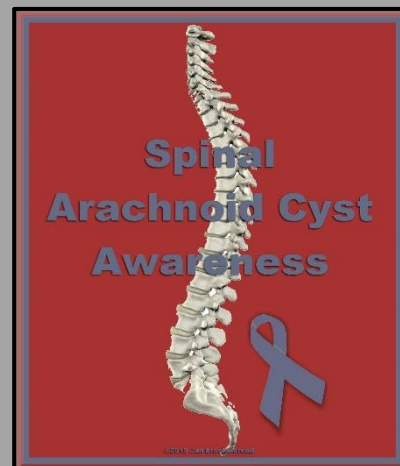
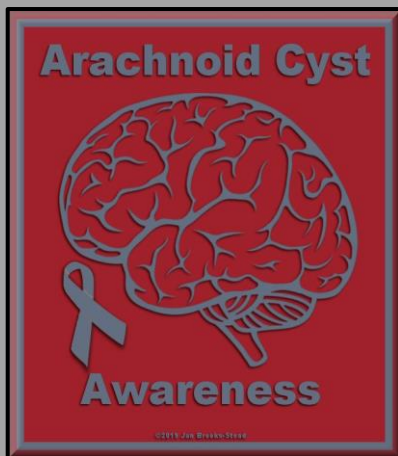


The Australian Arachnoid Cyst Awareness Support Group.

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Newsletter no 2: Nov 2019



Hi everyone!

Welcome to newsletter number two. I hope all of our patients that have gone through surgery earlier this year are starting to feel not as exhausted and are on your way to gaining more energy. I have been excited to read on face book, some of the children that have had surgery are bouncing back really well. It makes me feel so good to read this. Our children seem to have better energy and resilience! Unfortunately for some of us older patients, recovery does take time. To all those who are about to have surgery, I wish you so well.

I'm late with writing this newsletter. I wanted to write it in September, but I wanted to wait for the finished outcomes of some of the projects we have been working on.

As you can see Jan Brooks – Stead has designed a Spinal Arachnoid Cyst Awareness Logo too. Both logos that she has designed, will coincide with each other on all our correspondence.

I've had some wonderful offers of help from some of our patients and families and I will be in contact with you as group projects expand to see if you would like to be involved. There will be things like emailing newsletters to patients in your state

and other admin or any ideas and stories you may want to contribute. Thank you so much for your offers of help.

The website is being built as I write this newsletter. As you are all aware, we missed out on much needed funding for this year. But I have surfaced after my disappointment and worked out ways to get each project managed and completed. So, our website should be up and running by February. I'm giving it an extra month in case there are any hiccups! It may be up before then? I will be excited when it's completed so you will all definitely know when it is finally up and running.

I have decided because our patient booklet is going to cost a bit to print, we are going to add a download version to the website for families to print out themselves. If you have not seen the fb posts showing this patient booklet? It has been put together by patients, families and carers to help you know all about being diagnosed with an Arachnoid Cyst and what happens next. It gives an explanation on surgery and recovery and the different surgeries performed by Surgeons for brain cyst and spinal cysts. It also explains our condition and recovery expectations so family and carers can know what to expect after surgery.

Another exciting thing is we have finally received some samples of our products that will be available on the website. Photos added. Some of these items will also be included in our hospital patient bags.



These are our Patient Support Beanies: They will be Available



on line and included in our patient Support hospital bags.

These beanies are made out of a soft coral polar fleece. They come with soft pads that can be inserted into the inside pockets of the

beanie. This enables the patient to apply the soft padding on the areas of surgery making it more comfortable to lay down or if the patient is suffering with a pressure headache a cold pack can also be inserted. All caution is to be taken when warming this item. The hot/cold pack does not come in the infant beanie, only the soft padding. Colours available – grey and white with maroon emblem. **Sizes: Adult, Child and Infant.**



Patient Eye Mask and Wheat Bags:
They Will Be Available On Line and in the Patient Support Bag and come in the same soft coral fleece, in colours white and grey with maroon emblem.

Soft Cuddle Me Infant Koala Teddy:
It Will Be Available on Line and in Infant Patient Support Bag. This is

our cute little light grey cuddly Australian Koala Bear. He has no filling so that baby can snuggle into him. He has maroon trimmings and for the infants going through spinal surgery, teddy's bandage is on his back. He is fully machine washable.



Below is our Beanie for our Children's Game: How Does My Brain Work? It Will Be Available on Line and in Child Patient Bag. This Game and Beanie is designed to teach children about their brains.

Pick two players. Each player has a turn at throwing the dice! With their token they move to their space. If they have landed on a part of their brain, they take that piece of their brain and put it on their beanie. The first to finish their brain wins! The playing board gives the child an explanation of their parts of their brain and how it works.

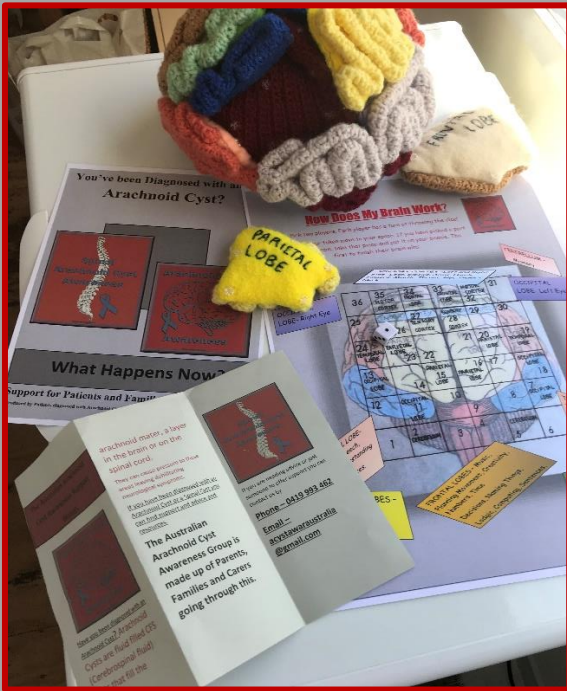
patient hospital support bags and are still in production.



We Also have designed our Patient Contact Support Brochure; these are available for distribution. If any one would like to help with the distribution of these to their main hospitals and Neurosurgery Depts/ Surgeries in your state, please email me and I will send you some.

This Game and Beanie may Also be available as a down loadable pattern for crafty parents or grandparents. The design is still in the process of production so it is yet to be decided.

We will also have available patient non spill drink bottles and non-spill thermo cups. These will go also in



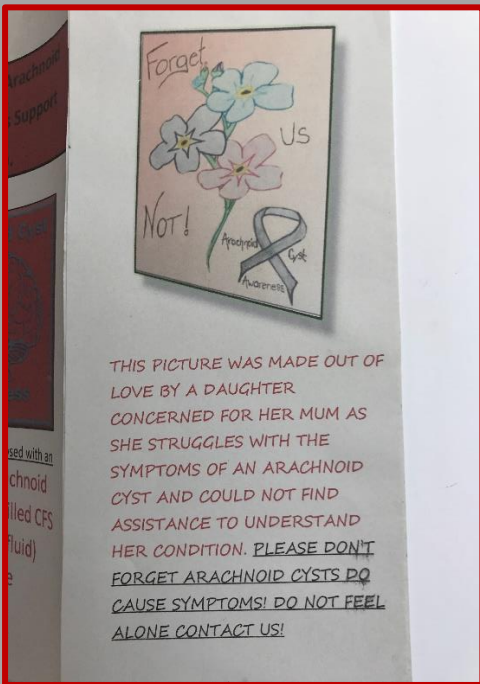
Thankyou Angel Rose for your heartfelt design!

I am just sorting out how we will distribute our patient hospital support booklet. Because we are on limited funds until I can manage to get us a grant. I've decided to do a printed version for our patient support bags, for those patients going into hospital for surgery. Otherwise it will be available for patients, families and carers to download on our website.

Patients are also welcome to download their stories on our site to help to create awareness that we can be symptomatic.

Also Included on our website will be support information and links to support services.

In the meantime, if anyone is needing help for any services please email us. Information on some services included will be:



As you can see, we have Angel Rose Harvest's design on the back of our leaflet. Her story for designing the **Forget Us Not** logo is very significant for our sufferers. It will be on the back and included in all Contact CFS Support Leaflets.

The Travel and Accommodation Assistance Scheme for each Australian State.

The National Disability Insurance Scheme. (NDIS)

Brainlink: Support Services for Families and Carers of Patients with an Acquired Brain Injury (ABI) through progressive neurological diseases and conditions.

The Australian Charter of Healthcare Rights for Consumers Patients or Providers.

This is just some of the links that will be available. We also have support information and literature available.

We will also have a page on the site for children, with activities and stories and support to help them learn about their condition.

I received some really good news the other day? We have now found a patient Respite Holiday House for our patients and families and carers. It is available in Central Northern Victoria.

Moria Gums Historical Homestead-

Is situated on the Murray River and boasts of Fishing, Yabbying, Canoeing, Skiing, Horse Riding, Bush walking, Swimming, picnic facilities or just Relaxing watching the beautiful Scenic River Birds,

Pelicans and Wildlife such as wild Brumby's Emus and Kangaroos.

The Historic Moria Gums Homestead is on and adjacent to the Magnificent Barmah National Park and Broken Creek and has delightful views of the Largest River Red Gum Forest in the world.

The Country Cottage has a cosy wood fire for winter. It is self-contained but some meals can be provided. The perfect place to relax, de- stress and unwind.

It is 30km from Echuca/ Moama

It is 63km from Shepparton.

It will be made available through bookings for those families, carers and patients who have gone through the stressful time of surgery of themselves or a loved one. If you are interested in this service please email us for further details.

This Free Service Will be Offered to Families in Need. It is the hope to find respite holiday houses in each state of Australia.

I hope everyone has an enjoyable Christmas and I pray everyone is as well as they can be throughout the season and for new year!



May Next Year bring us a much-needed grant and many more ideas and achievements for our Australian Support Group! Cheers Everyone.

How you can Help:

The Australian Arachnoid Cyst Awareness Support Group

: Governing, Co-Ordinating and Advocating a Support Group In your State.

: Distributing Brochures to Neurosurgery and Neurology Rooms, Drs Surgeries and Hospital Wards.

: Join the Committee.

: Contribute to Publications

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