IN THIS TOGETHER
parkinson's
AUSTRALIA

Newsletter
December 2019

Dear all

Welcome to the last newsletter for the year – also the Christmas edition. As I write this, I am looking towards Parliament House, cloaked in smoke. It is an eerie sight.

I do hope this email finds you and your loved ones safe and well.

To support our advocacy role, we have developed an 'Insta' page. See here www.instagram.com/parkinsonsaus. If you have your own account, and are out and about doing something with people with Parkinson's feel free to tag us **#parkinsonaus**

Keep an eye out for the new campaign in 2020. If you would like to make a donation towards to support the campaign, please click this link www.parkinsons.org.au/make-a-donation

All the best for a safe and happy Christmas.

Young Onset Parkinson's Information Hub

Parkinson's Australia in partnership with Parkinson's South Australia has been awarded over $1million under the Morrison Government's NDIS Information Linkages and Capacity Building National Information Program Funding Round to improve outcomes for people with Parkinson's and other movement disorders.

The Young Onset Parkinson's Information Hub – Information and training for people living with Parkinson's and their care providers – is an innovative app and online resource that will provide NDIS-contracted providers, allied health professionals, family and carers up-to-date information about the condition. The Hub will provide better outcomes for people living with Parkinson's or another movement disorder enabling them to participate in family, work, social and recreational life.

The Hub will remove barriers preventing clients, health professionals, NDIA staff and contractors accessing high quality education and information. The delivery of the information through online and app-based platforms will appeal, and is suited, to how the under 65s prefer to access information and support. The Hub will provide people living in rural and remote communities with access to quality information in easily accessible formats.

Work has commenced to engage a contractor to build the Hub.

Governor-General is a Patron of Parkinson's Australia

The Governor-General, the Hon David Hurley AC DSC (Retd), has agreed to be a Patron of Parkinson's Australia. The Governor-General said:

"I am delighted to become Patron of Parkinson's Australia.

The impact of the disease on those that live with it and their families and loved ones is profound. So too, though, is the difference and impact that Parkinson's Australia make.

As their motto says, we are 'In this together', and by advocating for people living with Parkinson's disease, providing education and support and promoting best practice, Parkinson's Australia makes a significant difference for many Australians.

I look forward to working with them and serving as Patron over the next five years."

Carer's Week

Carers play a vital role in the wellbeing of people with Parkinson's. Parkinson's Australia was a key member of the advisory group for the design of the Carerhelp website www.centreforpallcare.org/news/30/carerhelp-a-new-resource-to-support-carers-in-end-of-life-caring

Carehelp is a new resource to support unpaid carers, and was launched at Parliament House on Thursday, 17 October during National Carers Week 2019.

Developed as part of the Australian Family Carer Toolkit Project, this resource helps to prepare unpaid carers to care for a partner, parent, child or friend at the end of life.

Accessible Design Alliance

I attended the inaugural meeting of the Accessible Design Alliance held on 29 October in Sydney.

This alliance will provide accessible design of products for the use of people who have limited capacity either through disability or some other reason.

Research

There is a fabulous amount of research being done worldwide in the Parkinson's space.

Australian Parkinson's Mission

The Australian Parkinson's Mission (APM) is a $30 million initiative funded by the Medical Research Future Fund.

The clinical trial will use potential repurposed drugs for Parkinson's from drugs approved to treat other conditions. These treatments have demonstrated neuroprotective effects in preclinical experiments. By using drugs that have already passed rigorous safety and toxicology trials, the mission aims to cut the time for a potential treatment to move from the laboratory to clinical trials and to the patient.

The benefits have the potential to affect people with Parkinson's and clinicians:

- Determine which drugs are effective to change the progression of the disease for which patients
- Develop screening, prevention and early intervention protocols for individuals at high risk of Parkinson's
- Develop blood-based biomarkers to measure the existence and progression of the disease
- Proof of principle for a genomics-based precision medicine framework
- Better classification of Parkinson's subtypes based on their DNA

The APM strives to transform our understanding of Parkinson's, identify genetic targets to guide drug development in Australia, and generate the evidence for personalised treatments for patients with Parkinson's based on each individual's genetic information.

The APM website will be updated as more information becomes available - see theapm.org.au

If you are interested in registering for participating in the APM program, click here.

The APM is an Australian-led international collaboration, developed by the Garvan Institute of Medical Research, Parkinson's Australia, Shake It Up Australia Foundation, The Cure Parkinson's Trust and The Michael J. Fox Foundation for Parkinson's Research.

Melatonin for Insomnia in Parkinson's

Melatonin is used to help sleep, but this scientific study will determine whether there is a true effect in individual people with Parkinson's. By recording individual symptoms in a sleep diary and using a special watch to record sleep patterns, we will be able to identify individual responders and non-responders to melatonin. This will have positive impacts on health and quality of life for both people with Parkinson's and their family members (especially carers). The study is being run by The University of Queensland researchers. To find out more or get involved, click this link www.parkinsons-qld.org.au/research-participation-opportunity-melatonin-for-insomnia-in-parkinsons-disease/

Biogen

I met with Biogen in October to discuss their exciting announcement that their trial drug Aducanumab reduced clinical decline in patients with early Alzheimer's disease as measured by the pre-specified primary and secondary endpoints.

Based on discussions with the FDA in the United States, the company plans to submit a Biologics License Application in early 2020. The positive results of this new analysis were driven primarily by greater exposure to high dose Aducanumab in the larger dataset as compared to data available at the time of the futility analysis

Biogen is also investigating the efficacy of Gosuranemab as a potential therapy for Progressive Supranuclear Palsy (PSP). It is in the later stages of the phase 2, with final results expected in 2020. Due to the small numbers of people with PSP, a successful outcome may move straight to a TGA application.

Biogen is in phase 2 of a study to evaluate the effectiveness of BIIB054 (a human-derived monoclonal antibody) in reducing cell-to-cell transition of aggregated α-synuclein thus slowing progression of the disease. It is likely that this study will be completed by 2022.

We regularly post updates on promising studies on our Facebook page

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Movement Disorder Nurse Project

The Movement Disorder Nurse Specialist (Parkinson's and other disorders) Pilot Project is designed to improve access to specialised nursing care in the community for people living with neurological conditions, including movement disorders such as Parkinson's disease. This will be achieved by providing seed funding to pilot, in up to 15 sites, integrated nurse-led models of care in the community for this group of patients. Pilot locations will focus on attracting specialist nurses in a community setting and upskilling nurses in primary care (e.g. general practice). Rural and remote locations will be included in the pilot.

The Federal Government is in the process of contracting Primary Health Networks (PHNs) to have one or more pilot sites in their region. PHNs will be selected to participate based on

responses to criteria that include community need, service integration, and capacity to commission the relevant service. PHNs that are selected to participate would be expected to commission the appropriate service providers that may include state or territory health services, general practices or community organisations

Annual Review 2019/2019

Parkinson's Australia has published its latest annual review.

You can find it here

Education

For General Practitioners, Parkinson's Australia with the Australian College of Rural and Remote Medicine (ACRRM) offers an online educational course designed to help GPs address issues of most concern when confronted with a patient who may have Parkinson's.

Access is free for all ACRRM members and RRMEO subscribers www.rrmeo.com. Other users can apply for free access via Parkinson's Australia at www.rrmeo.com/parkaus

If you have any questions, please do not hesitate to contact ACRRM at rrmeo@acrrm.org.au

For other health professionals who care for people diagnosed with both typical and atypical Parkinson's there is a postgraduate unit of study which provides students with the opportunity to extend their knowledge of this speciality area.

Finally, I would like to take this opportunity to thank everyone who has supported Parkinson's Australia throughout the year. During the past few months since I was appointed, I have met many wonderful people who are working hard to improve opportunities for, and the well being of people living with Parkinson's.

I'd like to thank the Chair and the Board for their support. Without the voluntary contributions of these Board members, Parkinson's Australia would not exist. I'd also like to thank the state CEO's for their considerable efforts to support people with Parkinson's. They do an amazing job.

Thank you for your continued support and see you next year.

Warm regards

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