Greetings from the SCA-Remote study research team at the Harding Lab, Monash University! We've created this newsletter to provide updates about the study, as well as to share other ataxia news and resources that may be useful.

This newsletter will also be posted on our new study webpage: https://www.monash.edu/medicine/ccs/neuroscience/research/harding-group/spinocerebellar-ataxias-remote-assessment-study.

**WELCOME, SARAH!**

We were very excited to have Sarah Wallis join the SCA-Remote team as a Research Assistant in September 2022. Sarah recently completed her Honours in Psychology at Monash University. She will be conducting our participant Zoom sessions and managing all of the different data coming in from our participants’ monthly assessments. Sarah will also be the main contact for the study in 2023.

**CONGRATULATIONS HONOURS RESEARCH STUDENTS!**

Congratulations to our 2022 Monash University Honours research students, Yasmin Yassin and Tabitha Krishnan, who joined the SCA-Remote team this year.

Yasmin and Tabitha ran many of our SCA-Remote Zoom assessment sessions and successfully completed their research theses on computerised assessments in Friedreich ataxia and Spinocerebellar ataxia, respectively.

**THE SCA-REMOTE TEAM**

Principal investigator: Dr Ian Harding  
Project lead: Dr Louisa Selvadurai  
Research assistant: Sarah Wallis  
Research coordinator: James Morgan  
Co-investigators: Associate Professor David Szmulewicz, Professor Adam Vogel  
Clinical collaborator: Dr KIshore Kumar
Last month, researchers from the SCA-Remote team attended the International Congress For Ataxia Research (ICAR) and the Ataxia Global Conference in Dallas, Texas, USA. These meetings included:

- Scientific talks and posters, training workshops, scientific debates, and networking
- Social events, including a "Boot Scootin' Night Out" where we tried some Texan BBQ and line dancing!

The conference was a great opportunity to introduce the SCA-Remote study to the international ataxia community:

- Dr Louisa Selvadurai presented a scientific poster showing our first study results. We found that individuals with SCAs showed more month-to-month variability (ups and downs in performance) on some of our computer tasks compared to individuals without a SCA.

- Dr Selvadurai also presented a 3-minute "lay flash talk" of the results to an online audience of individuals affected by SCAs and other ataxias.

- Dr Ian Harding discussed SCA-Remote and related work in Friedreich ataxia during a conference session on "Clinical Outcome Assessments and Natural History Studies", highlighting how these studies can teach us new things about how symptoms progress in SCAs and other ataxias.
The SCA-Remote team are also involved in various other ataxia research projects, many of which were also featured at the conference.

**Professor Vogel**

Professor Adam Vogel discussed the development of a new scale called the Dysarthria Impact Scale which measures how dysarthria (speech difficulty) impacts quality of life for individuals living with a neurological disease such as ataxia. Professor Vogel also presented exciting new results from a study in which people with ataxia undertook a 4-week at-home dysarthria rehabilitation program - doing the program improved participants' speech.

**Associate Professor Szmulewicz**

Associate Professor David Szmulewicz presented a "late breaking" research study on a new SCA type. A/Prof Szmulewicz and his team identified a mutation in the "FGF14" gene that causes a type of adult-onset ataxia. This provides a genetic explanation for a group of individuals who previously had no known cause for their ataxia. This type of ataxia is referred to as SCA50 or ATX-FGF14.

Want to read more about the research shared at the conference? The team at "SCAsource" have put together a series of online articles for the ataxia community, recapping the main messages from each session: [https://www.ataxia.org/scasource/](https://www.ataxia.org/scasource/)

The SCAsource website is a fantastic online resource which helps the ataxia community to learn about new SCA research - we will feature this resource in a future newsletter.

Dr Selvadurai gratefully acknowledges the support of an International Congress for Ataxia Research Junior Investigator Bursary and a CASS (Contributing to Australian Scholarship and Science) Foundation Travel Award to attend these conferences.
This year, Dr Harding and ataxia research collaborators in Melbourne launched the first Australia-wide database of individuals with genetic or idiopathic ataxias.

The benefits of a registry:

- More quickly and easily identify individuals who are willing and eligible to participate in ataxia research studies
- Better understand the number of Australians living with different types of ataxia - this will help us make a stronger case when applying for competitive government research funding
- Attract drug companies looking for sites to run ataxia clinical trials
- Help plan future ataxia research and attract new researchers to the field

As of the 30th November 2022, 87 individuals with ataxia had joined the Australia-wide registry.

Many different types of genetic and idiopathic ataxias are represented in the database. The most common type so far is SCA6.

Are you located in Australia? Find out more and sign up to the registry at the following webpage. We are looking for people with genetic or idiopathic ataxia and those without ataxia (e.g., family, friends) to join the database.

https://www.monash.edu/medicine/ccs/neuroscience/research/harding-group/australian-cerebellar-ataxia-registry
LAUNCH OF THE CEREBELLAR ATAXIA RESEARCH NETWORK OF AUSTRALIA

This network, led by SCA-Remote investigators Dr Ian Harding and Associate Professor David Szmulewicz, is a new initiative to bring together Australian ataxia researchers, doctors, and allied health professionals. The network aims to help ataxia professionals to better work together, and to grow the profile of Australian ataxia research.

The inaugural meeting was held on the 30th November 2022 via teleconferencing, and was well-attended by ataxia professionals from around Australia.

ATAXIA RESOURCES

In this edition of the newsletter, we would like to highlight the website of the National Ataxia Foundation (USA), which contains a wealth of updated information and resources for people affected by ataxia. These include:

- Fact sheets and videos about ataxia:
  - https://www.ataxia.org/fact-sheets/
  - https://www.ataxia.org/webinars/

- "Ask the Expert" recorded webinars - a great opportunity to hear ataxia doctors and experts answer questions from people living with ataxia
  - https://www.ataxia.org/asktheexpert/

The National Ataxia Foundation also supports the SCA-Remote study through a Young Investigator Award granted to Dr Harding.

Thank you for your participation in and your support of our research! Please contact us at any time at the Harding Lab, Monash University: harding.lab@monash.edu