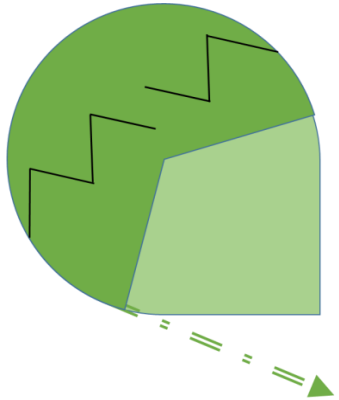
Introducing….
TAAD
The Aphasia Awareness Delegation



Sean O’Brien, Rotarian, Stroke survivor
Bernard Chandra, Rotarian, Brain Injury Survivor
Colleen Kerr, Optimal SP, Speech Pathologist
Diane Finch, Rotarian, Brain Injury survivor

Acknowledging the support of:

Employers Mutual
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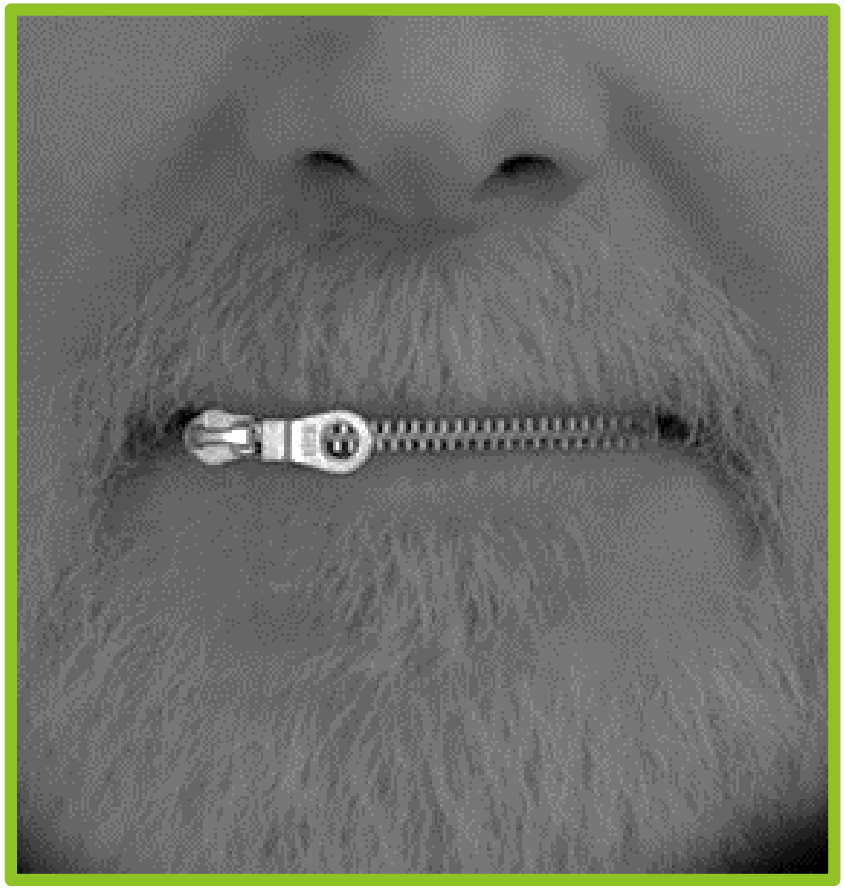
Department of Veterans’ Affairs

optimal sp
Speech Pathology Solutions



Aphasia is a communication disability caused by damage to the language centres of the brain.

It can impact on the ability to understand, speak, read and write.

It does not generally impact on intelligence.

Today we want to share the experiences of our team's efforts to increase awareness of Aphasia.

How common is Aphasia

In stroke (not including TBI, Brain Cancer, Dementia…)

'It is estimated that in 2012 between 93 744 and 156 240 Australians were living with the effects of aphasia'

Centre for Clinical Research Excellence Aphasia Rehabilitation, Submission to the Senate Standing Committees on Community Affairs, Submission 169, p. 2.

It is more common than Parkinson's Disease

'It is conservatively estimated that in 2014 there were 69,208 Australians living with PD'

Living with Parkinson's Disease An updated economic analysis 2014 prepared by Deloitte Access Economics, for Parkinsons Australia Inc

How much do people know about Aphasia around the world?

International Journal of Language & Communication Disorders

INT J LANG COMMUN DISORD, MAY–JUNE 2016,
VOL. 51, NO. 3, 276–284

Research Report

International patterns of the public awareness of aphasia

Chris Code†, Ilias Papathanasiou‡, Silvia Rubio-Bruno§, María de la Paz Cabana§, Maria Marta Villanueva§, Line Haaland-Johansen¶, Tatjana Prizl-Jakovac||, Ana Leko||, Nada Zemva#, Ruth Patterson**, Richard Berry**, Elizabeth Rochon††, Carol Leonard‡‡ and Amelie Robert‡‡

'This study reports the results of the largest face-to-face series of surveys of the public awareness of aphasia from six countries in Europe, North America and South America. Between 60% and 16% said they had heard of aphasia (40% overall), but the combined mean percentage of those with actual knowledge of what aphasia is was 9.2%.'

"It has been suggested that public awareness of aphasia is vital for extending services, research support, social inclusion and targeted raising of awareness"

Aphasia Awareness

I have had the pleasure of working with people with Aphasia for more than thirty years

All aspects of our Aphasia practice have been subject to constant scrutiny and research. As part of a committed and collaborative effort to improve the consistency of care for people with Aphasia, the NHMRC funded Centre for Clinical Excellence in Aphasia released a series of 82 best practice statements, and the first of these reflect the focus of the aphasia community on raising awareness

1.1 Community awareness of aphasia should be raised

Aphasia Rehabilitation Best Practice Statements 2014
Comprehensive supplement to the Australian Aphasia Rehabilitation Pathway

Conveniently in 2014 I happened to have three clients, all with different aphasia stories, all with a background in Sales, all on a mission to talk about Aphasia. They were also all Rotarians…

Sean O’Brien:

I was a Navy Diver for the R.A.N (Australia) and the R.N (UK)

I worked for GE (lighting)

I joined Rotary in 2002.

In 2012 I had a devastating stroke as a result of brain surgery which left me with Aphasia.

.

My Aneurysm 2012

Dr. Brian Richardson and Dr. Mark Dexter

These two men saved my life.

Large aneurysm – if it had burst I would be dead.

Long operation.

Small clot 2 days later - aphasia.

Sean

Diane Finch (Di)

Di has worked in sales, business and politics

Di has been involved with Rotary since the 1960's as the first ever Ryla youth exchange recipient

In 2014 Di had a severe TBI as a result of a car accident which initially left her unable to walk or talk.

Di made a great recovery but wanted to 'give back'

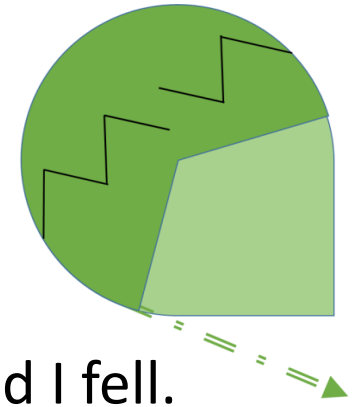
Bernard Chandra:

I am used to being in charge of a large sales and marketing teams in my work at MLA Holdings Ltd.

I have been a Rotarian since my early career in Fiji and continued with Rotary when I moved to Australia.

In 2012 I had a severe traumatic brain injury

MY ACCIDENT



8th August 2012. I was walking down the internal stairs and I fell.

I had a traumatic brain injury

Remember nothing for many weeks.

My talking was confused.

I couldn’t remember names or read or write well.

I didn’t know I had a brain injury or aphasia.

Bernard

We all had the same idea - why not use our Rotary Network to spread the word about Aphasia?

Bernard

Why Rotary?

Rotary DOWN UNDER

- Because it is HUGE

  There are 30,000 members around Australia

  There are more than 1,000 clubs
- Because we were all members and knew how it worked
- Because Rotary is more than running BBQ's. Rotary is about HEALTH

  - Rotary Health wiped out polio

  - Rotary funds regional doctors

  - Rotary funds indigenous students to study in health

  - Rotary raises $1000s of dollars for charities and disaster relief

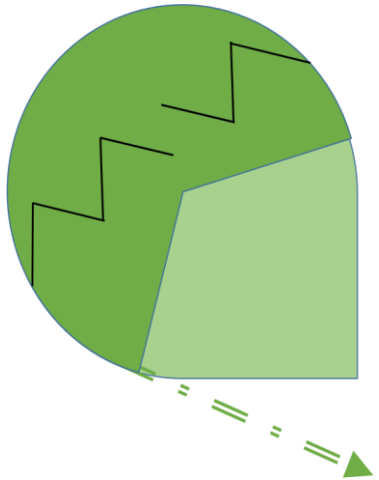
Bernard

We even passed the Rotary Philosophy known as the Four Way Test

- ✓ We would tell the truth about our stories
- ✓ It is fair to talk about Aphasia
- ✓ It helps build friendships to talk about Aphasia
- ✓ It will be beneficial to everyone to learn more about Aphasia

Sean

We gave everyone has a job.



- Step One – Think of a Name!
  TAAD The Aphasia Awareness Delegation
- Step Two – Picture/Logo (Sean)
- Step Three – News - advertising (Bernard)
- Step Four – Network/Talking (Dianne)
- Step Five – Practice Practice Practice!!! (Colleen)

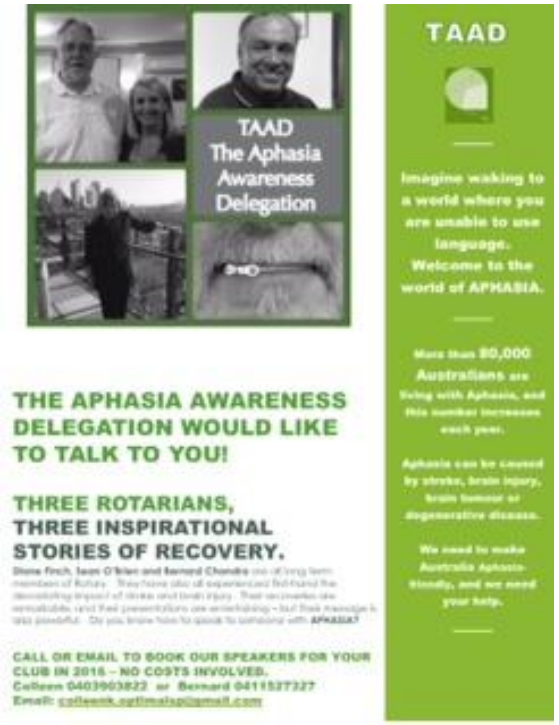
Sean

Aphasia in the News

In December 2015 TAAD - we placed an article in the Rotary Down Under Newsletter.

More than 1000 Rotary clubs across Australia read about Aphasia.

And then we waited…



TAAD: The Aphasia Awareness Delegation

Sean

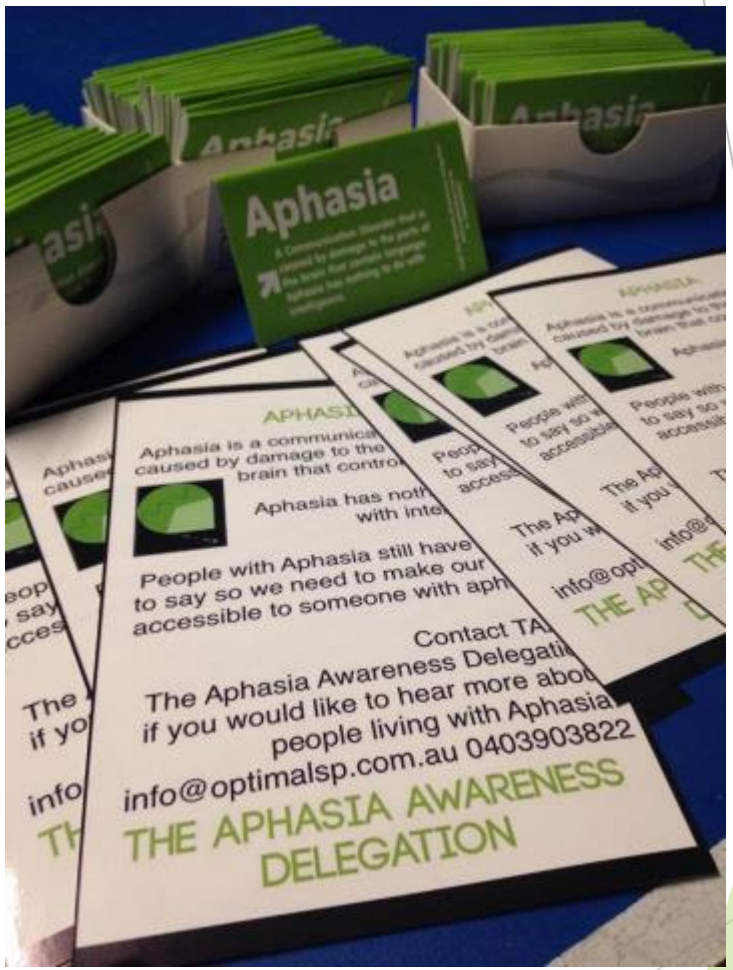
And the response has been…

Sean

We aim for one talk per month.

We have already spoken to 100s of people.

We have talked to 13 different Rotary Clubs all around Sydney



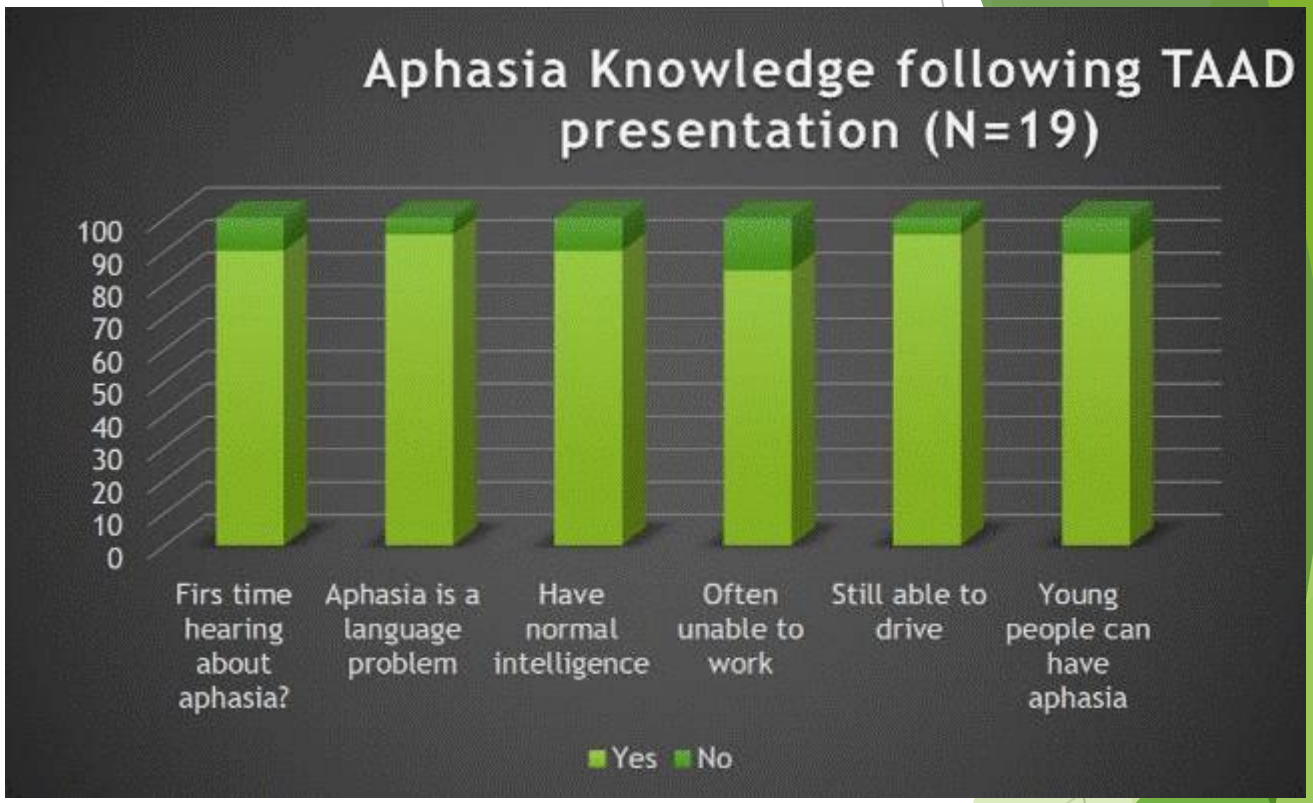
Sean

We speak for 20 minutes
Each person tells their story

We give a card with tips for talking to someone with Aphasia

And it seems to be working…

We asked our last two clubs to complete online surveys based on the Aphasia Knowledge Quiz (National Aphasia Association)



TAAD: The Aphasia Awareness Delegation

From a clinician's perspective this approach has ticked lots of boxes:

There is no clinician! This is a team.
Truly collaborative and client-driven.

Two of the TAAD members did not want traditional therapy but they did want to integrate therapy into real life goals.

This incorporated many different therapy approaches – scripting, biographical narrative, life participation – and allowed me to represent outcome goals in ways that were meaningful to these clients.

As such it falls solidly within our **Aphasia Rehabilitation Best Practice Statements**

Aphasia Rehabilitation Best Practice Statements 2014
Comprehensive supplement to the Australian Aphasia Rehabilitation Pathway

✓ **Goal setting should be a dynamic process that is reviewed across the continuum of care in order to reflect the client/family context, wishes and language recovery.**

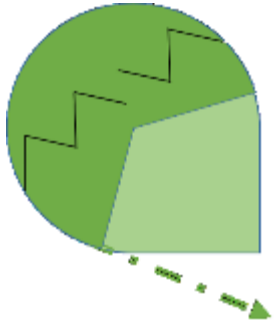
✓ **Systems should be established to ensure involvement of people with aphasia and their family as part of the rehabilitation team.**

✓ **Outcome measures for people with aphasia should be relevant, meaningful, and important to stakeholders. The ICF is based on the assumption that the ultimate desired outcome of rehabilitation is improvement in the ability to participate in the areas of life most important to that person**

Aphasia Rehabilitation Best Practice Statements 2014
Comprehensive supplement to the Australian Aphasia Rehabilitation Pathway

Bernard

What else have we learnt



- People don't know about Aphasia.
- Most people want to know about Aphasia – we always have lots of questions afterwards
- Some people are not that interested
- We all like getting out and talking to people
- Our speech is getting better the more we do this
- This helps us use our sales skills. Aphasia is our job.
- We have talked at the NSW and National Aphasia conferences to encourage people to get out and talk to other community groups

Bernard

TAAD: The Aphasia Awareness Delegation seems to be working

We'd like to reach bigger audiences

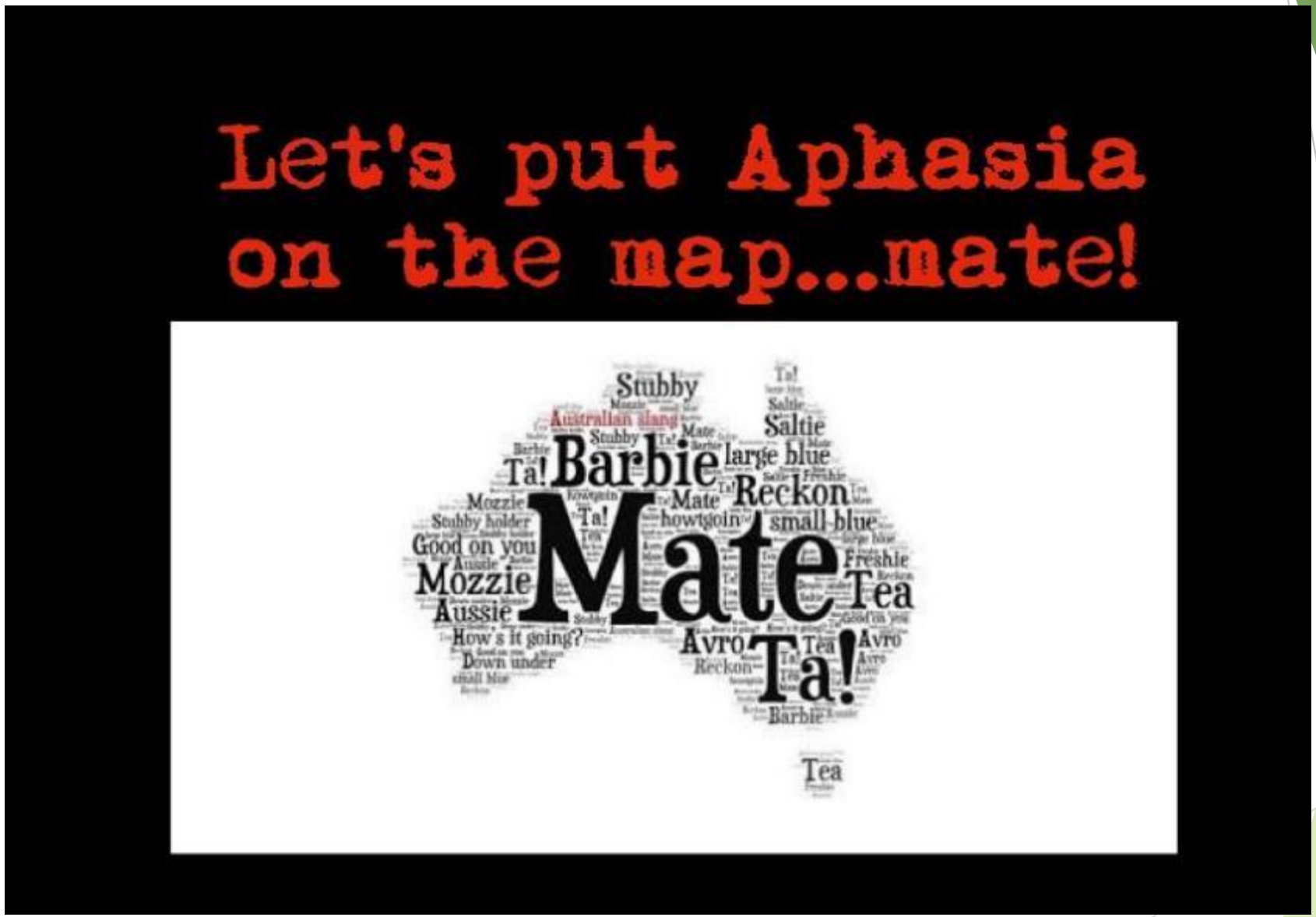
We need more facilitators like Colleen to help

We need sponsorship to run web-meetings and do more printing because we now have rep's in **SA, ACT and Victoria** who want to get started with taking TAAD presentations into other states.

We plan to go back to Rotary in January and ask them if they can think about making this Australia-wide

We've got a bigger goal:

Sean


Let's put Aphasia on the map...mate!
Stubby
Australian slang
Saltie
Barbie
large blue
Ta!
Reckon
Mozzie
Mate
Stubby holder
howtgoin
small blue
Good on you
Freshie
Mozzie
Mate
Tea
Aussie
How's it going?
Avro
Ta!
Down under
Reckon
Barbie
Tea