoid 'I' and discovered profound changes; something we could all try?
 - *Tim Hague* who has Parkinson's and his wife, Sheryl – Tim and his son (both utterly supported by Sheryl) won **The Amazing Race Canada**, a race across Canada's 10 provinces and 3 territories (9,000km); completely gruelling! They are a shining example of courage and fortitude. (*)
 - Amazing singing from *Les Patineurs Chanteurs du Mont-Royal*, a boy's school choir *par excellence*.
- The Opening Reception and participating in the 'Balloon Happening' along with 40 or so people with Parkinson's (including one partially sighted), within a set area amongst hundreds of delegates milling around socialising, chatting and drinking. Also, a wonder-

ful contribution from the *Move4Parkinson's Voices of Hope* choir singing "Something Inside So Strong." (*)

Congress

Each day there were many sessions, classes, lectures and films running in parallel from 8am through to 7pm, plus receptions and evening events. Mostly, as a team, we covered what we'd intended and more, adding a number of other events, lectures, poster views, and social opportunities too! Some highlights for me were (in no particular order):

1. Befriending many people with Parkinson's (or assisting as required) especially a wonderful German group staying at the same hotel as Werner and me; a delightful couple, John and Edna Ball – John was 39 when diagnosed with PD in 1983 having experienced symptoms for the previous 10 years yet he has run marathons since 1996; his concession to his age is now walking them! John and Edna run 'Team Parkinson' whose strap line is "*You gotta turn up to make a difference!*" This struck a huge chord with me. (Details of John's Book are on page 8). In a similar vein, the Brooklyn Parkinson Group movers/dancers were completely inspirational in their attitude.
2. Being invited by David Leventhal for drinks – I was so tired I almost didn't go; then I remembered "*You gotta turn up to make a difference!*" so went. By happy coincidence, Joe, the neuroscientist I'd previously met when hanging our individual research posters, was also there along with a *Dance for Parkinson's* (D for P) practitioner from Toronto, members of the National Ballet of Canada (training in and starting to teach D for P classes) and John Dalrymple, Director of Strategic Initiatives at the National Ballet School of Canada. Joe had just set up a research project at the School with the help and expertise of the current Toronto practitioners.

They have successfully run 4 classes in the Toronto area for approximately 5 years, but now find themselves in a tricky situation as a 'named' company has picked up on the D for P work. A situation our own D for P Network UK has also experienced and thankfully come through. I mentioned I was going to be in Toronto the following week and was promptly invited to attend their class at the School. I did attend! What an experience – a similar class to ours – so reassuring – and the chance to experience more brilliant work from fellow dance practitioners while being able to encourage and support them by explaining how our Network had overcome difficulties.

3. Meeting Steve Ford (Chief Executive, Parkinson's UK) in the hotel lobby and having the opportunity to chat over a drink. It was absolutely brilliant and a privilege to have private, relaxed time to chat freely about P-UK, their work and their presence at Congress (it had become clear P-UK is a shining example the world over). We also chatted about its relationship to the D for P Network UK practitioners whose expertise, dedication and generosity are tremendous but relatively unknown to the senior management of the charity. Partly thanks to this chance meeting (and with Toby Beazley, Executive Director of Dance Umbrella representing us), the D for P Network UK is now being incorporated into, and advising P-UK on, dance in its next 5 year strategy planning. "What these meetings are all about!" as Patrick (Hon. Chairman, Edinburgh Branch) reminded me at Congress in Glasgow, 2010 where our Network UK originated!
4. Being incorporated as UK and Edinburgh representative along with Claudia Nagama, (a D for P practitioner in California) by David Leventhal into the very heart of the D for P session; experiencing over 60 participants, many with Parkinson's, some expe-

rienced dancers, some first-timers but all moving with grace and enjoyment for a whole hour; being included so warmly by David Leventhal, the Brooklyn Parkinson Group and so many participants was humbling and inspirational.

5. Seeing the world premiere of Dave Iverson and the Mark Morris Dance Group's film *Capturing Grace* (*). Many of you may know Iverson's film *My Father, My Brother and Me* (*). *Capturing Grace* describes the Brooklyn Parkinson Group dancers over 18 months, from rehearsal through to their first performance and in my opinion would be worth viewing by anyone for the sheer brilliance of the documentary/film-making irrespective of the subject matter. The facts are delivered in the most effective way without sentimentality and the effect is utterly compelling and beautifully moving. Catch it as soon as you get the chance. As one of the dancers with Parkinson's states, "When the music starts, there are no patients; there are only dancers."
6. Seeing the musical of *The Alan Parkinson's Project* (*) based on the celebrated Canadian playwright Doug Curtis's experience of the onset and progression of PD, produced and co-directed by his partner/wife, Heather Moore. It was an immensely professional production, describing an award-winning film-maker's journey into PD with support from his devoted dog Target, his guardian angel Grace, his production assistant Kate and his medicinal hero El Dopa. Many of us already acknowledge and directly experience how powerful the arts can be in conveying messages and emotions that can be difficult to discuss and admit but this production did it more than admirably and with humour and pathos. One never knows, it may yet get to the Edinburgh Festival and beyond....

Finally, it is impossible to include the many areas in which Congress expanded my knowledge. However, for me there were a few "take home" messages that really "leapt out" and were referred to repeatedly over the 4 days. These were:

- A. **Raising awareness, empowered patients and self-efficacy:** it's up to all of us involved in any and every way with PD.
- B. **Delayed start trials** are the way to go: using two groups, the first is given the trial drug, the second a placebo for a chosen period then both groups are given the trial drug for a second chosen period, helping separate symptomatic improvement from a true effect on disease progression. Also important are a) proper *wash-out* or *run-in* periods in which treatments that participants were using before a clinical trial are discontinued and b) sharing knowledge and statistical evidence. All these factors can contribute to more reliable evidence for companies to invest in new drugs for people with Parkinson's now. Scientists want certainty but "... for a patient with a progressive condition, a treatment today may be worth more than a better treatment next year, as their condition will have progressed." [*Dave de Bronkart, Society of Participatory Medicine*].
- C. **Efficacy of medication** – the importance of the correct and specific dosage for each and every individual.
- D. **Doesn't matter what sort of activity/exercise/movement/dance** you do, because any and every type will help at any stage of PD and on every level of being – physical, mental and spiritual. Again self-efficacy comes into play – it's best to do something one enjoys. There's plenty of evidence for this already, no need to wait for more research.

Finally, happy memories to my fellow Congress delegates and my sincerest thanks to the Edinburgh Branch for enabling me to develop professionally and personally from this tremendous opportunity.

Useful Links and Publications

1. Downloads of presentations from the **Branch Symposium** in November 2013 are available via our web page: <http://www.edinburghparkinsons.org/wpc-symposium/> as well as a report by *Fella Hammachi* from the Scottish Centre for Regenerative Medicine, where she works as a member of *Tilo Kunath's* research group.
2. **Congress Webcasts and Highlights:** <http://www.worldpdcongress.org/>
3. **The Donald Calne Lecture October 2013**, presented by Dr Virginia M.-Y. Lee to the Parkinson Society Canada, *New Insights into the Mechanism of Parkinson's Disease Progression*. A DVD copy is available to borrow from the Branch. Contact Ken Bowler, ken@edinburghparkinsons.org, 0131 669 8961.
4. **The Alan Parkinson's Project:** search the web under *Alan Parkinson's Project Ghost River Theatre* for descriptive information.
5. **The Astronaut's Secret:** <http://theastronautssecret.com>
6. **Amazing Race Canada:** <http://www.youtube.com/watch?v=ZKkQciJD1hY> or search the web under *Amazing Race Canada Tim Hague*.
7. **Living Well, Running Hard: Lessons Learned from Living with Parkinson's Disease**, author John Ball, via Amazon.com.
8. **Voices of Hope:** <http://www.youtube.com/watch?v=VaP1rcAA5JY> or search the web under *Move4Parkinson's*.
9. **Capturing Grace:** <http://www.youtube.com/watch?v=8k3-lwWRYyk> or search the web under *Capturing Grace youtube*.
10. **My Father, My Brother and Me:** <http://www.pbs.org/wgbh/pages/frontline/parkinsons/> or search the web under *My Father, My Brother and Me Frontline*.

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The Parkinson's UK Helpline offers a 'listening ear' to anyone with Parkinson's or their families who need to talk to someone, safe in the knowledge that their call is confidential and the person listening understands Parkinson's. It is available Monday to Friday 9.00am – 8.00pm and Saturday 10.00am – 2.00pm, FREEPHONE 0808 800 0303 (calls are free from UK landlines and most mobile networks), hello@parkinsons.org.uk.

Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. It is a charity registered in England and Wales (258197) and in Scotland (SC037554), tel. 0808 800 0303, www.parkinsons.org.uk.