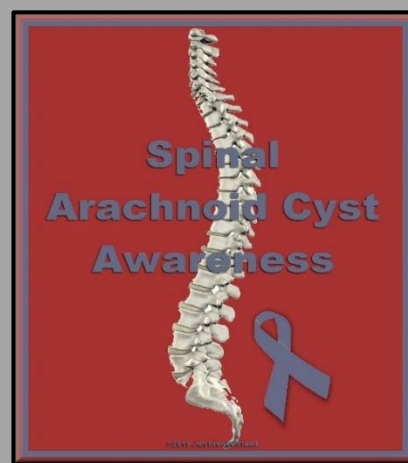
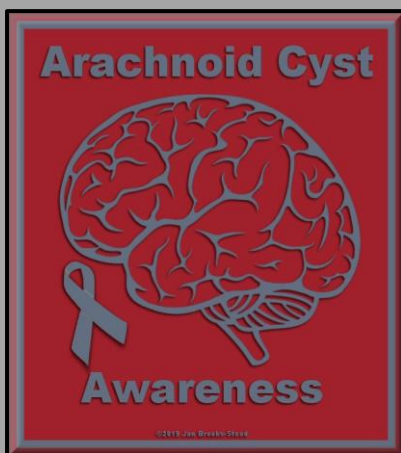


The Australian Arachnoid Cyst Awareness Support Group.

E: acystawar
australia@gmail.com
<https://www.acystawreaust.com.au>

Newsletter No:5 May 2021
P: 0419 993462.



Hi Everyone,

What a busy time the last few months have been. I hope everyone is doing well.

Some of you have had surgery and I hope through your recoveries, you are starting to feel better.

Unfortunately, we have also had some very worried parents who have had to have their children go back

in for surgery, due to their cyst not collapsing to release the pressure off their brains. This can sometimes happen in a patient and therefore these children have needed to return for an insertion of a shunt to drain the csf fluid off their cysts.

I really wish these families love and best wishes, my thoughts have been with you

and I hope that your children can go on to have a much better recovery and can bounce back to being normal happy kids.

We also had a few other families whose children have had surgery and I hope and pray they are recovering well and things are starting to return back to normal and we want to hear that these families do not have the worry of their child being so unwell.

In our last newsletter I discussed how we as patients are struggling to find good neurosurgeons to be able to receive correct treatment, so we have now started our good Dr's list on our website.

If you are looking for a good surgeon or even if you have had experience with a good surgeon, please can you help out and let us

know so we can help other families to find a surgeon, we have listed it under

Finding Support and Support needs and Support Organisations. on our Website.

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

If you know of a good neurosurgeon- can you email us at the above email at the top of the newsletter and we will add them to our list.

We now have a neurological support organisation in South Australia. I was very pleased to make contact with these guys.

Unfortunately, any mass that affects our brains can cause neurological defects and decline so therefore it is considered an acquired brain injury and I have found that on applying for the ndis or the disability pension, our

condition comes under this diagnosis.



Families 4 Families is founded by an ABI carer whose husband had an ABI. Both Committee members and families and patients and volunteers affected with ABIs help each other through lived experiences and offer support groups and referrals for ongoing needs and services, social links and research

They can be contacted by
ph. 8299 0015 email:
office@families4families.org.au

Website: Go to

<http://families4families.org.au>.

Head Savers and Dejay Medical Supplies

The other things we were wanting to organise was support helmets for those experiencing seizures and prevention of further injury to our brains while playing sport.

After a bit of research, we found Head Savers and Dejay medical supplies. These companies have some good quality head gear.

Besides helmets being available for sporting needs, these companies have protective headwear that can be disguised with a fashionable scarf or cap for patients or children needing to wear a helmet



Head Savers Head Scarf



Dejay Medical Supplies

Ribcap Head protection



Dejay Medical Supplies. Ribcap Head Protection

Comfy Caps.

We have found a lovely mum who has her own story of having to have her own son wear protective headwear.

Being a physical therapist, she knew all too well the risk and irreversible damage her son could have from hitting his head. To take the stigma out of her son having to wear an institutional type

helmet, she set about designing Comfy Caps.



Comfy Caps

Her designs are bright, soft and comfortable but passes the test of a devastating fall!

The link to these companies can be found on our website.



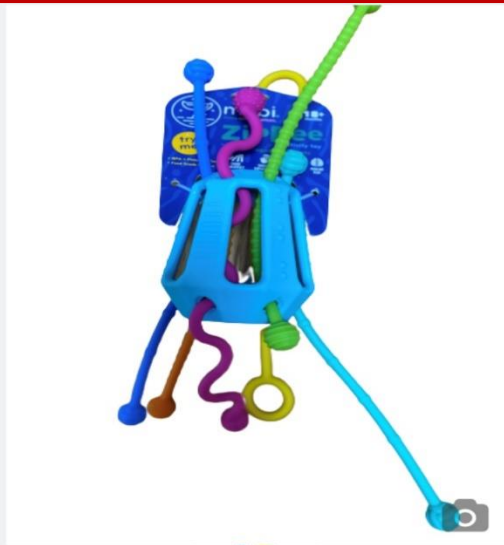
Comfy Caps

The other thing I wanted to look at was finding a good quality toy company and I came across the Kids Develop Store.

These toys and educational products are to help with all aspects of development, cognitive and sensory supplies. If you are looking to help your child with any developmental or cognitive needs or just good quality presents for a birthday or Christmas



[Kids Develop Store](#)



Zippee
Description

Zippee is a silicone activity toy perfect for pulling and hearing and feeling the various sounds and vibrations the cords make.

This toy may suit children who enjoy cause effect experiences and find repetitive play calming.

Practice using hands together in the midline of the body to explore.

[Kids Develop Store](#)

It is worth looking this website up, the link is from our children's page on our website.



Kids Development Store.

We try to cover all our ideas and projections going forward by each quarterly newsletter, it sometimes will take a little bit longer if I'm unwell but we aim all projects put forward will eventually be established.

Our Arts and craft co-opp still is to be opened and this will come about very soon we have been thinking of a

different setup than first thought, but you will find we will have this available on line very soon.

I felt it would be really good to see a branch of our support network in each state of Australia.

I am really happy to announce Debra Lane has been wonderful in coming on board to facilitate and be instrumental in co-ordinating the W.A Support Group. Deb is hoping to organise some meetups, so those wishing to can come along for a chat. We have had a great response from the W.A patients who are interested. If you are wanting to join the group and get to meet other patients, please can you express your interest by emailing

acystawaraust@gmail.com

marked Att: Debra Lane.

We are working on Qld next, so if you are interested in co-ordinating a group for your State to help to create awareness, or you want to be part of the group, please email me at the above email or if you are on Fb, you can pm me.

I have been working on some more Arachnoid Cyst Awareness Bracelets and I came up with two more designs.

One is based on Angel Rose Hargrest design she made because of her worry and concern for her mum.

It is of the forget us not flowers.



I have designed this bracelet with representation of these flowers. These bracelets also have a disk which can be engraved with the patient's birth date or an emergency phone number or blood group.

For the kids we have designed a loom band design that they can have a go at making themselves.

The kit comes with instructions. You will find

this on our children's page on our website. These kits will be for sale on the site.



We have another loom band design that comes already assembled, these will be available also.



I was really excited to design a beanie for one of our young pediatric patients who has a really groovy hairstyle and I also know of some of our other kids and adults who have some great do's as well.

So, I decided to add this to our collection of products to purchase to raise awareness for the Arachnoid Cyst Awareness Australian Support Group.





One more exciting thing is, we are about to launch our Australian F/b group!

There has been a need for this as we are applying for some grants this year and many corporate companies expect to see a f/b page as well as a website for transparency of who we are. I have had patients inquiring too.

Thank you so much for those patients and family

members that have agreed they will help to moderate our group.

It would be fantastic if you could join and post on the page, we need as many Aussies as possible to join and post on our page. It will be a closed site but we will approve corporate organisations offering the grants to have a look at our stories so they can understand what we go through. But this information is kept only to our site and is not shared past the nominators from these companies who are looking to award these grants.

I discovered this from the Hydrocephalus Association and thought it would be handy for our children that have shunts.

SHUNT WARNING SIGNS!

If your student exhibits **ACUTE** symptoms, they should be seen by a Neurosurgical unit within 4 hours of onset of symptoms.

Symptoms can vary considerably between individuals. Previous personal experience of a shunt problem is usually a reliable guide as to what to look for. Speak to parents for an example of their experiences.


** Sometimes a shunt can malfunction over a longer period of time. If you notice changes, please notify parent!*

Signs of an **ACUTE** shunt malfunction may include:


- Drowsiness
- Vomiting
- Headache
- Dizziness
- Sensitivity to light and other visual disturbances
- Seizures

Signs of **CHRONIC** shunt malfunction may include:

- Fatigue
- General Malaise
- Headache
- Visual Perceptual Problems
- Behavioral Changes
- Decline in Academic Performance
- Just not acting like themselves, something's off.



www.HydrocephalusKids.org



Student:

Neurosurgeon:

Phone #

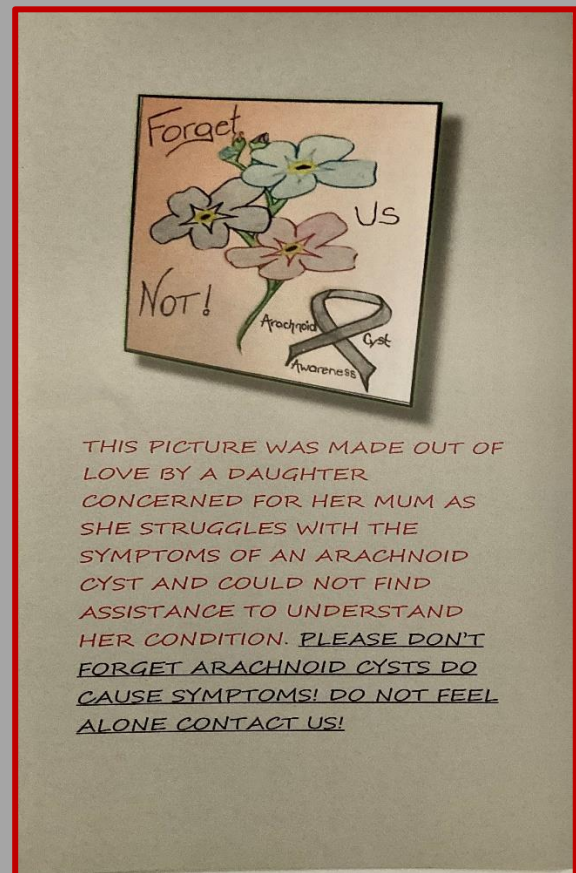
time it takes to get our projects up and going and that fatigue sets in and our condition holds me back. But we aim to get to them eventually. One step at a time we will succeed to create awareness in the community and help to provide support for anyone suffering the effects of an Arachnoid Cyst.

Until the next newsletter
Warmest Wishes everyone!!

I thought it would be good to laminate and put on the fridge or a smaller version can be made for carers and teachers to be able to understand effects of a failing shunt.

You can email for extra copies.

Well, I think I've covered most things, sometimes I get impatient and I wish our ideas could come about sooner. But then I forget the



How You Can Help:

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

: Distributing Brochures to Neurology and Neurosurgery rooms and departments. Drs Surgeries and Neurosurgery Wards. Email us for Brochures.

: Join the Committee

: Contribute to our publications.

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

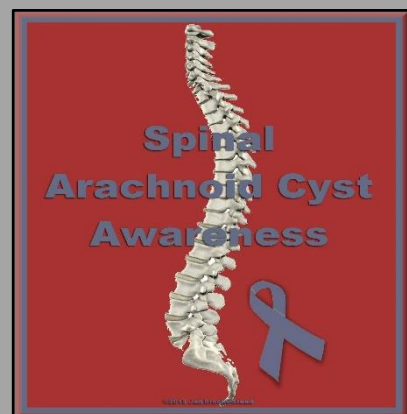
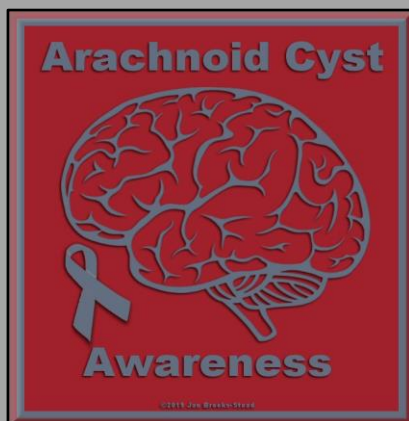
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E:

acystawaraust@gmail.com

<http://www.acystaware>

[aust.com.au](http://www.acystaware.aust.com.au)



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Student :

Neurosurgeon:

Phone #



www.HydrocephalusKids.org

