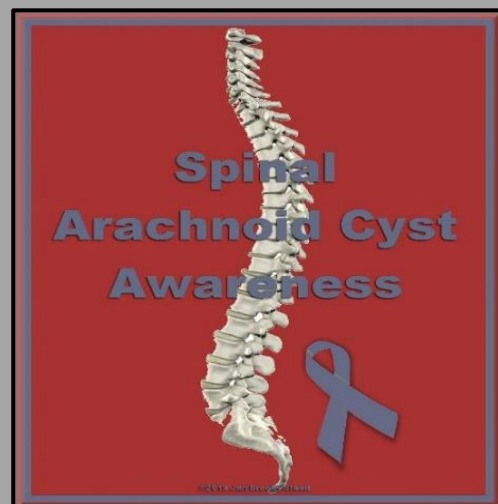
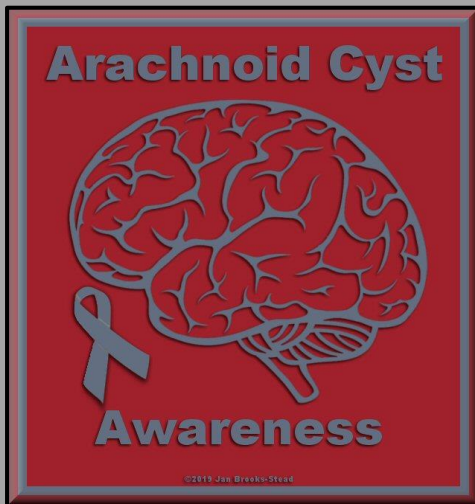


# The Australian Arachnoid Cyst Awareness Support Group.

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Newsletter No:13  
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Hello Everyone,

This newsletter will be a brief one as unfortunately I am having issues with my hands lately and prolonged use of the key

board is causing tingling and numbness.

This unfortunately is a symptom that can become part of our condition and I know of other patients who suffer with the same. It

can be quite frustrating at times but we keep going!

So I will outline our most up to date information that has occurred since the December newsletter.

### **Recent Surgeries**

We have had a number of families who have had their children need to have surgery in the last few months and this has been a time of stress and anxiety for those family members. Some of these patients have had to go in for shunt revisions and shunt replacements and unfortunately the parents of these children have had a really difficult

time accessing surgeons who understand our condition and have agreed to revise or replace their child's shunt. One of our Mums has been traveling back and forth interstate with her daughter for treatment which has been a long haul that had to be absolutely necessary!

I have really felt for these families as I know all too well the problems we face with follow up treatment and finding the right surgeon to assist with this. Then there is the worry of the surgery being successful and that the surgery takes away their child's symptoms and the hope

that there will not be a need for another surgery for some time.

We have also had a mum of a six-month-old baby girl who has had to experience her child having a fenestration surgery to remove the pressure from her little girl's cyst. To all these families I wish you all the very best and I hope by now your children are starting to recover and I hope all is going well and you can start to see improvement each day and you do not have to worry for a long while or hopefully there won't be any more

surgery at all in the distant future.

## **Kids Art Competition**



We had two wonderful pieces of art sent in by the mums of two very promising young artists. I have decided to give homes to both our lovely old fashioned handmade bears to both our young artist.

These bears were very kindly donated to us from a member of the community that wanted to do something to help our group.

This was such a lovely surprise and now I will be able to let her know the bears' destination and thank her again for her kind gesture.

Two paintings were posted on our FB page from Julie Quirke painted by her daughter Scarlett.



Scarlett called her first painting, let the rivers run.



Her second Painting that is called, Rainbows in the Sea.

We already know what she is naming her bear, as she picked the name Bowie. Good on you Scarlett!

The other piece of art that was posted was from Fiona Leigh Ryzak. Her son Blake created this little guy.



Blake has called his cute little guy Thumper!

Thankyou Blake. He is a terrific little Character. A big thank you to both mums for

sending in your children's artwork. Both Kids will be receiving their bears in the next two weeks.

### Questionnaires for our Australian Database.

We had a great response from our older group members thank you for your help.

However, when trying to get anyone in the thirty to forty age group to respond to our questionnaires I am disappointed. I have not received any? This is a shame because I want to be able to form a picture of the full

extent of our patient's needing assistance across Australia.

I've spoken to so many of our patients in this age group and they all stress just as we all do, that they cannot receive appropriate care. If we are to go forward and receive the help, we all desperately need people need to come forward and participate. It's such a small ask to be able to help themselves and others.

It's important to have data from all age groups as we can then follow the outcome of this condition as we age.

Even if you have been diagnosed and are symptom free or if you have had a good outcome after surgery and have remained well it would still be good to hear from you.

You can remain anonymous and it takes less time to fill in our questionnaire than it does to fill in an online generated survey or questionnaire we all receive whenever we spend or are asked for our shopping experience from various companies.

If you are in this age group, could you take time to reconsider

filling in our form you will be helping yourselves toward a better medical future.

The next group of patients, we would like to hear from is the teens to twenty-year-olds so if you are a parent or a young person, please can you help out with this questionnaire, so I can equip myself for future meetings and conferences with our statistics of sufferers of the symptoms from these a/cs or if you have been diagnosed with our condition, we also want to hear from you even if you have had positive

experiences and are not symptomatic or you have had surgery and have remained symptom free.

Please pm me through Facebook or email me at the email on the front or end of this newsletter.

**A letter from our WA Health Minister Amber Jade Sanderson.**

Western Australia is the worst state for our patients who are needing treatment and who are trying to access neurosurgeons with an understanding of symptomatic a/cs. Followed by Tasmania.

After receiving our first lot of correspondence from Mark Buttler our Minister for Health, one of the things that was mentioned was to write to each state health minister.

I wrote to WAs health Minister Amber Jade Sanderson. I got a very helpful reply and it was discussed WAs supportive and close collaboration with Rare Voices Australia also The Parliamentary Friends of People with Rare and undiagnosed Diseases has been established by the parliament of WA. This is to raise

awareness of rare and undiagnosed diseases collectively and increase liaison between people and organisations working in a range of rare diseases and members of parliament. (This is an excerpt taken from her letter)

It discusses how the future Health Research and Innovation Fund has been established.

You can read further information in this letter on our FB page in the featured section or on our Website.

The exciting thing is A Dr Kristen, Director, Office of Population Health Genomics at the Department of Health, leads a team that



considers policy aspects of Rare Diseases. She is also a member of the Scientific and Medical Advisory Committee for Rare Voices Australia.

Dr Nowak will be in contact with me to offer to meet via video conference to discuss our concerns of the care and management of patients with symptomatic Arachnoid Cysts in the Western Australia Health System.

This is a huge step forward for WA!

I am needing people to show interest in joining in the conversation with Dr Novak. This is your chance to have a voice.

I have asked for replies on Facebook but have only received three replies! You could become part of a clinical trial or be receiving help through helping your medical system in WA to understand what you go through in trying to find medical professionals and to have them understand there are many of you all suffering the same symptoms and how these symptoms can impact your daily lives.

This is a great opportunity! please show your interest in participating in this conversation with Dr Kristen Novak by emailing me at the email on the front and end of this newsletter or you can SMS me or pm me.

Let's get prepared for this very important opportunity.

**The Arachnoid Cyst Awareness Australian Support Group Fifth Birthday**

I cannot believe it's been five years since this group started. I would like to thank those patients and families who have contributed and supported our group and it's been so lovely to connect and become friends with so many group members. I am looking forward to seeing what the next five years brings us!



## How You Can Help

: Governing, co-ordinating a group and advocating a support group in your state.

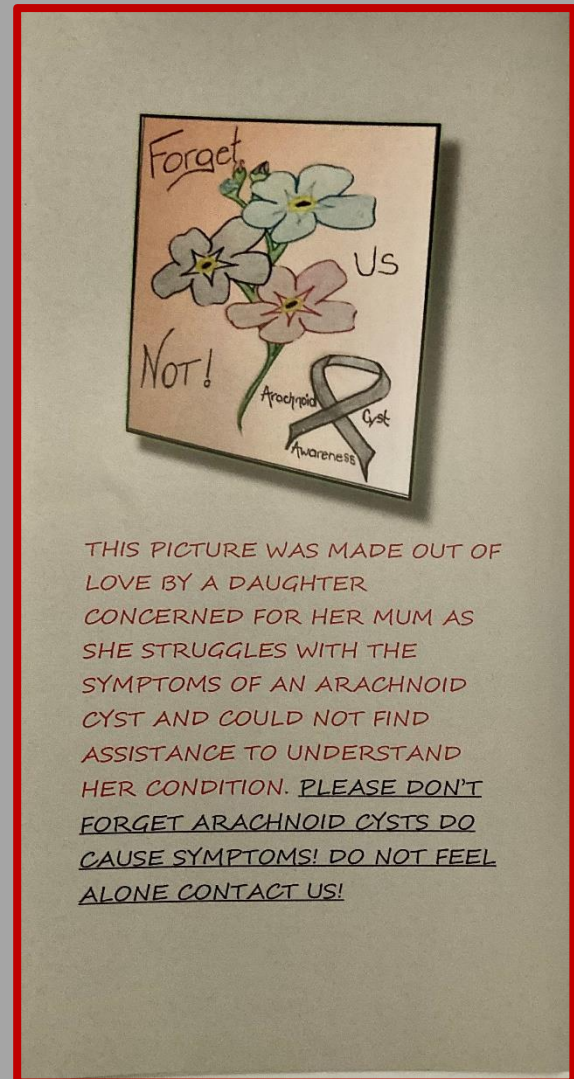
: Distributing brochures to neurosurgery and Neurology and Drs Rooms.

: Join The Committee

: Contribute to our publications.

: Contribute to our online Arts and Craft Hub.

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