The Australian Arachnoid Cyst Awareness Support Group.

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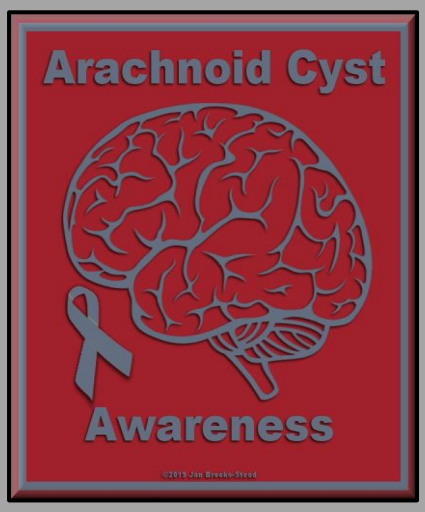
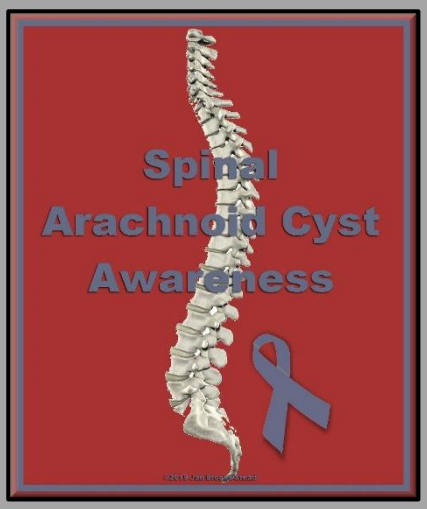




Hello Everyone,

My goodness I think as you get older the time flies so much faster, I cannot believe we are nearly through half of 2025 already!

We have a few things of quite good interest in this newsletter. Sarah Hammersley will continue to discuss Connective tissue disorders and the association with a/cs and I have had the privilege of being accepted from Rare Voices Australia in participating in RVAs co-designing Australia's Rare Disease Research Priorities. For those of

you who are new to our group, in 2022, I wrote to our Australian Health Minister explaining our plight to be recognised and heard here in Australia that Arachnoid Cysts can be symptomatic and we are tired of being turned away from our medical community and told our symptoms are not the cause of our a/cs. Also, the fact that we are so behind here in Australia compared with overseas research. We had a response explaining that in 2018 the Australian Government commissioned RVA to lead the collaborative development of the National Strategic Action Plan for Rare Diseases here in Australia.

The Minister for health launched the action plan on 26th of Febuary 2020, alongside an initial investment 3.3million. RVA continues to work with Federal and State governments as well as other stakeholders, in leading implementation of the Action Plan.(Ref: RVA website)

We were encouraged to write to RVA and become a partner and be put on RVA'S website and be recognised as a rare disease.

So, through RVA this workshop was held over two nights where with other rare disease groups, patients and family members and carers and the medical community participated in helping to shape the future of Rare

Disease research in Australia. This project was being led by Rare Voices Australia and the Kids Research Institute Australia.

I had to work with other community members to rank 19 themes from the previously taken stage one survey responses, from the most important themes to least important themes.

All the themes from this first workshop are listed below. I am sure many of you can relate the need for the following themes created.

<u>The following themes were –</u>

A -

Access to the best available treatments including clinical trials

B -

Access to resources and information for Australians living with a rare disease their family and carers

C -

Awareness and education for health professionals and service providers

D -

Care and support for all Australians including priority populations.

E -

Data collection and use

F -

Diagnosis using screening

G -

Disability guidance and support

H -

Disease progression and relevant prevention measures.

I -

Genetic testing

J -

Impacts of rare disease

K –

International collaboration of symptoms and commodities network.

L -

Centres of expertise and person centred best proactive care and support psychosocial and mental health impact and support quality of life.

Q -

Support and information for reproductive choice.

R - support for parents and carers.

S –

Treatment and cures.

Then during this first workshop we were asked to look over these themes and together work out what themes could be blended together to be able to manage to fit in all top 10 priorities.

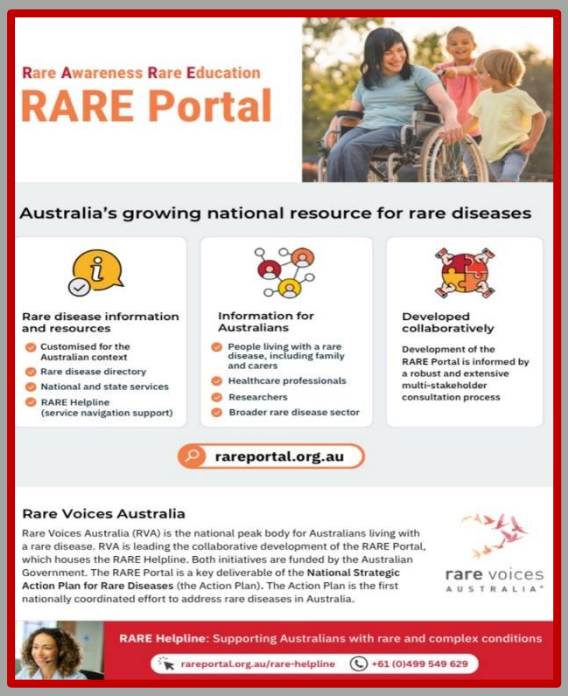
The second workshop was to nominate the top 10 themes once blended together and agree on this for the final outcome.

I’m sure many of you reading these themes can relate to many of these needs and priorities.

RVA will use this to determine the priorities of Rare Voices patients and families and carers of

the rare disease's community.

Rare Voices new Portal



After reading over the latest newsletter from Rare Voices Australia I made an inquiry about the new Rare Voices Portal for Australian's looking for information on their disease they are diagnosed with.

This has just been launched and on looking at it. I could not find Arachnoid Cysts, so following my inquiry I had a lovely phone call this morning from RVA. As the portal is so new, they are still loading on more rare diseases, it is a lengthy process as RVA have to go through all the rare diseases and ring the various organisations and groups and follow up on the correct information needed so then it can be loaded onto the portal and this all takes time.

I had a conversation with them about how here in Australia ACs are seen as asymptomatic unless they are quite big.

I explained how I considered us rare a disease because of the lack of knowledge here in Australia and asked would we qualify to go on the portal?

Rare Voices has noted that we are considered a rare disease in overseas countries and are registered as such. It is recognised that we need to be uploaded to the new Australian portal. In the meantime, there is a link put from the portal to our website. Go to https://rareportal.org.au/

Even though among our Australian A/C community at times it may seem like we are not moving forward to better treatment and outcomes, things are starting to happen for our community.

The other thing we discussed was connective tissue disorders associated with different conditions, this is something that Sara Hammersley is writing about her experience and the information Sara has found out about for our newsletters.

RVA is going to send us the information for the Connective Tissue Disorder Organisation so that we can find out further information on these conditions.

This is proving to be very positive and also it is providing more information for us, as many of us can relate to the other conditions associated with our ACs.

If you would like to read RVAs latest newsletter here is the link -

https://rarevoices.activehosted.com/index.php?action=social&c=122&m=290

What's The Issue with Our Tissue?

Written by Sara Hammersley

Hello, group and new members "welcome"!
I hope that the information I am about to share is informative, the more information we have and share will hopefully lead to better outcomes and better treatment for ourselves and family members.

As a group we are often finding ourselves needing answers that the medical community are unable to give us. I know in my experiences, that getting a 'true' diagnosis and understanding of my chronic health issues has taken decades. It's been a maze of new paths and dead ends. Knowing that this is often the 'norm' for people like me has made me want to try and help change the outcomes for others and hopefully bring answers and direction to be better advocates for ourselves and get clarity a lot sooner if possible.

In this issue of the newsletter, I am going right back to basics and want to highlight what for some of us maybe the original cause behind our Acs.
We are often told that most of us were born with our cysts, so unless we have had head trauma or another cause lets imagine that this is the case.

Our whole body is made up of connective tissues.

our bones, our ligaments, our tendons, organs, our eyes, even our blood and lymph nodes are classed as connective tissue because of the cells they contain. In dealing with these facts, it seems there is not much of us that is not connective tissue. Our CSF (cerebral Spinal Fluid) our souls and our spirit are not connective tissue. That leaves the majority of the matter in a human that has been made up of tissue that connects and works to make our bodies function.

We start to have problems when our connective tissue is weak and too stretchy. Collagen - (think of it as the glue that holds your body together) or more so it's the lack of collagen production that will cause your connective tissue to lose integrity. This is the case when it comes to EDS, Ehlers Danlos Syndrome, which we are finding is becoming more common in our AC communities and their families. Getting diagnosed with EDS or another connective tissue disorder is happening more often in people with an AC, much too often to just be a coincidence. The reason it's important to recognise this is because we need to understand fully where our symptoms are coming from and not rush into blaming the fact we have an AC as the only problem we may be dealing with.

Having healthy tissue is important when having surgeries, also we need awareness from surgeons

and anaesthetist this is very important.
Our bodies are different and it's important to acknowledge this. It also matters because some of us need special care when it comes to anaesthetics and after care for our wounds.
This syndrome can cause havoc in the body and can manifest many comorbidities and leave the sufferers very debilitated in some cases.
There are many variants of EDS as many as 13. These variants are able to be diagnosed genetically by a professional geneticist.

The most common type is hyper mobile EDS or heds. HEDS (Hypermobile Ehlers – Danlos syndrome) has not had its genetic markers uncovered as yet, but there are studies being done and literature has reported that they are getting close to having the genetic code markers identified.

To be formally diagnosed with heeds you will need an EDS aware rheumatologist to examine you and diagnose you. Also, a geneticist can rule out all the other forms of EDS by buccal saliva swab testing. They will go through your history and examine you to determine if you have the telltale signs and are bendy enough to be formally diagnosed with heeds.

Many rheumatologists don't recognise EDS and like many other rare disorders, it can take years to get a diagnosis.

Some of the signs to look for are, thin skin that tears easily, being bendy (hyper mobile joints not just flexible limbs), joint pain, a history of numerous injuries like sprains, tendinitis, rolling ankles easily, dislocated joints- e.g. shoulders, bruising with no obvious reason, subluxation, (unexplained pain or injury like something just feels out of alignment or pulled) digestive and stomach issues the list goes on.

You can find a list of telltale signs for EDS and the different variations by Googling - **The 23 signs I grew up with Ehlers Danlos Syndrome,** or by going to the EDS society the information is below,

You can also find support by joining the many forums or support groups on line and ask questions. I have put a great one that I belong to below.

Ok so how are EDS and Arachnoid Cysts connected? Often times when in the womb, as the embryo develops, there are many tissue defects that can occur. The one I want to highlight here is in the Arachnoid layer, a pocket may form and this can create a sealed pillow of connective tissue that is filled with our precious CSF or amniotic fluid (apparently).
This is an Arachnoid Cyst.

They can vary in size and thickness, and be on any area of the brain or spine. This layer is where we have CSF constantly flowing and circulating, renewing and washing

away the old CSF and cells to keep our brains and spinal cords clean and healthy.

The problem with these cysts is depending on where they sit on the structures of the brain, they can cause symptoms and damage as we know.

Another disorder that might occur if you have a connective tissue issue that is affecting the Arachnoid system is CSF leaks and I will go deeper down that rabbit hole in another newsletter.

Not all of us with AC's have a connective tissue disorder but through research and sharing our experiences through social media and on-line support groups we are discovering more of us are living with a tissue issue or that some of our family members are affected by these issues. They are affecting us differently and individually, but we are connecting through shared experiences.

So, take some time to consider if you might be affected or a family member is affected and if the dots connect you can look into better ways to help yourself and understand your body.

Getting a handle on understanding why we are suffering and feel different is a huge bonus when navigating and advocating for the best quality of life for ourselves and we all deserve to live our best life and love our human self that is us!

I have a theory as to why for ‘some of us’ we may have an obvious worsening of our symptoms after the age of 35 to 50 yrs and this seems to be a very active age group on our support sites.

We become more vigilant and start looking for help, our neurological symptoms get worse and our eyesight might become a problem that appears to be neurological, not just normal ageing of the eyes. Our cognitive function is becoming a problem and the headaches we may have always had are becoming harder to manage. Our collagen starts to slow down production in our thirties until we don’t make it anymore, so possibly this is when we start to run into obvious trouble?

Is it because with or without a connective tissue issue, we need our collagen to connect our brains health to our bodies. Just a theory?

I feel the need for a quick mention here some things to think about?
There is a very high number of people with EDS who also have conditions like ADD, ADHD and Autism (also common amongst our AC community and their families?)

Another significant syndrome called MCAS which is Mast Cell Activation Syndrome. This leads to our bodies reacting to outside influences causing numerous sensitivities

and allergies, leaving us feeling very unwell.

Lastly another syndrome connected is POTS postural orthostatic tachycardia …. in short it causes dizziness upon standing and other activities that cause blood pooling and abnormal heart activity that causes the heart to race which can cause syncope fainting or pre syncope and fatigue. Does this sound like yourself or a family member?

These are some things you may wish to to consider? I will go into more detail about MCAS and POTS another time.

Dealing with medical professionals that don't understand us is hard, being a complicated patient that doesn't fit into normal boxes will lead to advocating for ourselves time and time again so putting the pieces together that make us the individual jigsaws we are is important.

I hope this has helped shine a light on what may be going on for some of you. Feel free to post any questions I may be able to help you with on our face book group.
In our next newsletter I will talk about the CSF leaks I mentioned, as the symptoms and getting and understanding of these leaks can be eye opening to say the least.

Ehlers Danlos Society Australia

http://www.ehlers.danlos.com

This is a great support group on Facebook - **EDS & comorbidities Support Australasia Ehlers – Danlos Syndrome.**

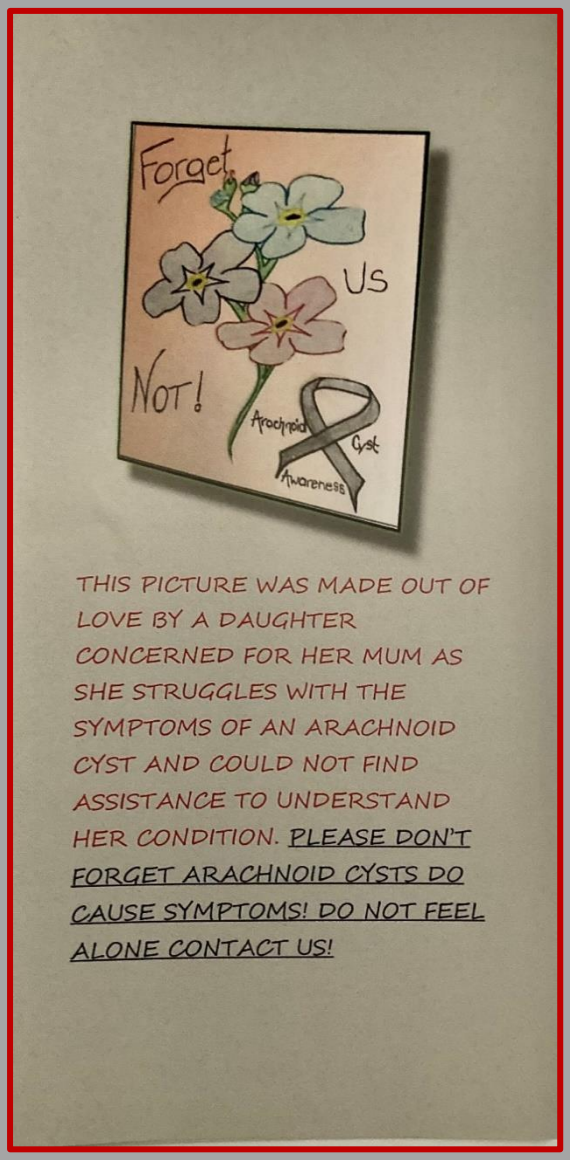
Our Petition

For all of our newest members, we have an ongoing petition. Show your support by signing our petition to be able to have more drs understand that Arachnoid Cysts can be symptomatic no matter the size of the a/c. How can so many of us all have the same symptoms? Please show your support by signing! You will find our petition on our website and if you are on our face book page you will find it in our featured section at the top of our f/b page.

Patient Stories.

I am also after some patient stories from anyone who would like to write about their journey of living with an Arachnoid Cyst. Your story will go onto our patient stories page on our website, if you are interested in sending me your story, you can email me acystawaraust@gmail.com or go straight to our website which is on the front of this newsletter and post it on there. Well, I think that's all we have

for this newsletter, until our next one I hope everyone can stay as well as possible and stay safe!



How You Can Help :

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

: Distributing brochures to neurosurgery and Neurology and Drs Rooms.

: Join The Committee

: Contribute to our publications

: Contribute to our online Arts and Craft Hub.