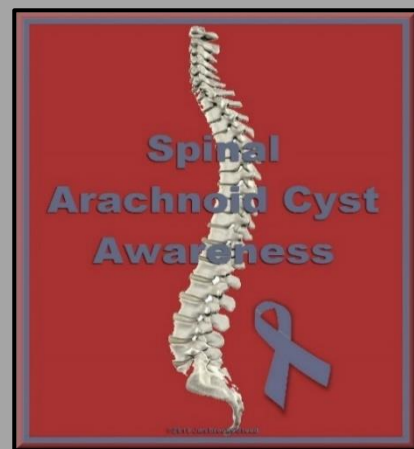
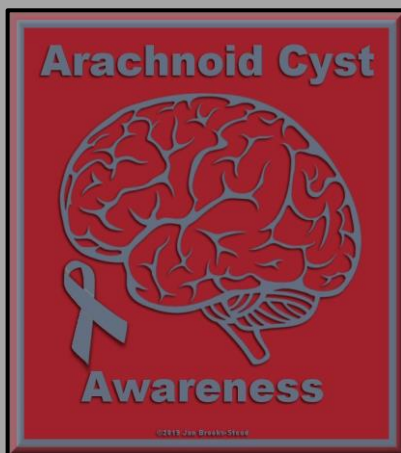


# The Australian Arachnoid Cyst Awareness Support Group.

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Phone: 0419 993462.

Newsletter No:6 Sept  
2021: [https://www.  
acystawareaust.com.au](https://www.acystawareaust.com.au)



Hello Everyone, what a time it has been in the months following our last newsletter.

I hope everyone is managing to stay covid free and you or family members are hanging in there with health issues regarding our condition.

I know some of you have been having real struggles and I must admit, I can join the queue as well. With our hospitals managing Covid outbreaks

there are just are not enough Drs and medical staff to go around as they are dealing with such an outbreak of covid patients. I've only just heard this morning 50% of elective surgery has been put back and it is going to get worse in Oct because of the Delta strain. I hope we can ease the spread for our other states. I really look forward to covid settling down so we can begin to feel safe again here in Vic and NSW so our surgeries can resume.



We have now started our Australian Facebook group and its so wonderful to see patients joining up. We can now share support and let you know of events or recent information and also show our numbers of symptomatic patients for anyone who is needing to know more about our condition.

It's great to see some new patients just recently diagnosed find us. We really hope we can be of help and support when you are unsure or worried about anything during your process of navigating the medical community and finding a specialist or sharing experiences when you are worried about any symptoms you may be having.

I wanted to mention we did have a glitch with Facebook with patients and families joining, I can see in our activity log we had some of our patients that were denied.

I have followed this up and its seems although those patients answered the two security questions, they couldn't be approved as their answers didn't show up on our Facebook feed.

Because we are a closed group, we do have two questions that need to be answered to keep any spam posts out. I have spoken to Facebook and this has been fixed, I have tried to let most people know so they can re-join but if I haven't contacted you yet I apologise for this and could you please try again. We would really love to have you aboard.

Go to / [www.facebook.com/groups/acystawareausupportgroup/](https://www.facebook.com/groups/acystawareausupportgroup/)



Our Arts Hub-

*The Imaginative Mind An Emporium of Arts and Craftworks* is up and running too.

I would love to see some more creative patient's show their skills. If you can paint, sculpt, draw, sew, knit, write poetry, photograph, whatever your skills are we would love to see what you can create.

You Can find the link to this page from our Facebook group, or you can follow us by putting in our name at the top of your Facebook news feed and you can also then post your art or craft on this page.

Please don't forget to like us!

I have also created some boards on Pinterest, as being new we are needing more traffic to our

page, so anyone who wishes to offer a piece of art or craft to raise much needed funds for our group can have their piece pinned to our boards on Pinterest I will be publishing them soon. We are happy to advertise your creations with a link to your social media pages too.

## CHILDREN'S ART COMPETITION



For those of you that are not on our Facebook page, you may not have seen that we are running a Children's art competition, this is open from

toddlers to teens, we are looking to give prizes for their piece of art expressing their experiences of living with a brain or Spinal Cyst. This can be in the form of a drawing, painting or piece of artwork of their choice.

There will be three prizes of a spinal or brain Arachnoid Cyst Awareness Australian t-shirt, a drink bottle and an engraved a/c bracelet (they can pick from one of our three designs) this will be for the for the most expressive and creative art piece.



*The winner's artwork will be displayed on our children's page on our website and on our arts emporium.*

Entries will be judged on the 1st of December 2021 and the winners and all our entries will be in our Christmas Dec newsletter. All of our participants will receive a certificate and some lollies.

Entries can either be photographed or scanned and you can email entries to - [acystawaraustralia@gmail.com](mailto:acystawaraustralia@gmail.com)

I have been researching some more fun recipes for our kids and I have found some fun crafts for Halloween and Christmas, these will be available on the kid's page on our website very soon, so watch out for these to help keep our kids amused and busy.

## Our Social Support Group Meetings.

Due to health problems and of course covid we have not had much luck with our support group meetings, but I'm sure once everyone is back on board and things settle a bit with covid we can look at these meetups again.

Debra will be in touch with the group in WA who are interested in meeting up at a more suitable time.

We will also resume setting up our support meetings in other states when Covid settles.

We do have one of our new patients from Tasmania who is looking to connect with other patients so if you would like to connect with her and share your journey and support with each other you can email me for her details.

If there are any other patients that want to participate in these support meetings you can also email me with your details

I am presently in the process of following up a support organisation for our families and patients in Tasmania.

We now have support neurological agencies listed on our website on our (Finding Support, Support Needs and Support Organisations) page for our other states.

This can be quite helpful if you are needing support with

referrals or resources and information that you may be seeking for yourself or a family member or you may be a carer that is requiring support.

I will give you further information on this very soon.

## **ndis Support** **Information** **Session**

I have had many of our patients report how difficult it is to apply for the ndis. Trying to fill in all the paperwork and chase correct reports the ndis are requiring and then understanding the process of how it all works can be very confusing and stressful. I have spoken with them and I am in the process of setting it up. It will be an on-line meeting with one of their staff members who conducts these sessions to help everyone to understand the process.

It is also an opportunity for you to ask questions or raise any concerns or problems you may be having.

This is also an opportunity for the ndis to become familiar with Symptomatic A/Cs and become more aware of our condition.

If you are interested in taking part in this information session, please let me know either through our Facebook group or you can pm me or email us.

I will let everyone know more about this shortly.

As Christmas is approaching quickly, I will add a few pages to show you some gift ideas.

For our newest patients, who may not have discovered, we have our online store with our support items and don't forget our arts hub for something unique and there are our support companies who supply safety helmets and hats and also plenty of ideas for great toys from The Kids Development store.

All these ideas can be found on our website. You will also be

helping much needed funds for us from some of our gift ideas.

Until our next newsletter, please stay safe and I hope most of you are feeling the best you can be.

Warmest wishes everyone!

### How You Can Help:

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

: **Distributing Brochures to Neurosurgery and Neurology Rooms and Neurosurgery Wards**

: **Join The Committee**

: **Contribute to our publications**

: **Contribute to our online Arts and Craft Hub.**

# The Arachnoid Cyst Awareness Australian Support Group.

E:

[acystawaraustralia@gmail.com](mailto:acystawaraustralia@gmail.com)

W:

<https://www.acystawaraust.com.au>



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!

## From our Web Site



*Calico Logo Bags \$ 8.00*

*Brain and Spinal Tees Adults \$15  
Children's \$10 Babies \$8.00 Sizes  
and colours on website.*

*Soft Patient Support Headache  
Beanie with soft pad inserts and  
hot/cold pack \$30.00*





*Soft Spinal Support Beanie \$17.00*

*Kids Spinal Support bag \$75.00  
adult bag available on website too.*

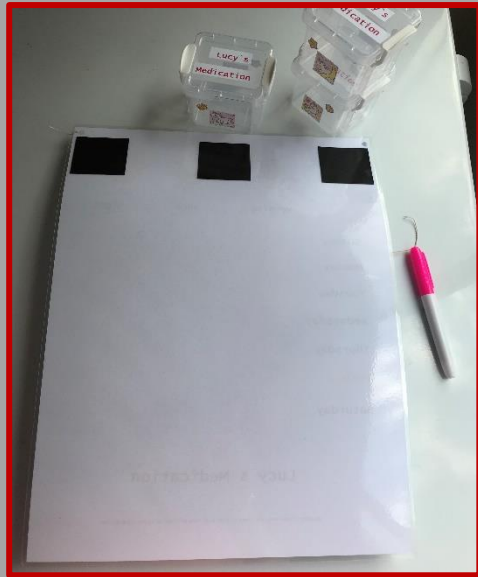
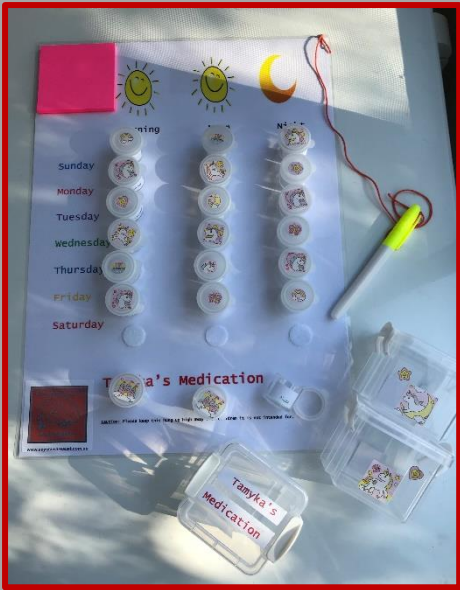
*Kids and baby Brain Support bag  
\$85.00*

*Adult Brain Support Bag \$ 96.00*

*Wheat pack \$ 16.00*

*Eye masks \$7.00*





*Children's magnetic medication charts \$20.00*

*Soft Cuddly Koala Support Bears \$20.00*



*Boho Knitted A/C logo Hat \$28.00*

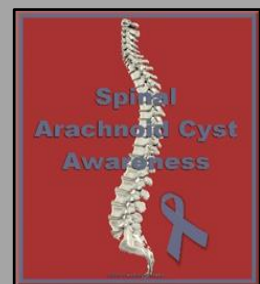
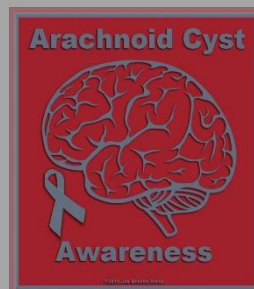
*Loom Band A/C bracelet Kit \$20.00*



*Forget Us Not Arachnoid Cyst Aware seed bead and flowers Bracelet \$22.00*

*Arachnoid Cyst Aware Leather and Bead Bracelet \$ 22.00*

**The Arachnoid Cyst Awareness Australian Support Group <https://www.acystawareaust.com.au>**





Hoot Fine Motor Owl

\$32.95

Spiky Slap Band

\$5.95

Zippee

\$36.95

# Fine Motor Explorer Kit - Large

\$159.00



## Comfy Caps



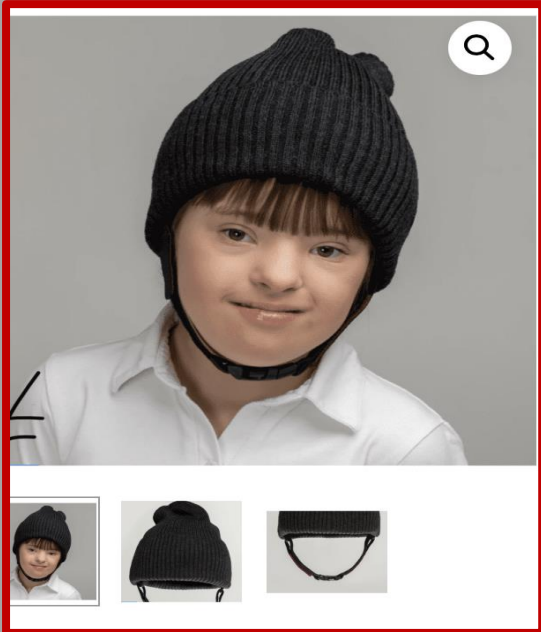
*You can find the link to these sites on the kid's page on our website.*

*These caps are \$85 U.S plus shipping.*

## Dejay Medical Supplies

*Rib Cap Kids Lenny Beanie \$ 195*

*Rib Cap Junior Baseball Cap \$275*



## HeadSaver Head Protectors



HeadSaver Soft Head Protector  
\$120

*Head Scarf to fit HeadSaver \$24.95*

