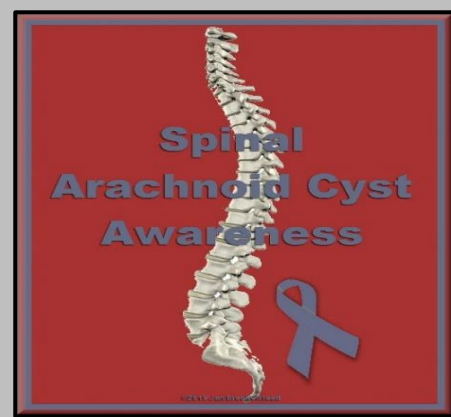
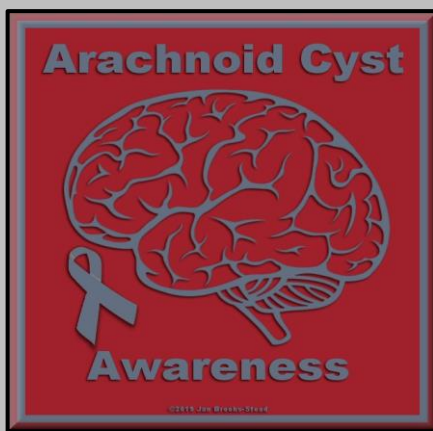


The Australian Arachnoid Cyst Awareness Support Group.

Newsletter No: 4
Dec 2020 Issue

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Hi Everyone

Well here we are to newsletter no 4 and Christmas is here again!

What a busy year it has been no only for myself, but I'm thinking every one of you have no doubt been kept pretty busy or have felt the pressure of the covid situation over the course of the year.

Those of you that are parents are probably feeling like you have had your school age children home all year with home schooling and now we have the Christmas holidays upon us!

We here at our small HQ have been quite busy with our administration, designs and planning our next projects and keeping in touch with everyone.

It has been great to send out our hospital patient bags to those patients that have had surgery and we hope it is helping to support and give information to them.

We hope also hope those patients are all starting to feel an improvement after your recoveries and are kicking goals!

Also to our parents of our children who have had surgery, we hope that all is going well and they are

returning to good health and happiness.

Some of you have been very unwell and due to COVID-19 your surgeries have been delayed. It is hoped that now things are easing you will be able to finally have your surgeries.

You remain in our thoughts and prayers and we look forward to hearing you have had surgery and are recovering and starting to feel better.

There are also our patients that have been struggling to find good neurosurgeons who will understand our condition. So we have been slowly trying to put together a good Drs list to go on our website for Australia.

As we have just introduced our Website to the world wide web, some of you may be having trouble finding it? It will not be available on google until there has been over 1000 visits to the site. So my gorgeous twelve-year-old grandson has worked out for the amount of patients in our group, we need to all visit the site five times a month. At the moment we are having to put in the URL. So if you want to find the site you need to put in <https://www.acystawareaust.com.au>.

So please everyone can you get on board and go and visit our site to make it more accessible on google.

This also helps with better accessibility not only for everyone but for the medical profession looking us up.

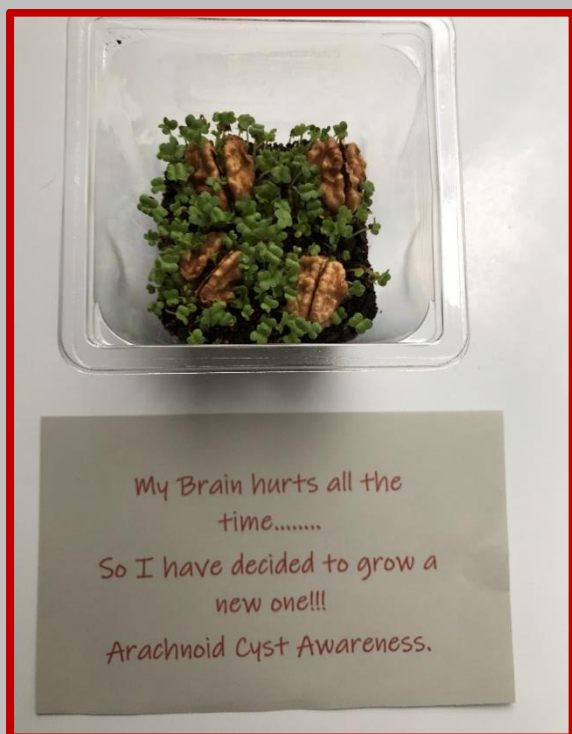
Many of you know, I have had my own health struggles and are waiting for surgery. So we have been a bit slow in loading new information on the site. But we have been lucky to find a great fellow who will be helping toward this.

So it is with this, that I'm able to tell you all that we have been able to load on an A to Z of Medical terms that we have put in Layman's terms so it makes it easier for us to be able to decipher all of the medical terminology we hear and see when Drs are discussing our conditions and also trying to understand reports.

It is hoped that we can ease the minds of parents, families and carers and if you are a patient by being able to understand all the medical jargon, especially if it is a while between tests and appointments it can become quite a stressful time if we cannot understand what is happening to us. This is in a downloadable format so you can print it out for reference.

It is available in "*Support Literature and Information*" on the website.

I have had a bit of fun on the Children's page too! With school holidays starting, I have popped on a couple of activities the kids can try out and perhaps even grow



themselves a brain or give some away for Christmas? I have also included and put together a brain Christmas Cake! I will add a pic at the bottom of our newsletter. There are instructions for the kids in their page on the website and perhaps mum or an older person can help them to make it.

We have managed to be able to get by this year on limited funds to be able to produce our patient support bags. But it is time for us to be creative and find more funds to be able to complete and provide projects going forward to create awareness here in Australia. We do not want to ask our patients and families to be continually donating \$\$ to our cause. So we have discovered ways of

producing an income if we can just ask for your help!

I have explained in our last newsletter of our Art and Craft Co-Opp. We will be opening this as an add on to our online shop. This is a place where if you have a talent in arts and craft. We want you!!!! If you are able to donate an item you have made and can to put a reserve price on it. Then we would take the highest bid for it from customers to add to our funds.

We have already started to collect items for this project but we are asking if you can help toward this. We do hope to start loading on our arts this week, so go to the site and check it out.

The other project we have come up with is to have access to an online Australian Survey Company. We have researched the most suitable one including User friendly to simplify completing one of these surveys. We will receive various \$\$ for participation of answering their questions in their online surveys depending on type of survey that you do. Then the money made would be deposited to The Arachnoid Cyst Awareness Australia`s pay pal account. We are hoping you can find time to participate in one or you can do as many surveys as you like.

One of my favourite pass times is to scour the treasures of second-hand

stores and repurpose and recycle items and give them a new life.

I have been pleasantly surprised to discover this brand new handmade wedding gown in a up market, high end boutique, it is in immaculate condition and does not have a mark on it and it would only need steaming. It would fit a size ten bride. I have placed it on eBay and gumtree, I am hoping to resell it on and make a profit to go into our funds.

It is an absolutely beautiful dress and I'm just in ore of how lovey it is. Myself and other family friends that have seen it are wondering how someone could let go such a beautiful gown, so if you know of any family member or friend or someone needing a beautiful dress for their dream wedding it is worth them taking a look or they can email us for details. The sale of this dress will go toward needed funds.

The gown has a 2.5mtr train, it is 1.4mtrs in height and would fit a bride 1.5mtrs in height. From what I can tell it has been totally handmade with an embroidered sweetheart bodice in ivory with lace, bead and embroidered embellishment's, it has a layered petty coat of tulle to carry its beautiful princess ivory layers. It is fully lined and the train and dress are scalloped with beautiful beaded embroidery.



It comes with a wedding dress keepsake box for safe transport and storage.



The train is 2.5mtrs.

We are starting to prepare for applying again for a grant for next year. This year I was so busy with concentrating on getting our website up and running so I didn't have time to look into any grants but I felt we needed to have our website up so we could show organizations and grants committees who we are and our stories.

I think now the website is up and running it will benefit us in many ways.

Along the way we did have some hiccups, every stage of us going forward was trial and error. Some things we needed to start again at the

drawing board, but we succeeded in getting everything right in the end!

We had trouble with the editing of our patient support booklet, the files were lost, then once printed it was disappointing to find the new files changed the font and the outcome in the print in some areas, but we are working to rectify this.

Then as you all know the website was a big project and at times, we had hold ups but we got there in the end.

One other problem was our first print run on our t- shirts, they didn't wash up well, so we found a different printer and the quality is 100% now.

I got to trial our patient support bag out myself as I had a hospital visit for a related condition.

I found our drink bottle really handy as I had some days where I was unable to sit up due to my surgery.

Our thermal mug and straw worked well too. I found the mug stayed warm for two and a half hours. Which is really good if you have to rely on the tea trolley coming around at the wrong times or if you are sent for tests or you are just not ready for your cuppa, it's good to know it will stay nice and hot for a long period of time until you are ready for it! They are \$12.75 on our website.



Our thermal mug stays hot for up to two and half hours.

The other item I absolutely love in is my Arachnoid Cyst Support Beanie.

I find when the pressure rises in my head, it really helps to have my beanie on. On the hot days when I've had a headache, I've used the hot/cold pack, cold straight from the freezer and inserted into the pocket of the Beanie where my headache is. Then other at other times when I was in hospital, I would get the nurses to heat the pack up for me. It's so soothing as it is a very soft beanie and also has the padded pads to go in the pockets where your wound site is, for extra comfort when laying down.

These items are available in our online shop. They come in white or grey and are \$30 available on the site.



Cody also likes his beanie, he found relief being able to insert the warm pack in his beanie for his headaches.





These beanies are so soft and come with a hot/cold pack and padded inserts.

The other item we have been working on is our Australian Arachnoid Cyst Awareness Bracelets.



These bracelets can be engraved by us with your birthdate and blood group on. They are available on our website for \$16 AUS or \$20

US and includes engraving and postage.

I only have one design to show off at present, but we do have two designs, but I cannot show off the second one until its completed and approved by its designer, who is the daughter of one of our patients.

We are just waiting on the COVID-19 postage to receive pieces for this bracelet in the post. So keep an eye out for it on F/B or our website.

Plans for Next Year

I thought I would just go over what we are working on for next year.

The opening of the new art and craft co-op, we are starting to load the new store on very soon.

Producing our second ACA bracelet.

Finding more respite houses around Australia for patients who have been through surgery to be able to have a holiday with family while going through recovery.

Looking for a neurological support organisation for S.A to be able to help with ongoing support and available literature to help patients on their journey.

Follow up with SBS programme insight, I think even though I've been emailing, COVID-19 has been a problem with this I suspect. Now things are settling. I hope we hear from them!

Setting up a business plan for the grant we are applying for to help with our funds.

Watch this space!!! We have a very exciting big project under wraps and I cannot wait to tell you all about it.

Until next newsletter everyone, I hope you and all your families, friends, carers and patients, young and old have a very enjoyable Christmas and thank you for a wonderful year of lovely support from you all!

Merry Christmas!



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 N and Neurosurgery rooms, Drs Surgeries and Hospital Neurosurgery wards. Email us for the Brochures.

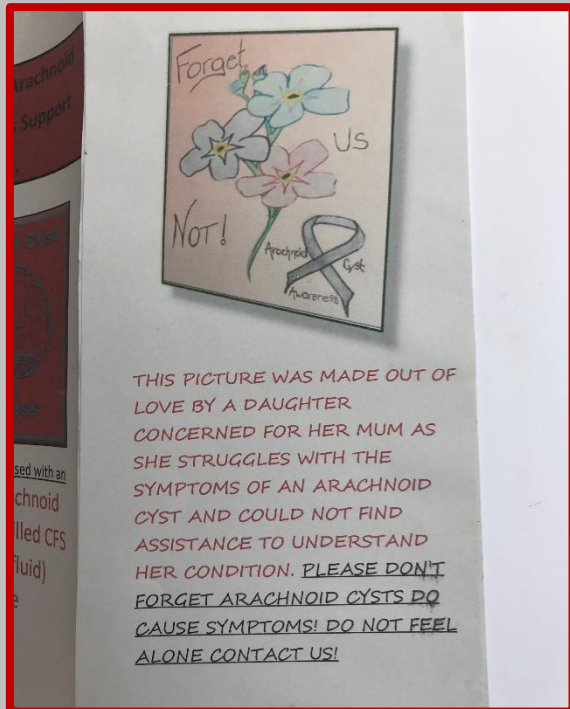
Join the Committee'

: contribute to publications

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

Cont:

:Complete a survey and help raise funds.



The Arachnoid Cyst Awareness Australia Support Group

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Have a Safe & happy New Year too!

