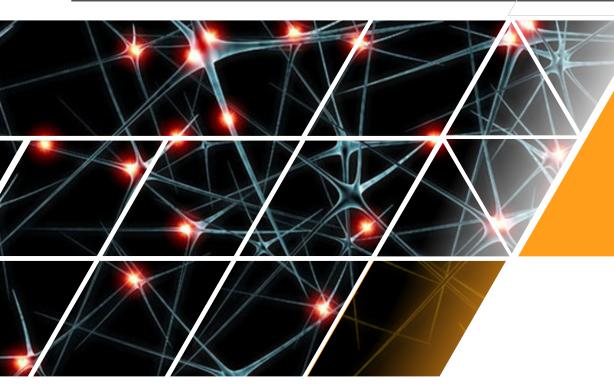


# ANNUAL REPORT



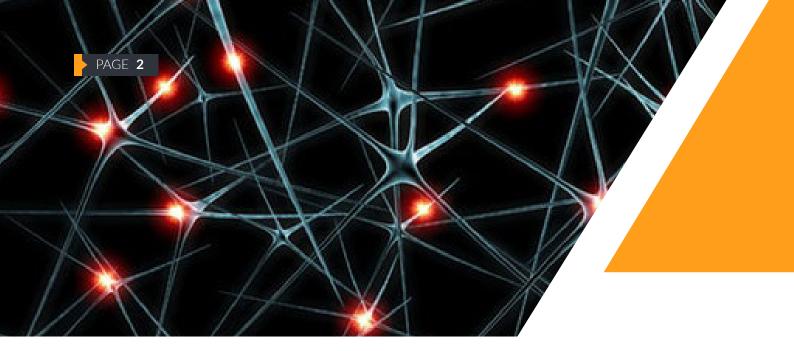
f



in



2020



#### **Our Achievements**

The Shake It Up Australia Foundation is a not-for-profit organisation established in 2011 and in partnership with The Michael J. Fox Foundation (MJFF) promotes and funds Parkinson's disease research in Australia aimed at better treatments and ultimately a cure. Our partnership with MJFF ensures that our research grants are globally competitive, strategically managed and non-redundant. 100% of all funds donated to Shake It Up are directed towards Parkinson's research in Australia which is made possible by the founding directors who cover all administration costs of the Foundation.

Since our inception we have co-funded 50 research projects across 13 Australian research Institutes to the value of \$15M.

2020 was a most challenging year with the global COVID-19 pandemic impacting on our community fundraising and slowing research progress. However, we are pleased to share the following highlights from 2020:

- Funding of seven new Australian research projects to the value of \$2.7M
- The start of the Australian Parkinson's Mission first clinical trial APM 001.



Parkinson's Research Projects



Australian Research Institutes



Million
Dollars
Invested

# TABLE OF CONTENTS

#### **SECTION**

# 1 INTRODUCTION 04 A Message From Our Patron 06 CEO Report 08 Our Vision, Missions & Values 09 About Parkinson's

#### **SECTION**

2	PARTNERSHIPS
10	The Michael J. Fox Foundation
11	Australian Parkinson's Mission

#### SECTION

3	RESEARCH
12	2020 funded research projects
19	Leave a bequest to fund Parkinson's research

#### SECTION

4	Living and working with Parkinson's
20	Real Stories

#### **SECTION**

5	FUNDRAISING
22	Pause 4 Parkinson's
24	Community Fundraising & Events
26	Our Heroes
27	Corporate Support
28	Get Involved

#### SECTION

6	OUR PEOPLE
29	Ambassadors
30	Our Team

#### **SECTION**

7	GOVERNANCE
31	Our Board
32	Financial Summary





# A MESSAGE FROM OUR PATRON THE GOVERNOR-GENERAL OF THE COMMONWEALTH OF AUSTRALIA, HIS EXCELLENCY GENERAL THE HONOURABLE DAVID HURLEY AC DSC (RETD).

A world without Parkinson's. It is an ambitious and important vision.

It is why the work of the Shake It Up Australia Foundation to find better treatments that will prevent, slow and stop the progression of Parkinson's and ultimately to find a cure, is so important.

I would like to commend the Shake It Up team, their supporters and the entire community on all that they achieved in 2020. It was, of course, a difficult year for everyone. Almost every facet of our lives was impacted by the COVID-19 pandemic.

Importantly though, while the 'how' of supporting those with Parkinson's changed, the 'why' did not. We continued to see countless examples of people helping others, of innovation and of the good in your community.

The Shake It Up Foundation continued its great work during the pandemic. From funding seven new research projects – bringing the total of research projects supported since the Foundation was formed to 50 – to the Shake It Up Virtual Challenge, their efforts in a challenging year were nothing short of extraordinary.

Congratulations to all for a successful 2020. I am delighted to serve as Patron of the Shake It Up Australia Foundation. Both Linda and I are looking forward to working with the team and to what 2021 and beyond will bring.

#### **DAVID HURLEY**

HIS EXCELLENCY GENERAL THE HONOURABLE DAVID HURLEY AC DSC (RETD)



#### **CLYDE CAMPBELL**

CEO - SHAKE IT UP

**MESSAGE FROM** 

OUR FOUNDER & CEO

"It is in times of crisis that incredible acts of generosity are witnessed and I would like to thank our donors who continued to support the foundation as our economy was impacted by the lockdowns."

To say 2020 was a challenging year would be an understatement. From bushfires to floods and a pandemic, 2020 challenged us all to re-think our lives and focus on what is important to us. For me, family has always been my number one priority and we worked together to navigate our way through the challenges the pandemic presented to our businesses, the foundation and our family.

It is in times of crisis that incredible acts of generosity are witnessed and I would like to thank our donors who continued to support the foundation as our economy was impacted by the lockdowns. In particular I would like to thank a few of our major donors who gave so generously this year to ensure our research focus was not lost during COVID. Tim Sims, Andrew Permezel, Greig Asbury Foundation, Noel Holmes, the MAST Foundation, Sohn Hearts & Minds and Rich Balanson. My personal thanks are also extended to each and everyone of our donors for your valued support this year.

Our annual Pause 4 Parkinson's campaign is usually the highlight of the year and we were looking forward to the official launch in April which was to be hosted at Admiralty House by our Patron His Excellency General the Honourable David Hurley AC DSC (Retd). Unfortunately this event had to be cancelled at the last minute as we went into lockdown and all of our community fundraising events were also unable to proceed. Our Pause 4 Parkinson's sponsors saved the day and I would like to acknowledge and thank them for their support - Noel Holmes Group

ANNUAL REPORT 2020 PAGE 7

and Daily Press, Telum, Active Tree Services, Novotech, Insurance Advisernet, Quality Steel, Medirecords, oOh!media, Pharmacy Club and Hutchinson Builders.

I would also like to acknowledge the kindness and support shown by the Governor-General who took the time to call me personally during lockdown to see how the foundation was coping and to offer his support. We shared a virtual cuppa and a chat some weeks later with our community to talk about the challenges of living with Parkinson's and COVID and our research progress.

At the end of each year His Excellency would usually invite all his patronages to attend a thank you event at Government House. That was not possible in 2020 because of COVID-19 restrictions, so in order to acknowledge and thank each of the charities His Excellency and Mrs Hurley support, they introduced the Governor-General's medallion for presentation to a member of our team who has contributed in some significant way to the foundation in 2020. There were a number of very worthy recipients but one person stood out for his contribution over the past nine years to the foundation. Noel Holmes is a member of the foundation's Board, a major donor and has contributed significant pro bono support to the foundation through his businesses. It was a great pleasure for me to present the inaugural Governor-General's medallion to Noel in acknowledgement of his generous support.



L to R Clyde Campbell, Noel Holmes and Greg Campbell.

On the research front there has been much progress made with the start of our first clinical trial in Australia under the Australian Parkinson's Mission. Whilst there was a six month delay to the start of this trial due to COVID-19 it is now progressing with all recruitment on schedule for completion by October 2021. We also funded seven new research projects in 2020 across seven research institutes to the value of \$2.7 million.

Decades of research focused on unravelling the Parkinson's puzzle is now paying off as we see the science progress at a more rapid pace. Whilst the Parkinson's new drug pipeline is more active than it has been previously, much work remains to be done in the quest to better understand the connection between Parkinson's pathology and the daily lived experience of the disease — and to translate this understanding into new therapies.

Finally I would like to thank our Ambassadors, Board members and staff for their valued contribution in helping to steer us through such a challenging year. Bring on 2021!

Clyde Campbell FOUNDER & CEO

PAGE 8 ANNUAL REPORT 2020

# OUR VISION, MISSION & VALUES



Our vision is a world without Parkinson's.



Our mission is to find better treatments that will prevent, slow and stop the progression of Parkinson's and ultimately lead us to a cure.



Our values are integrated across all aspects of the organisation.

**COLLABORATION** – our focus from the outset has been to create a culture of collaboration within the Australian Parkinson's research community and to promote international collaboration through our partnership with The Michael J. Fox Foundation.

**INTEGRITY** – we will act with integrity in all of our actions and partnerships and demonstrate a consistent and uncompromising adherence to strong moral and ethical principles and values in all internal and external comunications.

**COMMITMENT** – we are committed to our Vision and Mission and will not give up until we achieve success

**INNOVATION** – we only fund cutting edge Parkinson's research in Australia that shows promise to meet our Vision and Mission. Our partnership with The Michael J. Fox Foundation ensures that the research we fund is globally competitive, strategically managed and non-redundant.

**RESPECT** – we will act with respect at all times in our internal and external communications with all of our stakeholders.

**OPTIMISTIC** – we will always seek to push the boundaries in our search for cutting edge research to fast track better treatments for Parkinson's and ultimately to find a cure

"To me, hope is informed optimism" Michael J. Fox

# ABOUT PARKINSONS



Parkinson's disease is a progressive, degenerative neurological condition caused by a loss of dopamine cells in the brain that affects a person's control of their body movements. Commonly referred to as a movement disorder, Parkinson's has many symptoms with each person experiencing a different combination of symptoms, making it sometimes challenging to diagnose.

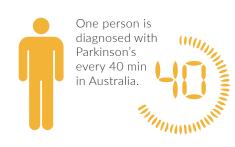
Motor symptoms may include tremor, slowness, stiffness, and walking and balance problems. However, non-motor symptoms such as sleep disturbance, constipation, depression and loss of sense of smell can pre-date motor symptoms by up to a decade.

There is no known cause for this debilitating disease and current treatments address symptoms, not disease progression. There are currently no laboratory tests to definitively diagnose Parkinson's disease and diagnosis is made by a neurological examination. Shake It Up is prioritising biomarker research to help with early detection and diagnosis and new drug treatments that will slow and stop disease progression.



2nd

Most common
neurological disease
in Australia after
dementia



20% One in Five are diagnosed under the age of fifty. Parkinson's is not an old person's disease.

10% are diagnosed before the age of 40.

\$3 Billion

Parkinson's costs the economy \$3 Billion annually and the healthcare system \$600 million each year.

- Without a medical breakthrough the number of Australians with Parkinson's will double every 15 years.
- The prevalence of Parkinson's in Australia is greater than prostate, bowel and many other forms of cancer and the total number of Parkinson's sufferers is 4 times the number of people suffering with MS.

# **PARTNERSHIPS**

#### The Michael J. Fox Foundation

Shake It Up's partnership with The Michael J. Fox Foundation for Parkinson's Research (MJFF) was established in 2011 to leverage Parkinson's drug development expertise in Australia.

MJFF is dedicated to identifying and funding research that can speed better treatments toward pharmacy shelves. Both MJFF and Shake It Up share a commitment to leverage donor-raised resources for potentially transformative research — sooner rather than later.

MJFF have one single-minded goal: putting themselves out of business by finding the cure for Parkinson's and they are making an IMPACT.

- MJFF-funded pre-clinical investigations have resulted in more than 20 early-stage therapeutic programs, which have attracted follow-on funding from venture capital, pharmaceutical or government funders for continuing development.
- MJFF have funded or sponsored scores of clinical trials in partnership with both academic and industry teams. Today, more than 15 disease-modifying interventions are in clinical trials with multiple improved symptomatic therapies having achieved regulatory approval or are poised to do so.
- The landmark MJFF-sponsored Parkinson's Progression Markers Initiative has built the most robust dataset and biosample library in the history of Parkinson's research. Data from brain scans, biosample analysis and intensive genome and RNA sequencing from 1,500 volunteers has been downloaded by researchers over 1.7 million times since the study's launch in 2010.
- MJFF's online clinical study, Fox Insight, has galvanised people
  with Parkinson's and their families to take an active role in
  research by sharing their lived experience of the disease. Since
  the study launched in 2017, more than 48,000 individuals
  have raised their hand to become citizen scientists to power
  PD research.

"This is an optimistic time for Parkinson's drug development... it is now more critical than ever that MJFF is positioned to continue supporting PD therapeutic research."

Todd Sherer, PhD CEO, MJFF



ANNUAL REPORT 2020 — PAGE 11

# **PARTNERSHIPS**

#### **Australian Parkinson's Mission**

The Australian Parkinson's Mission (APM) is an innovative five year research program that was established in 2018 to combine clinical trials and biomarker technologies with breakthrough genomics to revolutionise our understanding of Parkinson's disease. It is an Australian-led international collaboration between the Garvan Institute of Medical Research, Shake It Up Australia Foundation, the University of Sydney, the Cure Parkinson's Trust (UK), The Michael J. Fox Foundation (USA) and Parkinson's Australia.

Following delays in the first half of 2020 due to COVID-19, the first clinical trial (APM001) commenced in August, with eight sites across Australia (in NSW, VIC, SA, WA and QLD) opening for participant enrolment and recruitment. This clinical trial will use repurposed drugs (potentially disease modifying drugs already approved to treat other conditions, that could slow, stop or reverse Parkinson's progression), integrated with transformative research, to identify and fast-track effective treatments for people with Parkinson's.

These treatments have demonstrated neuroprotective effects in pre-clinical experiments and by using drugs that have already passed rigorous safety and toxicology trials, the APM aims to cut the

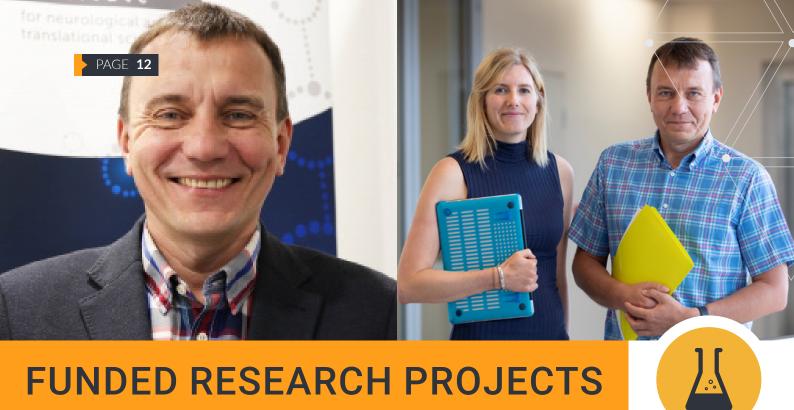
time for a potential treatment to move from the laboratory to clinical trials and to the patient.

The APM clinical trials program is available for all people with Parkinson's — those who have been newly diagnosed, and those living with the disease.

Clinical trial APM002 will commence in 2021.

"Parkinson's patients
are the experts on what
we have. We have a
responsibility as patients
to share our experience —
what works for us, what
we respond to, what we
can contribute to research."
Michael J. Fox





**Project** - Association of Repetitive DNA Elements In Parkinson's Disease Risk and Progression

**Institution** - Perron Institute for Neurological and Translational Science and Murdoch University - WA

**Duration** – 12 months

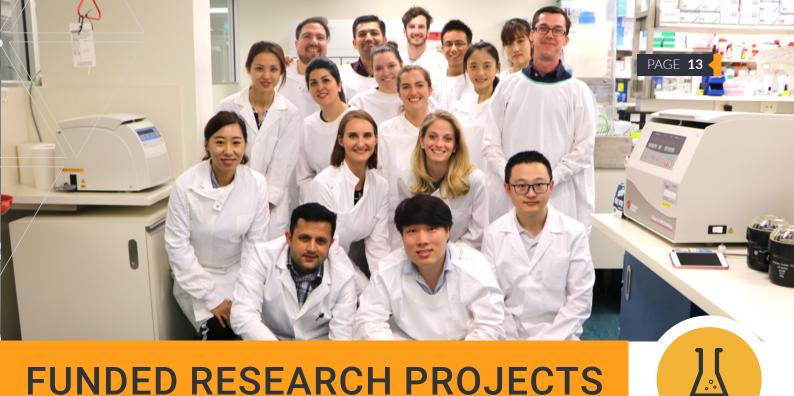
Researcher - Sulev Koks, MD, PhD, Abigail Pfaff, PhD

**Rationale** – Repetitive DNA elements such as "jumping genes" were previously considered 'junk DNA'. However, it is now known that these elements are involved in the development of several diseases and can regulate how much of a gene is produced. The study of these elements is complex and requires specialist software tools for their analysis, therefore they have not been widely studied in Parkinson's disease.

The aim of this study is to determine

- if specific types of these repetitive DNA elements increase the risk of developing Parkinson's disease,
- if these elements affect how a person's Parkinson's disease progresses,
- and the functional impact of these elements on how much of a gene is produced.

Repetitive DNA elements identified in this study could be used to identify individuals whose disease may progress quicker and direct treatment development to new targets that could modulate the effect of these elements.



**Project** - Identification of apoptosis-associated speck-like protein containing a CARD (ASC) as a disease-modifying therapeutic target in Parkinson's disease

**Institution** - University of Queensland

**Duration** – 2 Years

Researcher - Trent Martin Woodruff, PhD

**Rationale** – Inflammasomes are large multiprotein complexes that play a central role in the innate immune system, the body's first line of defense against microbes. Inflammasomes are key drivers of inflammation that are widely implicated in propagating neuron death in neurodegenerative diseases such as Parkinson's disease. Our prior studies have shown that a key protein in the inflammasome, called ASC, is increased in Parkinson's disease patients, and in experimental models. Pre-clinical models genetically deficient in ASC have reduced severity of disease, suggesting this protein could be a key target for therapeutic intervention.

This study will investigate the effect of targeted genetic therapeutic inhibition of ASC in two distinct pre-clinical Parkinson's disease models. It will then test whether this therapeutic approach also shows beneficial activity when administered after the onset of symptoms in these models.

The study aims to identify if ASC plays a key role in neuron death in experimental models of Parkinson's disease. It will also identify if administering a drug which inhibits ASC can slow the progression of disease, which could lead to the development of new treatment.



**Project** - More Than Pretty Pictures: Ion Imaging of Lipid Content and Flux Kinetics in Models of Parkinson's Disease

**Institution** - University of Wollongong

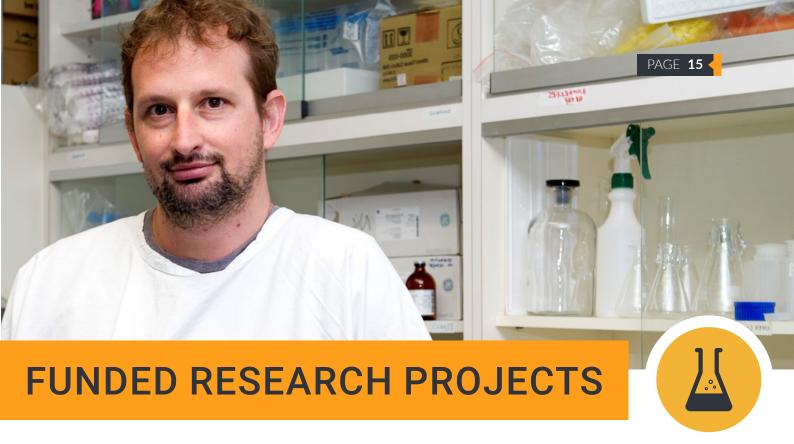
**Duration** – 12 months

Researcher - Dr Shane Ellis, Kim Ekroos, PhD, Ron M.A. Heeren, PhD

**Rationale** – Glycosphingolipids are natural cellular fats. They are components of cellular membranes that fulfill multiple functional roles, from cell structure and transport to signaling. The contribution of glycosphingolipids to Parkinson's disease is not fully understood. However, it is known that mutations in the GBA1 gene, encoding for the enzyme glucocerebrocidase (GCase), is the most prevalent risk factor for Parkinson's. The resulting deficit in GCase activity leads to accumulation of two glycosphingolipids, glucosylceramide and glucosylsphingosine. This research aims to better understand the mechanistic and metabolic details of these complex and essential fats, and their role within brain regions affected by Parkinson's.

The hypothesis of this study is that alterations in the metabolism of selective glycosphingolipids in specific brain regions contributes to early Parkinson's onset and accelerated progression rates.

This study aims to shed new light on the role of glycosphingolipid metabolism, formation rate and brain localisation in Parkinson's pathology. Understanding abnormal glycosphingolipid in specific brain regions in Parkinson's patients will lay the foundation for future studies to identify new biomarkers and therapeutic avenues for the treatment of Parkinson's.



**Project** - Assessing LRRK2, GCase and cytokines in cryopreserved monocytes

**Institution** - University of Sydney

**Duration** - 2 years

Researcher - Dr Nicolas Dzamko PhD

**Rationale -** The goal of this study is to determine the effect of LRRK2 and GBA mutations on activities of both enzymes under basal/stimulated (pathogens) conditions and with and without LKIs and GCase activators using cryopreserved PBMCs from patient cohorts (provided by Columbia University and Barcelona). The co-Principal Investigators of this project, Malu Tansey and Nicholas Dzamko were previously funded to compare various PBMC and monocyte isolation protocols for detection of LRRK2 and GCase activities by flow and immunoblotting.

This supplement now utilises the finalised protocol (cryopreserved PBMCs) to assess enzyme activities under basal/pathogen-stimulated conditions with and without LKIs and GCase activators in various PD cohorts. This study is an extension of three studies conducted in animal models indicating that LRRK2 and GCase activities can be easily detected and modulated in immune cells in response to immune triggers. The outcomes of these studies will indicate if GBA subjects would benefit from LRRK2 kinase inhibitors and vice versa and point to converging immune phenotypes (cytokines) in PBMCs from LRRK2 and GBA mutation carriers.

Two clinical sites (Columbia University- Roy Alcalay and Barcelona-Eduardo Tolosa) will provide PBMCs for this study.



## **FUNDED RESEARCH PROJECTS**

**Project** - Single Molecule Detection of Oligomeric Synuclein in body fluids

**Institution** - University of New South Wales

**Duration** - 12 months

Researcher - Yann Gambin, PhD and Emma Sierecki

**Rationale** – Pathogenic alpha-synuclein (aSyn) aggregates have been recently detected in the spinal fluid of people with Parkinson's disease where its concentration shows potential to be a biomarker or indicator of Parkinson's. This research project aims to dramatically improve on existing alpha-synuclein detection techniques (PMCA and RT-QuIC) by substantially decreasing assay time, increasing detection sensitivity, and determining if the assay will work on more conveniently obtained biosamples that include blood or urine. The study's single-molecule counting methods will provide new information on the "fingerprint" of aggregates found in people with Parkinson's disease.

The research team recently created AttoBright, a device that counts the number and size of Synuclein aggregates in biological fluids. The AttoBright instrument detects aggregates faster than any methods currently available but also provides quantitative and precise information on the number and size of the protein aggregates. This research project aims to establish this new profiling of PD biomarkers as a routine test. Protocols will be validated by using purified reference samples from MJFF, on two different instruments in two different institutes, before accessing samples from MJFF donors with Parkinson's.

This project seeks to demonstrate that the new single-molecule detection capabilities of the AttoBright will allow rapid, sensitive and reliable detection of pathogenic alpha-synuclein aggregates in either blood (serum or plasma) or urine. The in-depth aggregate profiling produced will provide preliminary evidence of being informative for either diagnosis and/or measuring disease status of people with Parkinson's. The sensitivity afforded may additionally provide the potential for early diagnosis in the pre-motor phase.



## **FUNDED RESEARCH PROJECTS**



Project - Photoreceptor-directed light therapy in Parkinson's disease

**Institution** - University of Queensland

**Duration** – 3 Years

Researcher - Beatrix Karoline Feigl, MD, PhD

**Rationale** – Non-motor symptoms including reduced sleep efficiency and excessive daytime sleepiness are common in people with Parkinson's disease. These symptoms often precede or contribute to worsening of motor symptoms. While studies using different methodologies of bright light delivery have shown beneficial effects of light on sleep and motor behaviour, the pathomechanisms as to why light is effective are not known. Proof of concept is required to provide clinical recommendations for light therapy.

Light, as the primary driver of circadian function and sleep, is transmitted by melanopsin expressing photoreceptors in the eye to the central body clock in the brain to regulate release of the dark hormone (melatonin) and modulate sleep and wakefulness. The research team made two fundamental discoveries concerning the mechanism through which light affects people with PD. They first discovered that melanopsin cells are dysfunctional in people with early PD (Joyce, Feigl, Kerr, Roeder, Zele 2018) and the second discovery was that melanopsin dysfunction contributes to sleep disruption (supporting preliminary data).

This study aims to demonstrate the positive effect of melanopsin-directed lighting on non-motor (sleep and circadian) and motor (gait, balance, tremor) symptoms. In the morning or evening during 4-weeks, people with PD will view their new lighting technology that generates light which preferentially increases or decreases melanopsin activity in the eye. Because both lights have the same (white) appearance, they can use a study design where both the investigators and participants are unaware of their light treatment condition. This research project aims to quantify melanopsin cell function using non-invasive methods (pupillometry) established in the laboratory and monitor sleep and motor behaviors before and after light intervention.



## **FUNDED RESEARCH PROJECTS**



**Project** - Brain-penetrating antisense oligonucleotide to down-regulate alpha-synuclein

Institution - Florey Institute of Neuroscience and Mental Health

**Duration - 13 months** 

Researcher - Fazel Shabanpoor, PhD

**Rationale** - Antisense oligonucleotides (ASOs) offer a new therapeutic strategy in Parkinson's disease (PD) because they can be readily targeted to genes causally linked to PD development or progression. Consequently, they may treat the underlying pathology of PD, not just symptoms, and hence profoundly alter its relentless progression and impact on patients.

To be effective in PD, ASOs must get into the brain, however ASOs show almost no brain penetration following intravenous or subcutaneous administration. A requirement for intrathecal administration would severely limit the number of PD patients who could benefit from ASO therapies due to cost, access and capacity of clinical services.

This project will develop an ASO therapy that reduces alpha-synuclein expression in the brain following subcutaneous administration. The target product brings together two proven technologies – an ASO that has already shown efficacy in downregulating human alpha-synuclein expression following intracranial injection in transgenic mice, conjugated to the research team's proprietary brain-penetrating peptide (BPP) that they have shown enables other ASOs to get into the brain following peripheral administration in neonatal and adult mice.

Many lines of evidence implicate alpha-synuclein in a causative role in PD and its progression, including over-expression being sufficient to cause an autosomal dominant form of the disease.

This project will assess the ability of BPP-ASO conjugates to downregulate human alpha-synuclein mRNA and protein expression in vitro in human cell lines and in vivo in brains of adult transgenic mice overexpressing human alpha-synuclein following subcutaneous injection. The study will optimise the chemistry of the ASO and BPP to select a lead BPP-ASO candidate and assess its in vivo pharmacokinetics (dose-effect, time-course) and toxicity.

My father lived with Parkinson's for the last 20 years of his life. What should have been a happy retirement for him became a slow decline which took away his independence and we watched as he became more and more isolated and depressed. We decided to leave a bequest to Shake It Up because we wanted to help fast track better treatments and a cure for Parkinson's so future generations and their families do not have to endure this very debilitating disease."

ANONYMOUS BENEFACTOR

# HAVE YOU CONSIDERED LEAVING A BEQUEST IN YOUR WILL TO ADVANCE PARKINSON'S RESEARCH?

Not only will this help the 100,000 Australian's living with the disease it will help future generations. 100% of all bequests to Shake It Up fund cutting edge research to find better treatments to prevent, slow and stop Parkinson's disease progression and ultimately lead us to a cure.

There is a misconception that only wealthy people leave bequests to charities. The reality is that most bequests are made by ordinary, hardworking people who want to make a positive difference to causes they care about after they are gone. Your gift, be it large or small, allows us to plan ahead to fund long term research projects over several years.



# LIVING AND WORKING WITH PARKINSONS

#### Sheenagh Bottrell

Sheenagh Bottrell was employed as a Registered nurse working in a busy General practice in Canberra when she was diagnosed with Parkinson's at 47. She first became aware of her symptoms when walking with a friend who commented "you look like you've had a stroke" as she was limping and not swinging her left arm. Sheenagh had seen her GP and was told she had bursitis in her shoulder and thought she was just protecting her shoulder by not swinging her arm. However she then noticed that her hand was slow to respond when she was brushing and drying her hair. She also found her voice became quiet as her husband was often asking her to repeat what she said and was always telling her to smile when taking photo's, when she thought she was smiling.

When Sheenagh was first diagnosed there was no real impact on her work, but as her hands slowed she did become aware that doing certain procedures in the medical practice became challenging. Sheenagh's employer was very supportive and assisted with anything she needed including time off to go to neurologist appointments.

"

"I was selective who I told initially especially patients at work but now I feel much more comfortable talking about it as I am very lucky my progression has been slow. My neurologist gave me a good piece of advice which I often pass on. He said to not make Parkinson's a focus of my life, but to live life to the best of my ability," said Sheenagh



#### Steve Woodhouse



In 2000 Steve Woodhouse achieved his dream job as GM with West Coast Eagles. The role was highly demanding but rewarding and Steve loved it. A few years into the job, Steve started to notice that he had difficulty writing and some problems with movement on his right side. As these persisted over time, Steve mentioned the issues to his doctor who referred him to a neurologist. In 2005, to Steve's great shock he was diagnosed with Parkinson's. Steve felt completely unprepared for the devastating news but the single-minded focus of the Eagles and its management helped to pull him through that first difficult post-diagnosis phase. Steve disclosed his diagnosis to his CEO, who responded with loyalty and practical support, ensuring Steve was provided with the workplace adjustments he needed to continue to do his job, such as voice to print technology.

As the Club became embroiled in some highly publicised difficulties Steve realised that the stress was impacting on his Parkinson's. With the support of the CEO and Board he set about developing a new business plan and restructuring the management, splitting his own role in the process. This enabled Steve to work reduced hours over the next two years as he bedded down the organisational changes he had designed and moved toward retirement.

Although Steve would have much preferred to continue his career for longer, he was pleased that, with the support of his CEO and Board, he was able to plan and manage his progress to retirement whilst making a significant contribution to the future of his Club.

ANNUAL REPORT 2020 — PAGE 21

#### Kate Stone Matheson

Kate Stone Matheson is a writer, digital artist, photographer, and works with her business partner, Brad McEwan, educating workplaces, sporting and news organisations about ways to manage and maintain good mental health in the workplace.

With a law degree and a master's in business, Kate comes from a very traditional corporate background, and has strong ties to the military, having been previously married to a naval officer for almost twenty years. Part of this involvement in military life meant frequent job changes and making new friends in various places, including overseas. An incredibly active team sports player, she was heavily involved in netball, skiing, sailing... pretty much any sport that was available, she crammed it in along with long arduous hours in the office – or in the circus ring, as she worked for quite some time with Cirque du Soleil (not as an acrobat!)

It was around the time of her role with Cirque du Soleil at the age of 29 that she first started to notice some weakness in her right side, then, after yet another posting to a new location with her husband, problems with movement and cramping, followed by tremor and handwriting starting to 'fall off the page'. She was becoming very fatigued, and her ability to maintain her self-exacting work standards and busy social life started to suffer.

After an initial diagnosis of MS, and five incredibly frustrating years with worsening symptoms, Kate finally was given the news at 34 – she had Young Onset Parkinson's Disease. She says that to finally understand what was happening to her was a massive relief, even if her only knowledge of the disease came from being aware that Michael J Fox – a 'teenage crush!' had it.

For a while Kate attempted to keep maintaining her usual lifestyle without considering the impact of Parkinson's on her body, mind, and routine – especially work. But what she rapidly realised was that in ignoring the way the disease physically and mentally affected her, she was not only making herself more unwell from the stress – she was letting her staff and work peers down. She began to accept that working full time was not sustainable, and that in undertaking part-time work, it would also give her the energy to raise awareness about YOPD and the disease in general – including the great gift she was given in being appointed a Shake it Up Ambassador.

Having recently worked with the mental health organisation Beyond Blue, Kate has learned to manage her energy and to make the best use of her time in promoting the importance of good mental and physical health when It comes to 'being the boss of your Parkinson's, not letting it boss you'. She also strongly advocates to those who love and care for people with YOPD to 'ask them what they want in terms of assistance, not tell them what they need'.

"

Her message to others diagnosed with the disease, especially those with YOPD, is very simple; "don't see this as a weakness – see it as an opportunity to make everything you do have meaning. The small stuff is exactly that – small. Make the most of your chances to realise the biggest dreams you've imagined, and don't ever be afraid to ask for help in making them come true".



PAGE 22 **ANNUAL REPORT 2020** 

# **PAUSE 4 20** PARKINSON'S 20

The COVID-19 pandemic significantly changed our lives and altered the course of 2020 for everyone. For us at Shake It Up, we were finalising plans to launch Pause 4 Parkinson's 2020 in April around World Parkinson's Day when government directives sidelined all events for the foreseeable future.

While 2020 was not our normal Pause 4 Parkinson's campaign, we were overwhelmed by the response from our supporters and although we couldn't host our Pause 4 Parkinson's fundraising events, we were thrilled to hear from so many who hosted virtual events or were looking forward to fundraising once restrictions lifted.

#### **Corporate Sponsors**

Our corporate sponsors rallied around Pause 4 Parkinson's, providing \$114,000 in sponsorship support. A very his The Avery his T in sponsorship support. A very big **THANK YOU** to all our amazing sponsors for their support through such a challenging year.

## **NOEL HOLMES**

**DAILY - PRESS** 

Sold









telum













We also extend a big thank you to our Campaign Partners – Ooh! Media and Pharmacy Club. Ooh! Media have supported Pause 4 Parkinson's year on year, helping to get the message out into the community about Parkinson's disease and how people can support us to find a cure. Ooh! Media billboards on roadside, shopping malls and offices helped to share statistics on the number of Australian's living with Parkinson's.

Pharmacy Club was integral in getting the message about Parkinson's out to pharmacists and pharmacy assistants. Thanks to them, our pharmacists will be better informed to talk to patients with Parkinson's about new treatments and clinical trials.

#### Paws 4 Parkinson's



Paws 4 Parkinson's was a new initiative inspired by our ambassador, Kate Stone-Matheson as we all came to terms with social isolation. The grassroots community involvement in Paws 4 Parkinson's was encouraging and motivational as people shared photos of their pets whilst in lockdown. Thank you to everyone who posted photos and shared what their pet meant to them during such a difficult time.

#### Pause 4 Parkinson's Community Fundraising Heroes

#### Shuffle 4 Parkinson's

Shuffle 4 Parkinson's hosted by father-daughter powerhouse, Stephen and Kitty Duffield, is a big fixture of the April Parkinson's calendar. The event pushed through the COVID-19 restrictions, converting to a virtual event where participants could run the 5km fun run or walk the 500m shuffle from anywhere in Australia. Stephen and Kitty did a fantastic job wrestling this event through challenging circumstances to **raise \$5,225**!



# COMMUNITY FUNDRAISING

Community Fundraising and Events were largely on hold for 2020 as lockdown kept us all inside and away from our networks. Despite this, a number of committed Shake It Up supporters found ways to navigate restrictions and fundraise for Parkinson's.

As soon as government restrictions began to shutdown traditional methods of community fundraising, Shake It Up sought new ways to connect with fundraisers. We launched the Shake It Up Virtual Challenge so supporters from all over the country could fundraise through personal challenges like running or cycling for Parkinson's.



Inspired by Dom's uncle Gaz and the challenges Parkinson's brings to his life, Dom decided to run 100km in a single effort. Dom said "We have watched Gaz totally lose his independence. When he couldn't balance on a pushbike properly on a family holiday in Vietnam we all had a bit of a laugh, including Gaz. Fast forward eight years and he is wheelchair bound, requires assistance in all aspects of his life, ... and even the thought of going outside is an enormous challenge." Dom raised \$9,825 and was met at the finish line by a small group of family and friends.



Inspired by his Aunty Denise, Ryan ran a half marathon or marathon every month dressed as Forrest Gump to raise funds for Shake It Up. Ryan originally planned to complete running events which have now been cancelled or rescheduled, so instead he got moving around a local park, pounding the pavement and taking his fundraising online. His amazing story was picked up by the Geelong Advertiser and 3AW Radio Melbourne. He smashed his fundraising target, **raising \$5,420**.



Looking for ways to keep active, mother/daughter duo Maddy and Judy took on a September Challenge to walk 10,000 steps per day and drink no alcohol. Maddy said: "We're here to strategise how Mum can continue to kick ass and have a great life, whilst living with PD. Staying active alongside diet and nutrition are two critical things to manage PD day-to-day." Their community really got behind them, leaving beautiful messages of support on their fundraising page and helping them **raise \$6,796** for Shake It Up.

ANNUAL REPORT 2020 PAGE 25



Could you do 100 burpees per day for 100 days? That is exactly what Averil Templar and the team at CrossFit Smash Canberra did this year for Parkinson's. Inspired by Averil's Mum who has Parkinson's, the team completed the epic challenge with lots of social media support. Together they **raised \$7,792**.



2020 was a challenging year for travel and fundraising adventure treks, and as such, our planned trip to Tuscany for September 2020 was postponed until 2022. In its place, we arranged a trek to Bay of Fires in Tasmania for 2021. Here are a few of our fundraisers for the Bay of Fires trek.



Steve was one of the first people to sign up to the Bay of Fires trek and his fundraising sky-rocketed in a very short amount of time **raising over \$11,100**! Steve said, "Living with my own diagnosis of Parkinson's for 5 years and witnessing firsthand the growing hold this disease can have on quality of life, this is personal." Steve, an artist, offered to donate a limited edition of his prints to those who donated to him which encouraged big donations.



Greta has been a regular donor to Shake It Up for a while and joined the Bay of Fires trek. Greta said that the trek will be a challenge for her: "Since my diagnoses of breast cancer in 2010 and subsequently Parkinson's in 2015, my personal mantras have become "expect the unexpected" and "never give up" which would appear to go hand in hand (a challenge in itself at present)."

# **OUR HEROES**

People from all walks of life feel compelled to do something to help a friend or family member when they are impacted by a chronic disease like Parkinson's. Here we share some of our community heroes from 2020.



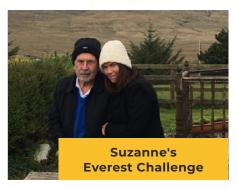
Year after year, the Monkey Mia boys take on outback challenges for Shake It Up, and 2020 was no different, despite the COVID-19 situation. With three outback challenges now conquered over the last three years and over \$117k raised for Parkinson's research they are real community heroes! In 2020 the group of friends hit the road in Western NSW raising another \$41,048 for Shake It Up. Team member Andrew said that the trip was full of camaraderie and never any arguments. "I think our success has come from a fortunate group of mates and most of our funds have come from friends and relations. They've been very generous with large donations."



Long-time Shake It Up supporter Gary McKitterick-Gillett had made plans to return to Nepal in 2020 with a new group of friends and trek Everest Base Camp for Parkinson's. When COVID put those plans on hold, Gary decided to make his challenge virtual, inviting participants to climb the same distance as Mt Everest from wherever they were. This led to Gary's own challenge to climb Mt Coolum 42 times (8 times per day for 5 days) to cover the same distance as Everest. A small group of supporters joined Gary and together the whole crew **raised \$11,930**. Gary said, "While we didn't get to Mt Everest, we did climb Mt Coolum 42 times and raised a conversation about Parkinson's in the community."



A big team of legends at Amaysim, lead by Jimi Suen, completed a challenge to run 30 mins per day for 30 days as part of a team building exercise while working from home. The team had over 30 members and ran together virtually all through the challenge. They found the challenge rewarding and invigorating – completing over 4,186km and 36,000 active minutes, as well as \$3,510 for Parkinson's



In late 2020, Suzanne Cox ran 130km in 14 days – the same distance and time it took her father to complete Everest Base Camp. Suzanne is honouring her father, who had Parkinson's, and challenging herself to get the message out there about Parkinson's. Suzanne said "I watched my Dad deteriorate over seven years to Parkinson's. He was fit, healthy and strong before Parkinson's took over his life. He was a fitness fanatic who ended up being wheelchair bound. I'm committed to find a cure in honour of my Dad and his fight with this cruel disease but also for all the victims and carers who are still fighting this battle every day." Suzanne has **already raised over \$10,000** and counting.

ANNUAL REPORT 2020 PAGE 27

# **CORPORATE SUPPORT**

2020 was a tough year for us all and we are especially grateful to the businesses who continued to support us through very challenging times and to a number of new corporate partners who came on board this year.



Social distancing and event restrictions meant that the annual Sohn Hearts & Minds Conference had to look at new ways of delivering their investment leaders conference and take this dynamic event to an online format. The event was a huge success and Shake It Up were extremely grateful to receive a **donation of \$100,000** towards Parkinson's research.



The events industry were impacted significantly by COVID-19 so we were especially grateful when Veritas Events reached out and offered their support to Shake It Up this year. They have produced some fantastic new video content for our website and we are looking forward to working with the fabulous creative team at Veritas in 2021 on other new initiatives.



We are so fortunate to have the ongoing support of PwC as a corporate partner. We are thankful for their generous support in providing us with meeting facilities on either side of lockdown as well as a COVID safe space to film our new videos.



We welcomed helloEd as a new corporate partner this year. helloEd is a digital marketplace that captures the world's health and lifestyle technology, and grows with you to make new outcomes possible. Their Parkinson's specific pages provide a wide range of products with reviews to assist people looking to improve their quality of life as they navigate living with Parkinson's.

# **GET INVOLVED**

There are many ways to get involved and support Parkinson's research and the work of the Foundation. When you support the Foundation with a donation or by fundraising, 100% of every dollar donated goes directly to Australian Parkinson's research. This pledge is made possible by our founding directors' commitment to fund all administration costs.

#### **REGULAR GIVING**

Can you support us by making a regular monthly donation to help us plan ahead and commit to world leading Parkinson's research? Our regular givers become a member of our Movers and Shakers Club and for every 50 new members we can commit to one new research project.

Want to make a difference for people living with Parkinson's? Join us on one of our adventure treks, or maybe you prefer to compete in a fun run, ocean swim or bicycle ride. Maybe you have a great idea of your own to host a fundraising event with family and friends or at work. Whatever you enjoy doing get on board and help us raise funds to support cutting edge Parkinson's research in Australia and help us find a cure for Parkinson's.



#### CHALLENGE YOURSELF FOR PARKINSON'S

Challenging yourself is a lot easier than it sounds! You don't have to trek Mt Everest or run 100km in a single effort like some of our fundraisers. Set a challenge that works for you! Whether it's running 30 mins per day for 30 days, no alcohol or sugar for a month, or walking with your dog, you can set any challenge and ask your friends, family and colleagues to sponsor you.

Saying goodbye to a loved one with Parkinson's is a heartbreaking and difficult time. Create a legacy in their honour by setting up an in memory or tribute page and asking for donations in lieu of flowers at their memorial. All funds raised will make a difference to the future of Parkinson's



**ANNUAL REPORT 2020** PAGE **29** 

## **OUR AMBASSADORS**

Our Ambassadors give generously of their time each year as they champion our cause. All have been impacted by Parkinson's in some way and share their experiences to help spread awareness about the importance of Parkinson's research in Australia to edge us closer to a cure.



Singer/songwriter and performer of the Linda Ronstadt songbook. Amanda Canzurlo lends her support promoting the work of Shake It Up with

her fans and raising funds

at her concerts.



Peter Byrne

International entertainer and star of the Neil Diamond Tribute act. Peter was moved to support Shake It Up when he heard of Neil Diamond's Parkinson's diagnosis.



**Liz Cantor** 

Channel 7 TV presenter Liz is passionate about making a difference after watching her grandmother, a former prima-ballerina, her grandfather and her Uncle all struggle with Parkinson's disease.



The Eagles Show

Award winning tribute band Desperado came to Shake It Up through keyboard player Vernon Aliberti, who was diagnosed with Parkinson's in 2015. The band makes a difference at their packed concerts as they spread the word about Shake It Up.



Lincoln Dews

A multiple world champion professional waterman Lincoln has witnessed first-hand the impact of Parkinson's on his grandfather and father who were both diagnosed with the disease.



**Craig Foster** 

Former soccer player and SBS Chief Football Analyst, Craig was inspired to support Shake It Up after hearing Clyde Campbell's story and having grown up in the same NSW Northern Rivers community.



Fashionista, blogger, mother and wife to Robert who has Parkinson's. Phoebes is dedicated to using her social media influence to help increase awareness about the importance of Parkinson's research in Australia.



Kate Stone Matheson

Journalist, author, and public speaker Kate was diagnosed with Young Onset Parkinson's at the age of 34. She continues to inspire everyone with her courage, determination, grit and humour as a vivid storyteller and Ambassador for living your best life with Parkinson's.

## **TEAM SHAKE IT UP**

In the words of Michael J. Fox "We are here until Parkinson's isn't!" The passionate and small team at Shake It Up is committed to raising awareness and funds to edge us closer to a world without Parkinson's.



**Clyde Campbell** Founder & CEO



**Vicki Miller**Executive General Manager
- Strategic Partnerships

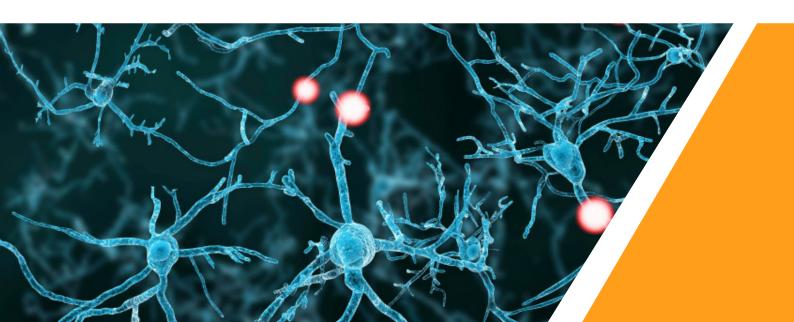


**Isobel Moore**Community Fundraising and Events Manager



Carolyn Campbell
Operations Manager

100% of all funds donated to Shake It Up are directed towards Parkinson's research in Australia. This is made possible by the founding directors who cover all administration costs of the Foundation.



ANNUAL REPORT 2020 PAGE 31

## **OUR BOARD**

Shake It Up is grateful to the members of our Board who give so generously of their time each year to guide the Foundation. Their considerable business experience and professional expertise brings a diverse skillset to the Board and ensures good governance. Shake It Up is a registered charity under the Australian Charities and Not-For-Profits Commission.











Clyde Campbell
Chairman

**Graeme Fear**Vice Chairman

**Greg Campbell** 

**Rick Crethar** 

**Tony Dormer** 



Jenny Hosie



Noel Holmes



Andrew Mulcahy



**Ben Young** 

The Board operates under a governance structure that complies with the ACNC governing standards.



# FINANCIAL SUMMARY

#### Shake It Up Australia Foundation

Shake It Up Australia Foundation Trust – ABN 65 270 391 304 Shake It Up Australia Foundation Charitable Trust – ABN 21 285 919 076 Combined Summary Financial Statement Ended June 2020

Income Donations	\$3,110,152
Total Income	\$3,110,152
Grants Funded	\$879,767
Administration Expenses *	\$440,707
Net Surplus (Deficit)	\$1,789,678

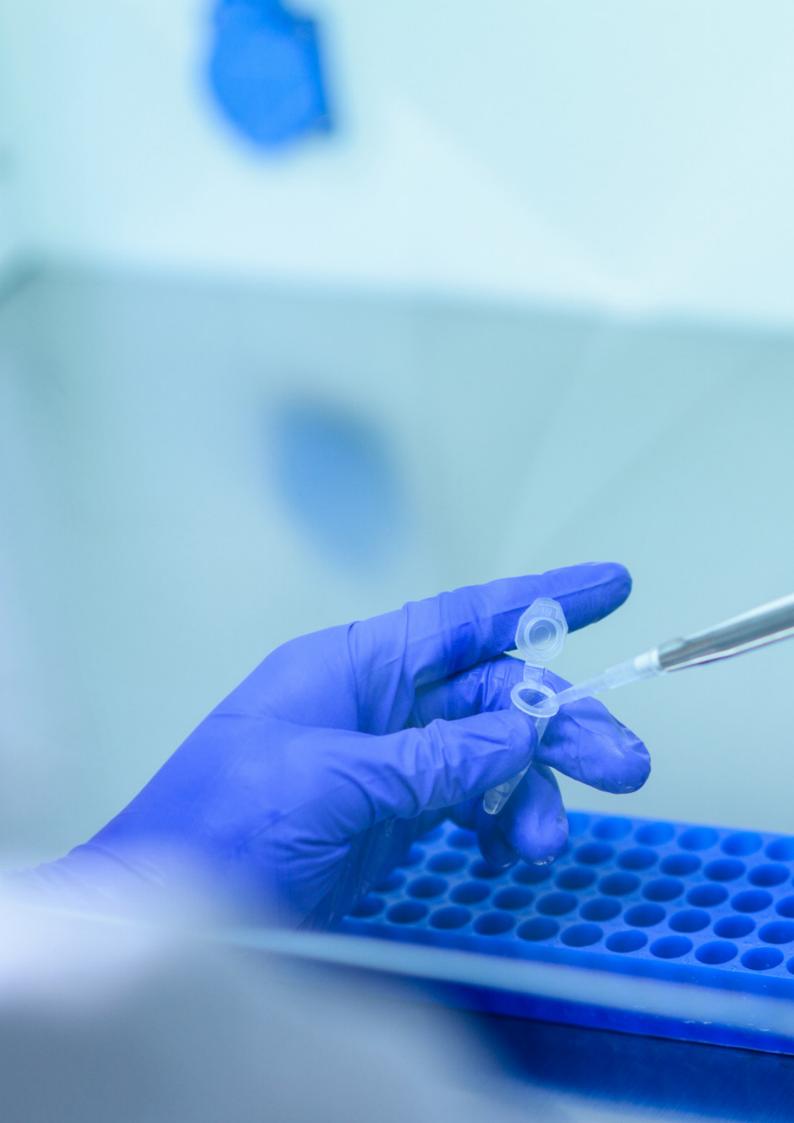
Net Assets	\$3,314,599
Research Projects Funding Committed	\$1,437,826
Current Liabilities	\$72,339
Total Assets	\$4,824,764

<sup>\*</sup>Note: 100% of all Administration Expenses are covered by our founding directors. Full 2019-2020 Financial information is available on our website or the ACNC.

# 1 IN 5 PEOPLE DIAGNOSED WITH PARKINSON'S ARE UNDER 50

FIND OUT MORE | SHAKEITUP.ORG.AU







"Did I want to be Clyde that has Parkinson's or Clyde that did something about having Parkinson's."

Clyde Campbell, Founder and CEO, Shake It Up Australia Foundation

#### **CONTACT US**

Shake It Up Australia Foundation
ABN 65 270 391 304
PO Box 710, Spit Junction, NSW, 2088

www.shakeitup.org.au

1300 361 803

(Q)

enquiries@shakeitup.org.au



DAILY - PRESS

Designed and printed by Daily Press Group 2021 dailypress.com.au email: info@dailypress.com.au