**HERTFORDSHIRE PSP & CBD SUPPORT & FRIENDSHIP GROUP**

The next meeting of the Hertfordshire PSP/CBD Support & Friendship group will be held on:-

**DATE**:-**Saturday, 14th March, 2020**

**TIME**:-**from 2.15pm to 3.45pm**

**VENUE:** - **the Parish Centre, The Park, Redbourn AL3 7LR**

Yes, it seems a very long time since I last wrote a newsletter to you all, three months in fact, and as I have only just stepped off a 24 hour plus flight from Australia, extended by a further delay awaiting some official from Public Health England to board the plane and declare us all fit to be let loose and not to constitute a health hazard to the local populace, I can’t guarantee this newsletter will be completely coherent but I’ll do my best. As you know, I was making my first visit back in 5 years, troubled by recent concerns about the health of my brother and other family members. My arrival in the Land Downunder seemed to unleash a deluge of biblical proportions on Sydney …..nearly 10 inches of rain fell in one day, (Sydney doesn’t do wishy washy drizzle…we have proper rain, twice as much as London on average but much less often) and I was applauded by everyone for having singlehandedly put out all the bush fires, broken years of drought and turned parched New South Wales into a lush green landscape almost overnight. Australia is a country of extremes and, climate change notwithstanding, always will be. However, I think that as a Rainmaker I may have exceeded my powers somewhat as the drought was quickly replaced in some areas by floods. It was 37 degrees when I left Sydney the other day and since I returned I still haven’t got the hang of remembering to put on enough warm clothes to go out!

At least I now have a realistic understanding of the health of the older family members and the chance to spend lots of 1:1 time with various nieces and nephews, as well as friends, was most valuable …and very enlightening at times! But how will I cope with the withdrawal symptoms now that I am denied Sydney style iced coffees, a dessert rather than a drink!

**STUDENT GROUP VISIT**

 At this March 14th meeting we are to be visited by Helen Chapman, the PSPA Communications Manager and some students from City University, Samantha Hayes and Charlotte Scarr, who are working on a project to raise awareness of PSP. Helen has asked if they may visit our group and I am sure you will be delighted to join me in welcoming them. Samantha lost her grandfather to PSP and so she has a personal motivation. On their behalf, this is what the PSPA have sent me about their project.–

***“Our project is a short television documentary about progressive supranuclear palsy. We are trainee journalists who have a strong interest in raising awareness of PSP and we want to help to tell people's stories.***

***1.We would like to interview people who have PSP and to ask them about their experience and how they were diagnosed.***

***2, We would also like to interview carers and family members who assist somebody with PSP to ask them about their responsibilities. These interviews will be conducted in a casual and relaxed manner and any requests will be considered and respected.***

***3 We are also looking for one or more participants who would like to speak/be represented by a carer in a longer and more in-depth case study about their life and experience of progressive supranuclear palsy. Please contact us if you have any questions about the project or would like to be involved as one of our case studies. Thank you.***

They have said in terms of usage – the film would just be marked by their tutors. Once it has gone through the grading process, they have said that PSPA can use the film as part of our awareness raising – but of course we would only do this if those that took part were happy with us”.

I hope that, like me, you will feel that not only do we want to support these budding journalists in such a worthwhile project but we also appreciate that they are providing a very welcome opportunity to raise awareness, which we constantly try to do. We also welcome the chance to meet Helen Chapman, the new Communications Manager.

**MEDICAL ALERT CARDS and other Publications (see Page 4 of the latest “PSP Matters”)**

The PSPA new Medical Alert Cards are now available for both PSP and CBD. These will fit into a wallet or purse and contain information about symptoms, a space for emergency contacts as well as a link to the new interactive online resource for health professionals. When people come across health professionals who are not aware of PSP or CBD they can be directed to the link to this new resource on the PSPA website and the health professionals will have access to all the information they need about both conditions, meaning you will receive the right, informed care. I have a number of these cards for distribution at the meeting as well as new brochures entitled “An Introduction to PSP and CBD”,/ “Welcome from Your Local Group”/, and pocket sized booklets “Living with Progressive Supranuclear Palsy”

These can also be obtained from the **Helpline 0300 0110 122** or helpline@pspassociation.org.uk

**HERTFORDSHIRE WHEELCHAIR SERVICE - Feedback and Priorities requested**

I have received an email from Sarah Wright whom some of the long term group members may remember as the former Co-ordinator for Rare and Progressive Neurological Diseases in Herts when the group started in 2014. Sarah was a great support to us and we have missed her since she left the service but I’m pleased to see that she’s back, working now for Herts Action on Disability. Her email concerns the Wheelchair Service and the fact that feedback is requested from users of the service now that the NHS contract currently held by Millbrook Services is up for tender. End user responses are especially requested. I will forward Sarah’s email .and attachment to you separately for your consideration and participation.

**CORONAVIRUS & GROUP MEETINGS**

Well, you were wondering weren’t you? So was I but I have today received this from Carol Amirghiasvand at PSPA

 ***Following a number of enquiries to the Helpline about the coronavirus, I wanted to share some guidance for Local Group meetings.***

***Government advice confirms small gatherings, such as our Local Group meetings, can still go ahead.***

***Although PSP & CBD have not specifically been mentioned, older adults and those with medical illnesses seem to be more at risk, so extra care should be taken.***

***Where possible, please ensure group attendees have access to onsite facilities that allow hand washing with soap and water.***

***Recommend using a tissue or sleeve to cover the mouth when sneezing or coughing.***

***Also advise any attendees who have travelled to publicised locations or have experienced symptoms of a cough, high temperature and shortness of breath, to follow guidance to stay at home and avoid vulnerable people.***

***Further information about the coronavirus and up to date guidance is available at***

[***www.gov.uk/guidance/coronavirus-covid-19-information-for-the-public***](http://www.gov.uk/guidance/coronavirus-covid-19-information-for-the-public)

 On the basis of this advice the meeting will go ahead and I hope you will be able to attend.

 ****1. Please let me know **by email** or **phone ASAP if you intend to come to the** **March 14th** meeting. If I know you plan to attend I can try to ensure you are contacted in the event of a cancellation.

2. Please check your email and/or voice mail before you leave home in case of a late change caused by illness or any other reason. I’d hate you to make a wasted journey.

I and the rest of the team look forward to seeing you on March 14th

Best regards

Maureen

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