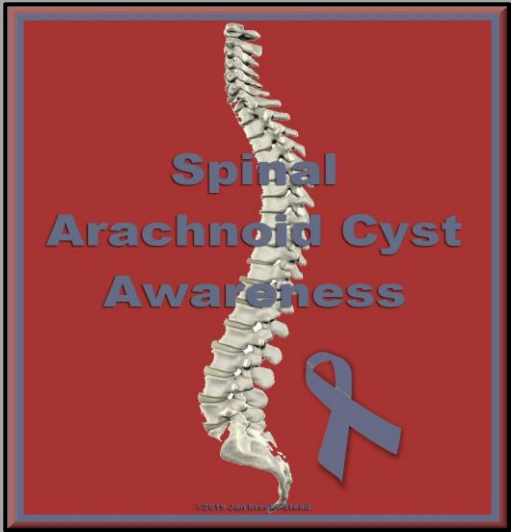
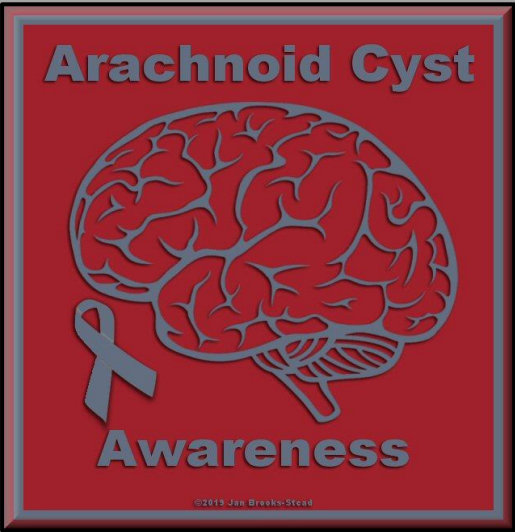


The Arachnoid Cyst Awareness Australian Support Group.

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Newsletter no: 3. Aug
2020: [https://www.
acytsawareaust.com.au](https://www.acytsawareaust.com.au)



16th August 2020.

Hello to everybody,

I did promise to have a Newsletter quarterly however we have been so busy and so much has been happening. We are now a support group of 230 members strong, so we have grown considerably from this time last year.

It has been so wonderful to be in communication with so many of you. I know I have been promising and promising that our website will

be finished, but it has taken a lot longer than first anticipated but we are nearly there. We did have some trusty technicians from a reputable company that were paid to take the job on, however when the 3 month mark was up that had been promised it would be finished, our trusty technicians had failed to come through.

As you all know when I first started to get use to using technology on FB I had no idea of what I was doing and still don't however with

determination and a driving force of frustration and days of hinderance because of poor health I have battled through many frustrating hours later and in the months that have gone by and have finally fed all of the information onto the site.

Unfortunately due to not being able to decipher the instructions on how to make the site the site go live, it has had to be put back into the hands of our trusty technicians. One week and one day later my impatience is getting the better of me, if it's not up in the next day I shall be marching into their premises with Covid mask on and retrieving our website and placing it in the hands of another technician.

Please say some prayers as it will be like Christmas once it is finally up. The importance of this site will be so valuable for our patients as we have the wonderful support from Brain Link Victoria and Synapes for patients in Queensland, WA, NSW. I am in the process of finding support for SA.

These organizations support all patients with Acquired Brain and Neurological conditions. The importance of this becomes apparent because although we are not recognized with our neurological condition, we do have a mass in our brains and although some of us have or have not had surgery it still does

leave us unfortunately with similar neurological impairments like other conditions. These organizations are available to help us with needed supports for our children, family members and carers.

Another terrific organization is the Child Neurology Foundation. They have some amazing and much needed tools, children's comics, on line psychologists and connections to support peers and other families. They also have an array of wonderful downloadable presentations and literature. The children's comics are a fun and interesting way of helping children with cognitive and emotional support in a way to help them to learn to manage their condition.

The other exciting thing is we have managed to find some wonderful companies that have a fantastic range of educational and cognitive toys, books and games, we will have links to these companies and it is hoped we can set up a link directly from our site for the toy you have selected and to go directly to the sites checkout. This saves sorting and time, changing from one site to another.

Our own online shop will be up and running too with all of our support products. These funds from here and some other ideas we have will help to fund our support group. Just a note on our nonspill patient drink

bottles and thermo tumblers. At present we only have the brain logo



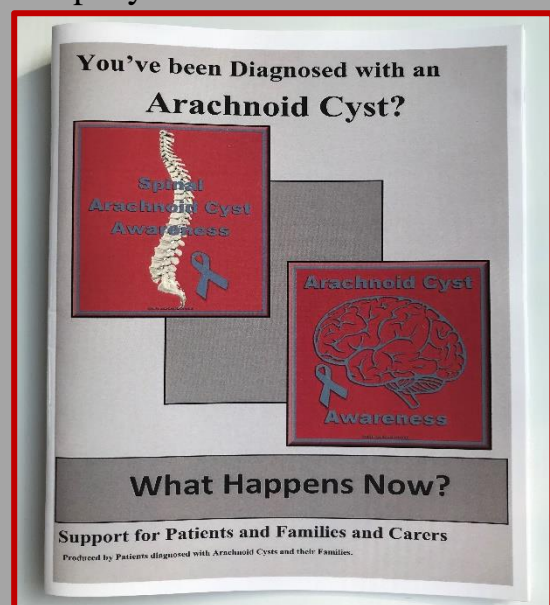
on them however with the next lot of funds received, we will have them with the spinal logo as well.

We have plenty of helpful information on the website regarding the NDIS as it is apparent many of us are wanting to know how it all works.

The next thing is we have been very pleased to announce finally have our patient support bags going out. It has been busy although it's a really good feeling that these bags are helping our patients who are having surgery with items they may need and also information on support during and after surgery.



Our Patient support booklet is now available on our Website and hard copies will be in the online shop for five dollars. This covers printing costs. However as with most planned things, they can go wrong and we had a near disaster, we were having the booklet edited and the company lost our files!



so it has been put back together with the files we had and when it came to printing, the font was out in places. We are having to do a re – print, so we will let you know when they are available for sale in our store.

Just recently, we have had four Mums unfortunately whose little bubs have been born with A\Cs. It has been a very worrying time for them and we are so pleased to support them and it's wonderful to communicate with them, most of you know them through fb and adore seeing their little faces and progress. We welcome them and wish them love and support and all the best life can offer going forward!

One of our Mum's is presently preparing for the upcoming surgery of her gorgeous little girl. Sending our love and prayers to her and wish her all the best.

Another up and coming surgery is young Cody Bailey, he will be going back in under the guidance of Charlie Teo in October. Sending best wishes love and prayers to Natalie and family.



I was sitting sewing one Sunday afternoon and happened to catch Arhns Brush with Fame, he was interviewing and painting Charlie Teo. Dr Teo spoke of his life growing up and how he became a neurosurgeon. It was very inspiring. You can find the show by googling Arhns Brush with Fame or Facebook.

Most of you who have young children are on the Paediatric Facebook group for families have heard the terrible news of Jessica the mum of Ethan and creator of this group and her family's car accident. She has sustained terrible injuries, other members of her family also suffered injuries. It was just terrible to hear of what the family are going through. It was great to finally wake this morning and hear that Jessica is finally on the mend after all her operations. She is finally sitting up eating and drinking and other family members are also recovering well too.

I'm sure all of us feel the same and send our love more prayers and well wishes from our Australian Support Group and can't wait to receive a post from Jessica herself.

(Update 15th August)- Jessica has now posted to everyone herself and is doing well and is now waiting for a bed at a rehabilitation hospital. We send our love and wishes for the next lot of treatment she will need to be well again.

None of us expected this Covid situation, to most of us it has been frustrating as we have had our surgeries or appointments postponed. I hope no one has been affected by this terrible virus and you or your loved ones are staying safe and not struggling too much with symptoms until you are able to receive treatment for, your a/c.

An update on our application emails to Insight, as most of you saw last year I was pretty disappointed we didn't get a grant to help us create some awareness of Arachnoid Cysts here in Australia, so I thought that also after trying to get some research going on our condition through some of our research facilities and having no success, I would try to get us on the sbs program Insight.

It looked to be very encouraging as after the first email we sent and I rang to see if they had received it and after having a further update with the news Charlie Teo had

performed his first three surgeries on some of our patients it was recommended that I send an updated email to the CEO of sbs and we should hear something.

Unfortunately Covid started and we have not heard anything up to date and as I have been so busy with the website and its contents and getting our patient hospital bags ready, I now have the chance to follow it up and keep working towards an interview on their program. Having the website up may help as well as now as they can go on site and read our patient stories and find out more about us from all the information we have put on.

I was hoping to progress further this year and try to organise some patient group meetups and further into the future, see if we could have some support persons from the different support organisation's we have on our website come and give a talk for us.

However because of covid19, this will have to wait. But perhaps we could organise some virtual meetings to get to know each other from each state. Can you email or message me if you are interested?

There are two more ideas we are working on; this is our own Australian Arachnoid Cyst Awareness bracelet. We are in the process of developing a few designs,

once decided they will be available for sale in our online store.

We have been looking at some more ideas to raise funding and have come up with an add on idea to our store and that is a sub store being an arts and craft co-op hub.

I relax and sooth my stresses and anxiety through art and craft. The idea being that if you have some talent in art or a craft, perhaps you may like to donate something to the store. You can put a reserve price on it and customers can bid in our online store for that item.

We hope to have it set up soon, so if you would like to donate you will be able to add that item on line.





Here are some examples of our Art and craft Co-opp. We hope to get some interest from your own crafty or art skills



We have just received the news finally our Australian Website is finally up and running. Yay!!!!

Go to
<https://www.acystawareaust.com.au>

Until next Newsletter, stay safe and I hope your health can be as good as expected.

Cheers Everyone!

How you can help:

The Arachnoid Cyst Australia Awareness Support Group.

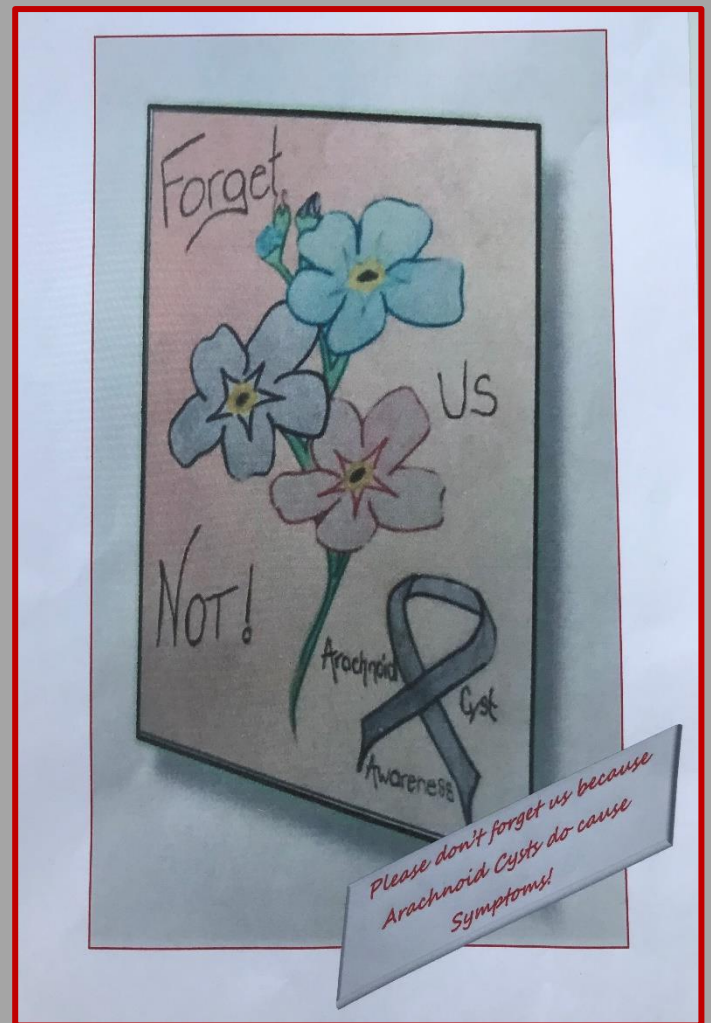
: Governing, Co – Ordinating a
Group and Advocating a Support
group in your State.

: Distributing Brochures to
Neurology and Neurosurgery rooms,
Your Drs Surgeries and Hospital
wards. Email us for Brochures.

: Join the Committee.

: Contribute to Publications.

: Contribute to our online Arts and
Craft Co-Op Hub.



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