The Australian Arachnoid Cyst Awareness Support Group.

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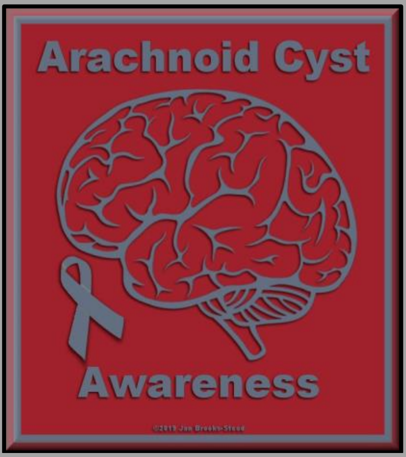
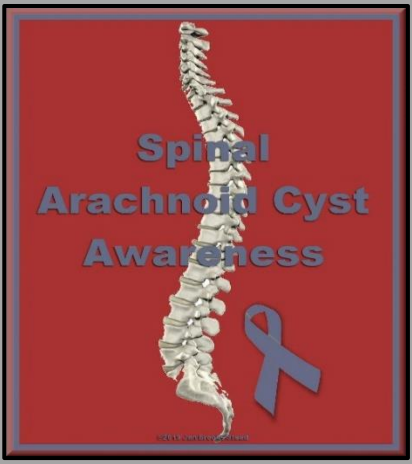




Hello everyone,

Firstly, my apologies for not getting our September newsletter out. I had organised and written it up to go out in time but I had some unforeseen circumstances delaying it and then I became unwell with an infection which involved a hospital visit and unfortunately it became too late to publish, so I will combine some of our news in our December newsletter.

Over the past few months, I’ve been grappling with the decision of whether to transition our group into a registered charity or remain a grassroots organisation since becoming involved with Rare Voices Australia.

To be able to secure funding for our group I thought this was the pathway we needed to take but after doing some research and making inquiries and giving everything a lot of thought I’ve chosen to stay a grassroots organization.

Keeping things personal, warm, and community-focused is incredibly important to me, and I feel this path allows us to maintain the close connection we’ve built together.

I have found there are ways for us to access funding by partnering with another organisation or auspicing. Auspicing means we can arrange for a larger charity to manage our funding and receive the funding through them.

Becoming part of a committee.

With all these thoughts on remaining a grass roots organisation and looking to secure much needed funding in the near future, we desperately need to form a committee for our group.

I have had a few members put their hand up, but we do need more people.

Please can you spare some time, three times a year to help with the future decision making of our group.

This is desperately needed, we need a committee to be a legal entity to secure funding.

Please can you help out?

You can contact me via Facebook or you can email me of your expression of interest to join.

A warm welcome to all our new members who have joined us over the past month.

We're so glad you've found your way to our community. I hope you discover plenty of helpful information on our Facebook page.

If you visit the *Featured* section at the top of our Facebook page, you'll find a link to our website.

Under **Newsletters & Publications**, you'll find a booklet written by patients, sharing their experiences of being diagnosed with an arachnoid cyst and what to expect throughout their journey.

You'll also find information about one of the biggest challenges we face in Australia: the major shortage of doctors who truly understand the complications of symptomatic arachnoid cysts. To help address this, we've kept our **online petition** running in the hopes of gathering as many signatures as possible to present to the Health Minister. Every signature helps move awareness forward.

While you're visiting the website, you can also explore our **Patient Stories** section.

These personal accounts help others feel less alone, offer guidance, and strengthen our collective voice. If any of you would like to share your own story, I would absolutely love to hear from you. The more stories we can share, the more awareness we can create.

I'd also like to mention our four members who recently underwent surgery. You have all been in my thoughts, and I’ve been following your recoveries.

I hope each of you begins to feel better with time, rest, and support. I am sure our whole patient community is wishing you all well too.

Can you believe Christmas is upon us again already?

I’ve just finished decorating the house, wrapping presents, and getting organised. I’m especially excited because my granddaughter and her girlfriend will be visiting for a week—something I’m looking forward to immensely.

I imagine many of you with children in your families are feeling that rising excitement of the season too!

Kids Christmas holidays art competition on.

I thought we would have another art competition this year for all of our lovely kids.

With this competition, I would like to see some wonderful pieces of art showing what you have been doing on your holidays to help create healthy brains.

This could be a photograph of some cooking or of your favourite food with a story attached or you could make a collage or do a painting.

The prize will be an Arachnoid Cyst Awareness support bag containing a t-shirt with logo, a drink bottle and thermo tumbler to keep your drinks hot or cold and an Arachnoid Cyst Awareness Bracelet.

All entries can be emailed to me at the email on the front of our newsletter or have a parent post a picture of your work on our face book page.

Sara Hammersley has been contributing articles on her experiences and research on Connective tissue disorders.

Sara is one of our members who is recovering from surgery.

We wish her well and look forward to reading more of her articles when she feels heaps better. Thanks, Sara, for your contribution this year. It has been very interesting reading.

Thank you to all our moderators this year on our Facebook page, your contribution in helping give lived experiences and directing members to much needed information has been very much appreciated.

Well, I think that’s all I have until next newsletter.

Wishing you all a peaceful, joyful, and gentle lead-up to Christmas. Thank you for being part of this wonderful community.

Merry Christmas!

With warmth,

Leonie (Stacey) Axton - Hooper
Founder, Coordinator
Arachnoid Cyst Awareness Australian Support Group.

How You Can Help:

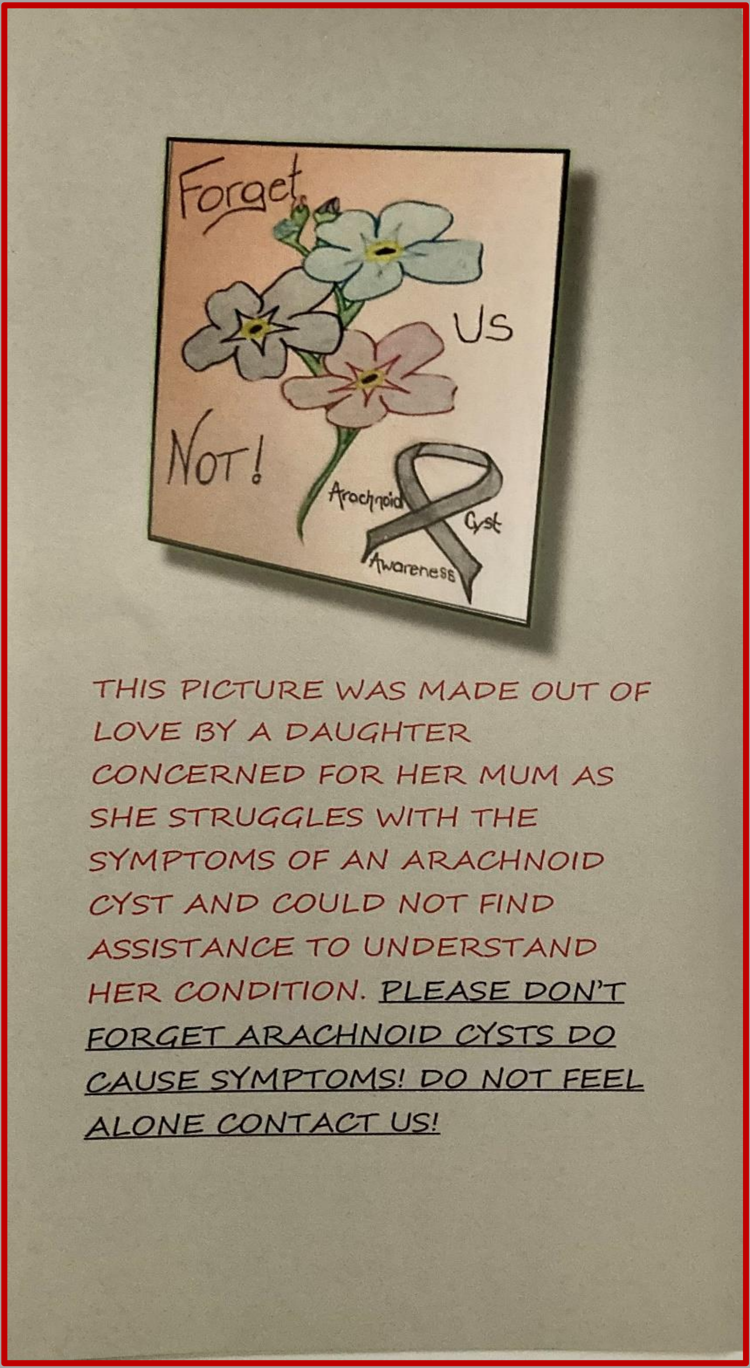
: Governing, coordinating a group and advocating a support group in your state.

: Distributing brochures to neurosurgery, neurology and drs rooms.

:Join the Committee

:Contribute to publications.

: Contribute to our Arts and Craft Hub.



THIS PICTURE WAS MADE OUT OF LOVE BY A DAUGHTER CONCERNED FOR HER MUM AS SHE STRUGGLES WITH THE SYMPTOMS OF AN ARACHNOID CYST AND COULD NOT FIND ASSISTANCE TO UNDERSTAND HER CONDITION. PLEASE DON'T FORGET ARACHNOID CYSTS DO CAUSE SYMPTOMS! DO NOT FEEL ALONE CONTACT US!

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