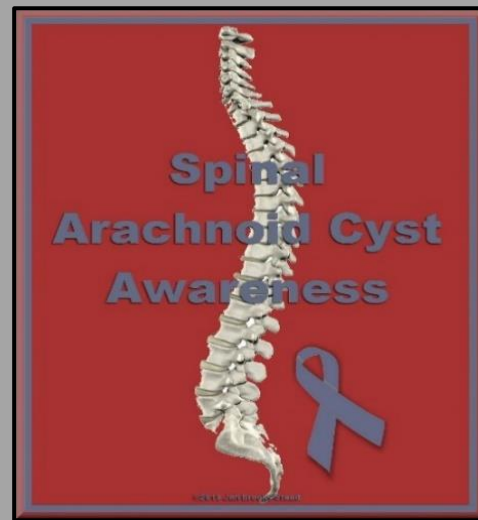
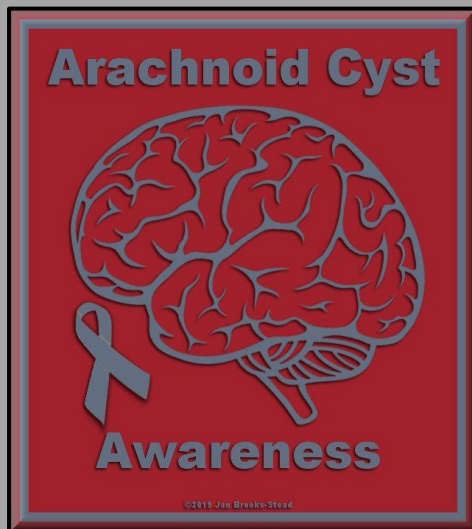


The Australian Arachnoid Cyst Awareness Support Group.

Email: acystawar@gmail.com
www.facebook.com/groups/acystawareaustsupportgroup/

Newsletter no: 8 May 2022.
Ph: 0419 993 462.
www.acystawareaust.com.au



Hi Everyone,
The beginning of this year has been pretty up and down for many of us.
For many patients our health has been a struggle and the thought of any surgeries going ahead has been dampened with the backlog of elective surgeries now presenting a problem in Australia.

I have really felt for those patients going through the floods in N.S.W and Qld.

We never expected these floods to be so damaging, yet again! I have been talking to a few of you and along with your health it has been really trying and difficult times and some of you are needing to relocate to new homes so the stress and anxiety will be around for

some time. Please know you are always in our thoughts.

In my last newsletter I mentioned finding a support organisation for some of our Tasmanian patients. We have found an organisation, however I am having to wait to speak to the appropriate parties in their organisation so we can put their details and a link on our website. This is taking a little bit of time as I received an email from them to say most of their staff are away with covid.

So as soon as I hear I will post on our face book pages and in our next newsletter the details.

If you have not been on our face book pages or our website of late, with the input of some of our patients I have put together a letter to our Minister for Health- Greg Hunt, The Australian Commission on Safety and

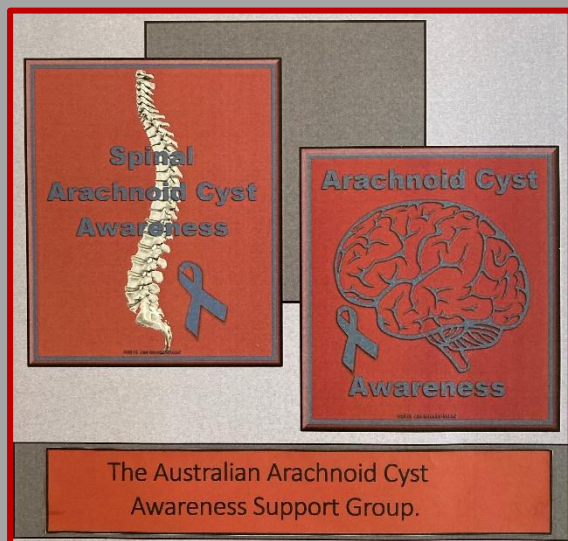
Quality and Healthcare Standards, The Healthcare and Complaints Commissioner and The Australian Government Department of Health.

I have organised this as I have become very frustrated hearing of continuous patients and families and also myself being turned away from the healthcare that they desperately need. If you wish to see the full letter you can find it posted on the About Us page on our website. Go to <https://www.acystawareaustralia.com.au>

I have also generated a petition following this letter for patients, carers and families to sign if you are interested in helping to improve the quality of healthcare and support and recognition of symptomatic Arachnoid Cysts here in Australia.

I know many of us are passionate towards this cause, so please help us by signing our petition, we need as many signatures as possible. You can also share the petition to circulate between your own families and communities. To sign go to:

https://www.petitions.net/please_help_us_to_receive_better_medical_and_follow_up_care_for_the_treatment_of_arachnoid_cysts.



Please sign our petition. Thank you!

Patient Advocacy Services.

I have also been looking into patient advocacy

services as some of our patients are finding because of fatigue and a constant feeling of being unwell, when it comes to specialist or hospital appointments, trying to put your health situation and needs forward can be very confusing and overwhelming. These Patient advocacy agencies are there to help.

They are independent to medical and hospital services and this may be of help if you or family members are finding you are having difficulties navigating and understanding your health plan.

By making contact with one of these agencies you can explain your situation or problem you may be experiencing and they can organise someone with trained medical knowledge to make contact on your behalf and explain your

circumstances or go along to the appointment with you and act to help your case with you or on your behalf.

I have come across two Services and these are –

Patient Advocates

Australia

patientadvocates.com.au/index.html

Australian Patients

Association

<https://www.patients.org.au>

Navigating the NDIS online zoom meetings.



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

In our last newsletter we advertised an online NDIS zoom meeting very kindly held for us by My Integra Plan Management and support co-ordination Group.

These guys provide support in managing and paying of your statements from the supports you are needing and providing the balances of your funding that you have been provided with in your NDIS plan. They look after and pay any invoicing in areas of any Support Services you may use or support supplies and equipment you may require to help you or a family member manage.

This takes the worry out of you or a family member needing to keep ongoing records and keeping of receipts as with them helping to manage it takes the confusion out of you navigating your provided funding.

The meeting was held on December 14th 2021 and provided some very useful information for some of our patients. We would really like to thank Marcus for a very informative meeting, we

really appreciated the time and energy it took to plan and coordinate this event for us. It was planned to follow up with another meeting but these guys have had an extremely busy start to the year, so another support organisation that affiliates with my Intregra is Hire up.



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

Hire up provide services to match support workers with patients and families.

I have had the pleasure of speaking on a number of occasions with Jane who is a relationship manager at Hire Up and she contacted their marketing department who have very kindly sent us some links for us to their

Events page

<https://hireup.com.au/events>

[/](#).

There are some very informative events on in each state.

Hire Up also hold monthly **Navigating the NDIS: ask our expert panel.**

I will advertise these on face book and also on our website so watch out for their next online panel.

I use both these Services to manage my NDIS plan and have found them to be very helpful for finding carers and managing my plan.

One of our patients who is active in our group sharing lots of support is Sarah H. Sarah has just recently completed an online Chronic Conditions Course, which she found very interesting and helpful with her chronic pain, which many of us are dealing with this on a daily basis.

It would be lovely for our patients to get to know each other through a patient story in our newsletter and also help to spread awareness to other organisations, Drs and other neurological and support communities about our condition.

If you would like to contribute, I would very much appreciate your story, perhaps it could be a positive story with a positive outcome regarding you or a family members treatment.

You could let us know about family life and your daily activities and where in Australia you are from.

Or you may want to write about any struggles you are having managing your condition and the help and support you are needing.

If you would like to contribute you can email me at

acystawaraustralia@gmail.com.

Well, I think that's all for this newsletter, I hope all our families enjoy a great easter and our kids enjoy their school holidays!

Until next newsletter,

Happy
Easter!



How You Can Help

: Governing, coordinating a group and advocating a support group in your state

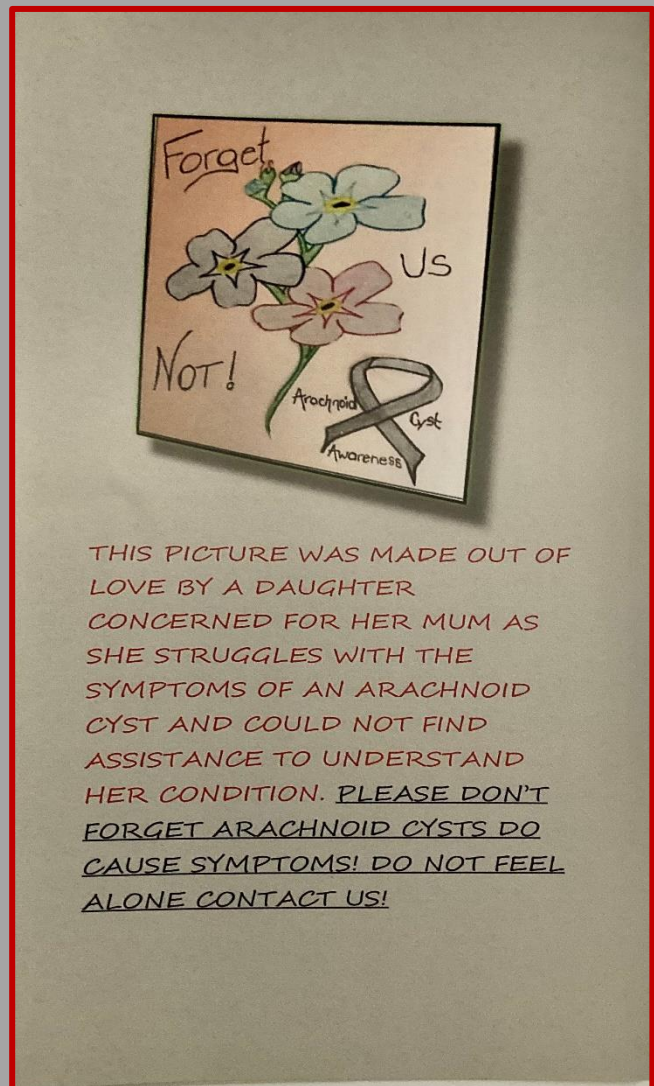
: Distributing brochures to Neurosurgery wards and Neurology rooms

: Join The Committee

: Contribute to our publications

: Contribute to our online Arts and Craft Hub

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W:

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