



APRIL 2021.

HUNTINGTON'S
South Australia & Northern Territory Inc



GM Report

Hi all,



In this issue:

- GM Report & What's on at Huntington's.
- From the Front Desk & Churchill Fellowship Update.
- Save the Date for Upcoming Events.
- Volunteering.
- Research Updates.
- Contact Details.

Welcome to the year of positive , progressive refreshing change on many fronts as you will see throughout this newsletter. There is much happening within the HD space and many areas that the HD Community can be part of. Our Hd programs are back for 2021 as you will see in this newsletter. Our website is being updated so keep an eye on that So get yourselves a coffee, put your feet up and have a read about the exciting things coming up for 2021.

Cheers Michele

INTRODUCING HUNTINGTONS SA & NT Inc. Board members for 2021.



Chair
Dr Elizabeth Thompson



Vice-Chair
John Stronnar



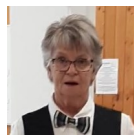
Secretary/Treasurer
Chris Glasson



Board Member
Dr Tim Porter



Board Member
Michele Giles-Clark



Board Member
Janet Andrewartha

WHAT'S ON AT HUNTINGTON'S

COFFEE & CO



Our C&C crew have done it again with a fantastic line up of activities and outings. With the impact of COVID restrictions being ongoing C&C has a new program & format. Still the same fun and enjoyment.



We look forward to your participation.

Held on Wednesdays from 11.00am till 1.00pm.

For those on our C&C list you will receive your program soon.

If you are not on our list & would like a program let us know at enquiries@huntingtonssant.org.au and we will send one out.



SOME HIGHLIGHTS FROM COFFEE & CO

FROM THE FRONT DESK.



Welcome back everyone, I hope you all had a wonderful Christmas and New Year.

Catching up with friends & Family. I did. Now hopefully we can get back to some sense of normality.

All of us here are hoping this year is a lot better than last year. It is always great to see everyone's smiling faces and great chit chat as you all come into the Office.

Regards Anna.



HOLD THE DOOR
SAY HELLO
SMILE
USE "PLEASE" AND "THANK YOU"
OFFER TO HELP
BE POLITE
PAY A COMPLIMENT



CHURCHILL FELLOWSHIP UPDATE

On February 16th, 2021 I had the honour of being presented with my Churchill Fellowship by His Excellency the Honourable Hieu Van Le AC Governor of South Australia.. My escorts to the ceremony were Mrs Elizabeth Thompson and Mr Garry Schilling.

Thank you Liz and Garry.

I am currently touching base with contacts in South America so we are able to connect virtually until I am able to travel safely. (unfortunately the situation in South America is still an emergency situation. Churchill are giving full support and have assured all fellows they will be able to complete their fellowships in a longer time frame.



This is such an exciting journey not only for me but for Huntington's throughout Australia and I thank the Churchill Fellowship for this amazing opportunity.



Save the Date



IT'S THAT TIME OF THE YEAR AGAIN.

May 9th is

MOTHER'S DAY

Flowers will be sold at the Office:
16 Malwa Street, GLANDORE SA 5037.

Call into the Office to Choose your
Flowers from

Thursday May 6 – Saturday May 8
Time: 0:930am till 2:30pm

Sunday May 9. Time: 0900 till 12.00pm

Or place an Order

Phone: 0424 062 121.

Prior to Thursday May 6.

Orders can be collected from the Office

VOLUNTEERS NEEDED

for Mother's Day flowers
from Tuesday May 4th through to
Saturday May 8th.

From 9.30 till 2.30 each day.

Come and show your creative side.

You do not have to be a florist.

Please consider spending a few hours to
help. Call 0424062121 & let us know
when you are available.

THE COUNTDOWN BEGINS COME & JOIN THE FUN

CITY TO BAY HUNTINGTON'S LEGENDS

SUNDAY SEPTEMBER 19



COME AND JOIN THE FUN.

WALK , RUN ,VOLUNTEER, SPONSOR.

**The Association will pay your
registration fee when you have raised
\$100.**

It's easy

Click on or Copy and paste the link below
and press the **FUNDRAISE OR START
FUNDRAISING BUTTON** to set up your
page.

[https://citybay21.grassrootz.com/
huntington-s-legends?vero_id=campaign
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**Start letting people know about
the City Bay September 19th, 2021.**

Any Queries

Call 0424062121 or Email:
enquiries@huntingtonssant.org.au

"Let's Dance " alongside those with
Huntington's disease.



“NEXT BBQ DATE”

5th June 2021

*Please consider volunteering for 4 hours
 If you are unable to do that*

COME DOWN & BUY A SAUSAGE OR 3

A FUN DAY FOR ALL.

BUNNINGS EDWARDSTOWN IS THE PLACE TO BE.



WE ARE LOOKING FOR PEOPLE TO HELP OUT WITH

- COFFEE & CO:** 3 hours each Wednesday to interact with those who attend and help them have a great experience. The smile & the enjoyment you will not forget. We do in house activities and outings.
- MOTHER’S DAY FLOWERS:** From May 4th to May 8th. Do you like flowers, come and let your creative side shine. Anyone can do it and there are areas for everyone to be involved. We will help you every step of the way.
- BUNNINGS BBQ’S:** 4 hours morning or afternoon. A great way to meet people whilst having fun. Full instructions given. Or come and help with preparation the day before.
- BECOME A COMPANION:** Call and have a coffee with someone from our HD Community on a regular basis to see how they are travelling. Help to put a smile on someone’s face & brighten their day.

A couple of hours a week, a month or when needed as a reserve let us know your availability.

Ask a friend to come along with you

Our volunteer list is currently being updated please reply when you receive it or contact us to send you our form on 0424062121 or email: enquiries@huntingtonssant.org.au

UPDATES

RESEARCH

Overseas there is much happening in the HD Research space. Those of you who follow HD Buzz would be aware of this.

<https://en.hdbuzz.net/>

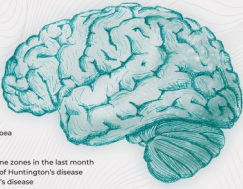
What you may not be aware of is the massive amount of work being carried out within Australia to put us in a position of being able to participate in this research. There is much to be done for this to occur and a great deal of help and participation is needed from the HD Community. Over the next 12 months we will keep you posted on progress in this area and how you can be involved. Hats off to Julie Stout and her team for having the foresight in getting Australia ready for this huge step forward for the Australian HD Community. I very much look forward to introducing you all to Julie in person when we are able to safely do this.

HOW YOU CAN BE INVOLVED.

SLEEP IN HUNTINGTON'S DISEASE

We are looking for people with and without Huntington's disease to take part in a study investigating sleep quality.

Who are we?
 This study is being undertaken by Emily Fitzgerald (Clinical Neuropsychology PhD) under the supervision of: Professor Julie Stout, Dr. Yifat Gilkemann-Johnston, Associate Professor Clare Anderson, Dr Melinda Jackson



You may be eligible if


- You're not a shift worker
- You don't have diagnosis of sleep apnoea
- You're not drug or alcohol dependent
- You're aged 18-65
- You have not travelled across three time zones in the last month
- You are within the premanifest stage of Huntington's disease
- You are gene negative for Huntington's disease
- You do not have Huntington's disease
- You have no history of traumatic brain injury, psychiatric illness or learning disability

What will I need to do?

- Wear an activity monitor, like a FitBit, and complete a sleep diary every day for 14 days
- Complete a set of online questionnaires
- Complete a set of cognitive tasks via mobile and telehealth
- This study will be conducted from your home, which means you don't need to travel anywhere to participate!

Reimbursement
 You will be reimbursed up to **\$80** upon completion of the study

For more information contact: Emily Fitzgerald (03) 9905 1918 med-HDsleepgutstudy@monash.edu



RESEARCH Project ID: 20212



Monash University is conducting research to understand how young people aged 18-35 are affected by Huntington's disease

LET US HEAR YOUR VOICE

What's Involved?
 - 30 minute online survey (link below)

[HTTPS://TINYURL.COM/HDYOUTHSURVEY](https://tinyurl.com/hdyouthsurvey)

For more information contact Kelly Atkins kelly.atkins@monash.edu



WITH SO MUCH HAPPENING WITHIN THE RESEARCH SPACE THE ASSOCIATION WILL BE KEEPING YOU INFORMED BY PUTTING OUT A MONTHLY UPDATE WHICH WILL LET YOU KNOW WHAT IS HAPPENING & WHAT IS COMING UP

IF YOU HAVE SOMETHING TO SAY ON THE ACCOMMODATION FRONT YOU MAY BE INTERESTED IN JOINING THIS SURVEY BEING PUT OUT BY THE SUMMER FOUNDATION.



Do you have Huntington’s disease or care for someone with Huntington’s disease?

Have you had difficulty getting suitable housing and support?

Our study looks at housing, services, and supports for people living with Huntington’s disease. We want to understand people’s experience of good or inadequate housing.

Researchers from the Summer Foundation and La Trobe University are recruiting people for a study. If you would like more information about the study, please contact Professor Jacinta Douglas by phone (03) 9479 1797 or email J.Douglas@latrobe.edu.au.

If you wish to participate, please contact 1300 626 560 or email research@summerfoundation.org.au.


The study will be a one-on-one interview with a researcher in our team, which will last for 60 minutes via telephone or by Zoom, and you will get a \$40 gift card.



COVID- SAFE UPDATE



CHECK IN USING THE QR CODE

GO TO  on your Smart Phone or

Register with our **COVID TRACING RECORD.**

REMEMBER:



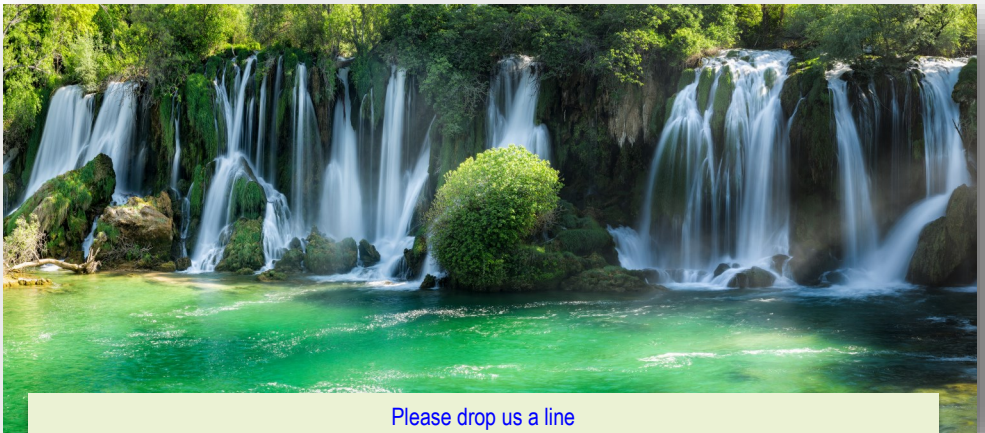
DO NOT ENTER IF YOU ARE UNWELL.



**STAY 1.5 METRES AWAY FROM OTHERS
NOT IN YOUR GROUP.**



REGULARLY WASH & SANITISE YOUR HANDS.



Please drop us a line

We look forward to your feedback & Ideas. Your input is important to the Association

CONTACT DETAILS: PH: 0424 062 121: EMAIL: enquiries@huntingtonssant.org.au

ADDRESS: FitzJames Building, 16 Malwa Street, GLANDORE SA 5038.

W: <https://huntingtonssant.org.au/> F: Huntington SA & NT Inc.