

JUNE 2019

Australian Arachnoid Cyst

Awareness Newsletter: Thank you to Royalyn for letting me post this on her F/b Community Page.

I feel we have enough Facebook pages, for our cause, so because there are so many Australians using this page I felt it was just better for us to network in with this great community.

I noticed another Australian patient joined the other day and it prompted me to get this newsletter written.

For thirty years I felt I was the only person with this condition? I had never met other patients and felt so alone. It was after my last shunt malfunction and after nine operations and still being told I was not symptomatic and realising we are so behind in Australia that I had had enough! Is now time to get that awareness out there for us? I have spoken to so many of you in despair and suffering while trying to find help.

So where are we now? Well little steps make big steps eventually!!!

This is What Has Been Achieved so

Far: I have applied for a grant, if these funds were awarded to us; I wanted to put it toward a research trial. So far the outcome regarding research trials, I have written to the Brain Foundation, The Royal Melbourne Clinical Research Dept., Murdoch Children's Research Institute and Dr Brinda Shivalingham. Dr Andrew Morrikoff. Unfortunately, they were unable to assist, even though we would have

patent numbers and may have the funding if we were awarded for the next trial. Very disappointing, but I won't give up; I'll keep pestering different clinical science depts... Westmead is on my list next?

Given that we are unable to go forward with this at this time, if we received funding, I decided we needed to direct our funding straight to our patient support groups and a patient support bag to be distributed in our hospitals. This will be especially helpful for newly diagnosed patients.

As you probably have followed, my goal is to meet up for twice yearly meetings. This can help everyone with support and start getting assistance we need. **Brainlink have offered** their premises here in Melbourne so the idea is some of the funding we receive is to help with accommodation and travel for interstate patients wanting to meet up.

Eventually we may be able to

branch off into a support group in each state.

The next thing that was achieved was **Brain Tumour Alliance** have put our first Australian article in their magazine and on their website. I watch in anticipation for it to come out and want to thank the patients involved with this.

Unfortunately the patient that works on their website is unwell, but Catherine Hindson who is a very important part of their organization and is on their board has assured me it will come out and we are being advertised on their page of their support organizations.

With the generous help of networking with other patients we have managed to produce a booklet on what to expect when you are first diagnosed and also if you are needing surgery.

Thank you so much to Brianna Kerr, Sarah Alexander. Geoffrey Ricks for your photos of your journeys and

contributions. Jan Brooks- Stead for letting us use your design for our Australian Logo. The hope is to give our patients much needed support. We all go through such a tough time.

Our logo is starting to circulate our medical community so we are starting to be recognised which is great. Another essential item that I have mentioned and is being produced is a patient support bag for hospital. The contents contains a no spill patient drink bottle and cup for patients for use straight after surgery an eye mask, earplugs, a wheat bag with cover for pain relief, and the patient information booklet and other support info that is needed. In the paediatrics bag is a teddy bear with a bandage on his head or on his back, and some activities for them when they are feeling well enough. These items all have our logo on them. One other item that has been designed to go in the bag and to raise funds for us is a special patient support beanie,

this is also to be marketed to other medical organisations and we will be getting it patented as our design. I should be getting our first one sent from production any day now, so I'll post it for you to see, all of these will be available starting November this year if our grant is successful.

There is also a leaflet to circulate our major hospitals and waiting rooms with our contact details on.

The last thing I have worked on and decided we need for our awareness campaign is a well- known media personality for our Ambassador! I found out Rachel Finch the model and fitness guru has been diagnosed with an Arachnoid Cyst? So I have written to her. It would be a dream if she was able to. The next person I will try is Dr Karen Phelps?

Moving forward: I am planning to start an Australian Website with the Arachnoid Cyst Facebook link attached and a page for our kids to learn of their condition with

activities and link up with other children for support.

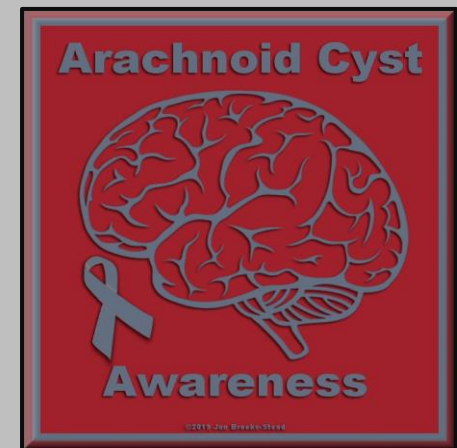
I have had to prepare a model of our plan for our grant; it will be wonderful if it comes through. I have found an accountant who will handle the grant in trust for us, so funds can be dispersed for each project properly.

I will in the meantime apply for other grants too in case we don't get this one.

I just want to see help for our patients. I'm determined to see this happen.

If you would like to join our **Australian Support Group** you can pm me and I will provide you with details. It will be easier once we have our website, at the moment we only have a phone number, but we are expanding. I will circulate a newsletter every quarter. If you have skills and would like to help with our group it would be very much appreciated the more

involvement of patients the more success we will have at getting awareness of our struggle when we are symptomatic out there! PM me if you would like a copy of this newsletter emailed to you.



**THE AUSTRALIAN
ARACHNOID CYST
AWARENESS SUPPORT
GROUP.**

