



Spinocerebellar Ataxia Australian Newsletter

June 2015 Edition 20

Welcome to the latest edition of the SCA Australia Newsletter.

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Upcoming dates

Next meetings

VICTORIA

Sunday 9th August 2015, 2.30pm

Spinocerebellar Ataxia Australia Meeting- Victoria Located in the Neurological Conference Room, 4th Floor, Centre Block Lifts, The Alfred Hospital, Melbourne

Guest speaker Professor Storey will be giving Part 2 of his talk on 'Genetics'.

NB: Professor Storey will be on long service leave all of July, when the group normally hold the AGM

QUEENSLAND

Saturday 20th June 2015, 1pm-4pm

Spinocerebellar Ataxia Australia Meeting- Queensland Located at Carindale PCYC, 27 Narracott St, Carina 4152. Guest

Speaker is Neurologist Dr. Paul Sandstrom

Upon entering the car park turn left, then right and go towards end of car park. The entrance to the room where we will be having the meeting is at the back of the PCYC building. The meeting room has its own entrance and ramp.

Please bring \$2 to cover costs and refreshments.

Any questions or queries, contact Lillian Di Mascio: Phone: (07) 3324 9342

E-mail: lillianadimascio@gmail.com

SOUTH AUSTRALIA

Wednesday 16h June 2015, 1.30-3.30pm

Combined SCA and CMT support groups meeting- South

Australia Located at 36-38 Henley Beach Rd, Mile End SA 5031.

Guest speaker is from the Independent Living Centre

RSVP to Hoda

Phone: 8234 5255 E-mail: HTeimorzadeh@mdasa.org.au

Meetings are normally held on the second Wednesday of each month.

Social dates and fundraisers

VICTORIA

Saturday 10th October 2015, 10am-3pm

Ataxia Awareness Day BBQ

Located in the community room at Lilydale Lake, Lilydale, Victoria.

QUEENSLAND

Ataxia awareness day BBQ

Details and Venue TBA

Spinocerebellar Ataxia Australia news

Scooter and trike for sale!

A scooter and trike have been donated to SCAA for sale. The proceeds will be used to assist our research fund.

Both are battery operated and have electric chargers. They are currently in Boronia.

Any inquiries regarding the scooter and trike, please contact Roger Thomson. E-mail: robert38@bigpond.com



SCAA donation envelopes

A reminder that donation envelopes for SCAA have been printed and are available for special events; including birthdays, anniversaries and farewells.

Donation envelopes can be a great idea for Christmas, or any other upcoming gathering where you would prefer to receive donations to SCAA instead of gifts.

These envelopes can be requested at no cost from the secretary, who can be contacted via

e-mail: mdunn6418@gmail.com

or post : PO Box 115, Howlong NSW 2643.

A big thank you!

SCA Australia would like to thank all of those who have assisted with fundraising and donations to the SCA research appeal.

If you are interested in making a donation, please click the button below.

MyPost Concession Account

Australia Post now offers concession stamps (along with other qualifying products and

services at the concession rate) to eligible* customers.

Customers must register for a MyPost Concession Account in order to be eligible.

Application forms can be found by [clicking here](#), and upon completion and return to any post office, a MyPost card will be sent to the applicant, along with 5 free stamps.

Applicants can then produce their MyPost card at any post office in order to purchase up to 50 concession stamps (60 cents each) per year.

- The MyPost concession account is available to holders of the following Federal Concession cards:
 - Pensioner Concession Card
 - Health Care Card
 - Commonwealth Seniors Health Care Card
 - Department of Veteran's Affairs Card
 - Veteran's Repatriation Health Card

Spinocerebellar Ataxia links

SCAA on social media

Spinocerebellar Ataxia Australia can be found on both Facebook ([click here](#)) and Twitter ([click here](#)), to help you keep up to date with the latest news and events.

The SCAA website ([click here](#)), is also still up and running. **MJD Foundation**

Established in 2008, the MJD Foundation is a charity which aims to "improve the quality of

life for Indigenous Australians and their families living with Machado Joseph Disease in Arnhem Land and beyond".

For more information on Machado Joseph Disease and the MJD foundation, [click here](#).

Wobbly TV

[Click here](#) to watch part 6 of Ataxia UK's 10 part Wobbly TV series.

Wobbly TV is a collection of short videos created for people affected by ataxia. The videos aim to provide people with a better understanding of ataxia, and to help those affected overcome some of the obstacles it poses.

Funded by the James Tudor Foundation, Wobbly TV will cover many topics, including diagnosis, research, assistive technologies, ataxia later in life and caring for a child with ataxia.

If you have missed any of the other short videos, you can catch up on them by clicking [here](#).

If you have any feedback on the newsletter, or if there is anything you would like to have included, please don't hesitate to contact Alice Poulton.

E-mail: alice.poulton@gmail.com

Daily living tips

Talcum Powder

If you have difficulty putting on socks, talcum powder can make it easier to slip socks on and off, and it smells great!

Shampoo Pump Dispensers

At times it can be difficult to have both hands free in the shower. Putting pump dispenser lids on your shampoo, or pouring your shampoo into pump bottles, can help make showering a bit easier.

Pump dispenser lids and bottles can often be found at supermarkets, hardware stores and pharmacies. They can also be bought online by clicking [here](#).



Photo credit: <http://www.rnrassociates.com/wordpress/shampoo-pump/>

Epworth Balance Disorders Clinic

Epworth Camberwell

Epworth HealthCare has announced the commencement of a new Balance Disorders Clinic at Epworth Camberwell.

The clinic offers cutting edge technology, including infra-red and high speed video-oculography. These can be used in the diagnosis of vestibular and cerebellar conditions.

Onsite vestibular and neurological rehabilitation (provided by specialist trained allied health clinicians) complements the Balance Disorders Clinic.

Dr David Szmulewicz and Dr Michael Tan will be leading the clinic.

Dr Szmulewicz is a neurologist and neuro-otologist who is a lead investigator on research defining a novel ataxia (Cerebellar Ataxia with Neuropathy and Vestibular Areflexia Syndrome (CANVAS)). He has also developed an interactive vertigo assessment tool (iVAT) and an objective bedside tests of imbalance (the video VVOR). Furthermore, Dr Szmulewicz is co-director of the Australian Temporal Bone Bank.

Dr Tan is a neurologist and rehabilitation physician who is interested in vestibular rehabilitation, neuro-otology and balance disorders, epilepsy and first seizure management, and botulinum toxin treatment for chronic migraine.

Carers Australia

Around 1 in 8 Australians have an unpaid caring role.

Are you looking after someone? If so, Carers Australia is there to help.

Carers Australia is a not-for-profit organisation that provides advice, information and support to carers in order to improve their health, wellbeing, capacity and resilience.

Carers Australia offer a free Carer Advisory Line in each state. These lines are available Monday to Friday 9am-5pm and can be reached by dialling **1800 242 636**.

Each call is answered by an experienced staff member who will listen, provide information, and support you in your caring role.

Temporal Bone Donor Society Inc.



The Temporal Bone Donor Society Inc. is an Australian health promotion charity that aims to raise awareness for the Australian Temporal Bone Bank. The society also provides education regarding the after life donation of temporal bones for medical research.

Why is temporal bone donation important?

Temporal bone research has resulted in important knowledge concerning the cause and location of balance and hearing disorders. This knowledge can help develop more effective medical treatments.

What is the process of donation?

Soon after life, a small part of the temporal bones (the bones that form part of the side of the skull, enclosing the middle and inner ear) are surgically removed. These samples are then used for research into the cause of the patient's balance and/or hearing disorder, or the positive impact of cochlear implants on speech.

For more information about donation [click here](#).

NB: Upon registering, the donor may elect to donate DNA, meaning that the research may

involve genetic testing. In some circumstances this can result in early detection and diagnosis for the donor's biological relatives.

Recent research and funding

Positive proof-of-concept results announced for Cabaletta in the treatment of SCA3.

On March 28, 2015, BioBlast Pharma Ltd. (a clinical-stage biotechnology company) announced positive **in vivo proof-of-concept** results for Cabaletta in the treatment of Spinocerebellar Ataxia type 3. These results were presented at the International Ataxia Research Conference, held in Windsor, United Kingdom.

Cabaletta acts to protect against pathological processes in cells, and has been recognised to prevent the pathological accumulation of proteins within cells in several diseases associated with abnormal **cellular-protein aggregation**.

Cabaletta was tested in two different mouse models of SCA3 (a **transfected** mouse model and a **transgenic** mouse model).

BioBlast's President and CEO, Colin Foster, stated that the findings from these studies indicated "Cabaletta's efficacy in reducing Ataxin3 aggregates, reducing neural markers for neural damage and preventing typical phenotypic deterioration in animal models."*

Foster went on to add "This is powerful support for our ongoing SCA3 Phase 2 clinical trial program underway in Israel. We anticipate expanding the number of SCA3 clinical study centres later this year."

*More simply: the drug has been shown to reduce the toxic build up of protein. This reduction prevented typical symptoms from being exhibited by the mice.

Glossary of terms:

In vivo: performed in a living organism.

Proof-of-concept: demonstrating the feasibility of this method.

Cellular-protein aggregation: A biological phenomenon in which proteins clump together, often with toxic implications.

Transfection: Cells take up foreign DNA. This DNA is replicated and passed on, and consequently changes the genetic constitution of the organism.

Transgenic: An organism that has a gene from another species incorporated into its genome.

The newly launched Peesh Foundation commits up to \$20,000 AUD to Spinocerebellar Ataxia and Body Dysmorphic Disorder related research projects.

Peesh Venture Capital, a US-based company that invests in disruptive technologies has recently launched the Peesh Foundation, which aims to support research and development for currently incurable disorders, such as Spinocerebellar Ataxia. The foundation currently has just under 12 million AUD in funds, of which up to 20,000 AUD will be allocated to Spinocerebellar Ataxia and body Dysmorphic disorder-related research projects.

The executive director of the Peesh Foundation, Sunita Chopra said "We not only help fund research to find better treatment options and an eventual cure for this disease, but also show the incredible diversity of people affected by Spinocerebellar Ataxia and Body Dysmorphic Disorder."