arthritis matters

Focus on Fibromyalgia

What do Lady Gaga and Florence Nightingale have in common? Well, it certainly wouldn't be their choice of attire! No, they both have lived or live with symptoms consistent with fibromyalgia - a complex condition characterised by widespread pain (felt in the muscles, tendons, and ligaments), that is often accompanied by extreme fatigue, and impaired memory and concentration.

As a condition, fibromyalgia has had a checkered history - from its names changes and uncertainty about its cause/s, to its fight for recognition as a 'real' disease.

In the 1500s, the term 'rheumatism' was used to describe conditions featuring musculoskeletal pain and encompassed all types of arthritis, and also what we now know as fibromyalgia.

Then for the next four centuries, as medicine began to allocate specific names for diseases and better understand their disease processes, this condition had many name changes leading to 'fibrositis' being introduced in 1904, as it was thought that the pain came from inflammation in the connective tissues.

Then things began to get murky. With the majority of patients being female and no evidence of the condition seen on newly invented x-ray, some in the medical fraternity began to regard the condition as a type of hypochondria or hysteria. Then as World War II servicemen returned from the Front with pain but no visible signs of tissue damage, they were labelled as having a 'psycho-neurotic' condition or personality disorder. These labels and attitudes served to cause despair in those who lived in pain and cast doubt on the nature of the condition, calling into question whether they were experiencing any physical symptoms at all.



It would take another thirty years to get its current name [coming from the Latin 'fibro' (connective tissue) and the Greek 'mio' (muscle) and algia (pain)], and until 1987 for recognition as a 'real' disease (by the American Medical Association). Sadly, even to the present day, there is still a degree of stigma and suspicion associated with Fibromyalgia.

In this edition of Arthritis Matters we seek to shine a light on this challenging and very real condition.

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Arthritis Matters is available in print or electronic format. Please let us know if you prefer to receive your copy by email.



19A Main Road, Moonah TAS 7009 Tel: 03 6228 4824 Email: info@arthritistas.org.au www.arthritistas.org.au ARTHRITIS INFOLINE: 1800 011 041



Disclaimer: The content provided in this newsletter is for information purposes only and should not be used in place of medical advice.

what's news

Board Retirements

Arthritis & Osteoporosis Tasmania recently farewelled two outstanding contributors and long-time members of the Board with the retirement of Brian Claridge and Rhys Jones at the AGM in November 2023.



Brian Claridge, 2008-2023



Rhys Jones, 2007-2023

Brian Claridge was first elected to the Board in 2008, taking on the role of Treasurer. An experienced accountant and Fellow of the Institute of Public Accountants, Brian provided valuable financial oversight and guidance to the Board during his 15 years of service (9 as Treasurer), including during some difficult periods of financial uncertainty and instability. He sold his accounting practice and retired in 2020. Brian continues to be involved in the Rotary Club of North Hobart and has joined a bushwalking club.

Rhys Jones – owner and manager of the Rhys Jones Pharmacy in Bellerive, was elected to the Board of Arthritis & Osteoporosis Tasmania in 2007. In his 16 years on the Board Rhys served as Vice President (8 years) and President (1 year). However, well before his formal involvement at Board level, Rhys regularly supported AOTAS' community education activities, providing his expertise and experience as a community pharmacist.

All Board positions are voluntary, and we are indeed fortunate to have individuals such as Brian and Rhys who give their knowledge, skills, and time so generously in community service roles. The outstanding contributions made by Brian Claridge and Rhys Jones have been recognised with Honorary Life Membership.

Welcome Janene!

Meet our Smoother Movers Strength Training Program Officer

By now some of you may have already met our newest staff member – Janene Glover. Janene joined the team late last year as Program Officer for the Smoother Movers Strength Training Program, and she has lost no time in familiarizing herself with our programs and getting to know everyone. Janene's role over the next 18 months will be to expand our existing Smoother Movers Strength Training Program statewide. A trained fitness professional, whose experience includes working as Get Active Program Manager with Womensport & Recreation Tasmania, Janene is a valuable addition to the AOTAS team. Janene works part time (Mon to Wed; and on alternative weeks: Tues to Thur) and can be contacted by emailing jglover@arthritistas.org.au



what's news

What we do, how well we do it, and is anyone better off?

Arthritis & Osteoporosis Tasmania is committed to making a positive difference to the lives of Tasmanians of all ages living with, or at risk of developing, arthritis, osteoporosis, and related musculoskeletal conditions. But understanding the impact (or difference) our efforts are having is essential if we are to remain an effective organisation and provide a value for money service to the community.

Measuring what we do, how well we do it, and is anyone better off enables AOTAS to set benchmarks, targets, and measure performance over time. Jackie Slyp, CEO, provided the following snapshot of performance for the financial year ending 30 June 2023:







Medical Cooling or Heating Concession

Do you or someone you live with have Fibromyalgia, Lupus or Scleroderma? Some people with these conditions (and some more as listed on the website linked below) can be affected by changes and/or extremes in temperature.

For this reason, the Tasmanian Government, through the State Revenue Office, offers a daily concession to eligible customers who have, or live with a person who has, one or more of the specified medical conditions, and who are eligible to receive the annual electricity concession (i.e. they have a Pensioner Concession Card issued by CentreLink or the Department of Veterans' Affairs, or a Health Care Card issued by CentreLink).

This concession recognises that people with these condition/s require the heating or cooling of their residence in order to manage the condition/s - either to mitigate 'deterioration of the condition in temperature extremes or have a worsening of their symptoms with temperature changes.'

Applicants will need to complete an Application Form and provide certification from their medical specialist or GP that their medical condition is significantly worsened by extremes in temperature. At the time of writing, the daily concession is 51.648 cents per day (GST inclusive).

For more details on qualifying medical conditions, eligibility criteria, how to apply, the current daily discount, and a link to the Medical Cooling and heating Concession Application Form, go to:

https://www.sro.tas.gov.au/electricity-concessions/ medical-cooling-or-heating-concession



Fibromyalgia in Focus

Fibromyalgia whilst being an 'old' disease still holds onto many of its secrets. It is not a nice, neat condition - with an easily understood cause, simple symptomology, able to be seen in diagnostic tests, or which responds to a single medication or modality.

Rather, it is 'messy' and extremely complex. The condition affects widespread parts, and systems, of the body. It affects the body, the brain, and the mind - impacting physical and cognitive function, mood, and emotions. Symptoms can be mild or severe, can move, present themselves randomly, and flare for no apparent reason.

For this reason, it is often referred to as Fibromyalgia Syndrome (FMS), a syndrome describes a group of symptoms that often occur together.

The primary symptom of FMS is widespread musculoskeletal pain, stiffness, and tenderness in the tissues throughout the body, that has lasted longer than three months. In addition, many people will experience:



Arthritis

- fatigue, tiredness, and lack of energy - reported by 90% of people with FMS
- sleep issues not able to get to sleep, stay asleep or wake feeling unrefreshed
- problems with memory and/ or concentration (referred to as 'fibrofog').

Some may also have:

- pain or dysfunction in the jaw (in the temporomandibular joint)
- headaches or migraines
- tingling, numbness or swelling in the hands and feet
- restless leg syndrome
- painful menstrual periods
- irritable bowel symptoms diarrhoea, constipation, bloating or tummy pain
- interstitial cystitis a bladder condition with urinary urgency and frequency, without infection
- sensitivity to bright lights, loud noises, strong smells, and changes in temperatures
- a feeling of stress, anxiety, irritability, or low mood.

And yet, the person will appear 'normal' with no visible signs of the condition - making many wish that they would break out in bright green spots, that would at least stop the comment "but you look fine."

Who Gets Fibromyalgia?

Anyone can develop FMS, however, some factors that increase the risk include:

 gender: people assigned female at birth are more commonly diagnosed than those assigned male (80% of people with FMS are female)

- age: those between the ages of 25 and 55 years most commonly develop the condition, although it can also affect children and teenagers
- family history: having a close family member (parent or sibling) with FMS
- other conditions: such as having Rheumatoid Arthritis, Lupus, chronic low back pain, chronic fatigue syndrome or inflammatory bowel disease.

Some 3-5% of the population or one million Australians are estimated to live with FMS.

What Causes Fibromyalgia?

The underlying cause of fibromyalgia is not known, however, there are many theories, and research is being conducted in a range of areas. Primarily, it is thought to be a painprocessing problem, whereby the nervous system becomes oversensitive, signaling tissue damage when there isn't any present. The brain 'makes pain' to warn of this apparent danger, like an overactive alarm system going off when there is no threat. Over time the brain interprets all information coming from the tissues as being 'dangerous.' This could explain why people with fibromyalgia are sensitive to noise, smells, and bright lights. The question is why does this pain amplification start?

Research shows that people with FMS have subtle changes in chemicals called neurotransmitters found in the brain and nervous system which, true to their name, transmit messages between nerves and brain cells. This includes an elevated level



of 'substance P,' a protein which is both a neurotransmitter and a neuromodulator which modifies signals in the brain. It is believed that this may be one of several abnormalities that increase pain sensitivity.

Other research has demonstrated an autoimmune aspect to the condition. By injecting mice with blood from people with FMS, scientists were able to observe changes in the behaviour and function of the mice including their sensitivity to touch and cold, and reduced grip strength. This demonstrates the immune system, through activation of antibodies, is responsible for or contributes to increased activity of pain-sensing nerves.

There is also a genetic component associated with fibromyalgia. The risk of developing FMS is eight times higher in those with a first-degree relative with the condition. There are currently about one hundred genes associated with pain sensitivity, so this will take some unravelling.

Another theory is that both genetic and environmental factors (such as trauma, illness, or infection) may put some people at increased risk, more research is needed to examine what role these factors may play in the condition. Research is also being conducted into the role of stress hormones and how they may serve to amplify pain and fatigue.

These areas of research are serving to inform our understanding of FMS the underlying disease process/es, its cause/s, and potential treatments, and diagnostic tests.

How is Fibromyalgia diagnosed?

There is currently no specific diagnostic test for FMS. A GP/specialist will take a patient history including details of symptoms, their duration, other medical/health issues, and any family history. They will then conduct a physical examination to assess tenderness in the tissues. X-rays, scans, and blood tests have limited value and would only be useful in excluding other conditions.

How can Fibromyalgia be managed?

Unfortunately, there is no magic bullet for curing or treating FMS. That is not to say that there aren't things that can reduce symptoms and enhance function, and quality of life. It is likely that a range of strategies will need to be employed (and tweaked over time) including accessing information to better understand the condition, working well with your healthcare team, finding ways to stay physically active (aerobic and strengthening exercise, meditative movement), engineering a good night's sleep, making food choices that count, reducing stress, utilising pacing strategies, and optimising medication use.

For more information on strategies and lots more, get our new Taking Control of Your Fibromyalgia Booklet: Go to https://arthritistas.org.au/wp-content/ uploads/2023/10/Fibromyalgia-Booklet-A5-web-v.2023.pdf or call your Arthritis Tas InfoLine on 1800 011 041.

Other resources for living well with Fibromyalgia:

Fibromyalgia Information Sheet:

https://arthritistas.org.au/wp-content/ uploads/2022/11/Fibromyalgia___ update_180517.pdf

Exercise and Fibromyalgia Information

Sheet: https://arthritistas.org.au/wpcontent/uploads/2020/05/ArthAus_ ExerciseFibromyalgia_1705.pdf

Fatigue and Arthritis Information Sheet: https://arthritistas.org.au/wp-content/ uploads/2022/11/FatigueArthritis-2017.pdf

Arthritis and Emotional Wellbeing Information Sheet: https://arthritistas. org.au/wp-content/uploads/2022/11/ ArthritisEmotionalWellbeing_2017.pdf

Healthy Eating and Arthritis Information Sheet: <u>https://arthritistas.</u> org.au/wp-content/uploads/2022/11/ HealthyEating-2017.pdf

Working with Your Healthcare Team Information Sheet: <u>https://arthritistas.org.</u> au/wp-content/uploads/2022/11/Workingwith-your-healthcare-team-2017.pdf



research news

Gutsy researchers may have the answers

Could the health (or not) of the gut be the cause of diseases such as Parkinson's Disease and multiple sclerosis (MS) believe so. In a study that could have implications for the treatment of rheumatoid and other types of inflammatory arthritis, scientists have been investigating how the gut microbiome and the immune system interact. More specifically, they have been looking at how the gut can control or promote the damaging inflammation that is a feature in MS (and types of inflammatory arthritis).

"We are approaching the search for MS therapeutics from a new direction," Andrea Merchak, from the University of Virginia School of Medicine, Department of Neuroscience said. "By modulating the microbiome (the collection of microorganisms that naturally lives inside us), we are making inroads in understanding how the immune system can end up out of

Raynaud's - how the genes fit

Researchers from London and Berlin have mined the health records and genetic information of five hundred thousand study participants and been able to identify the genetic causes of Raynaud's.

Raynaud's Phenomenon is a condition that causes the body's extremities to become cold and turn white/blue. Small blood vessels in places such as the fingers, toes, ears, the tip of the nose spasm, constricting blood flow to impacted parts.

Affecting as many as one in five people worldwide (more commonly women, those experiencing stress and/or living in cold climates), Raynaud's can be extremely painful and impact a person's ability to do daily tasks. The condition control. We can use this information to find early interventions."

The team hopes that their research, which has been published in the journal PLOS Biology, will provide a foundation for finding ways to positively influence gut health in people with these conditions. "Ultimately, fine-tuning the immune response using the microbiome could save patients from dealing with the harsh side effects of immunosuppressant drugs."

Source: Multiple Sclerosis Discovery Could End Disease's Chronic Inflammation (uvahealth. com)



is associated with types of arthritis including rheumatoid, lupus, Sjögren's Syndrome, and fibromyalgia.

The findings, published in the journal *Nature Communications*, significantly increased the teams' understanding of the role genetics has to play through the identification of variations in two genes that predisposed participants to Raynaud's. It is hoped that the discovery could lead to new, safe and effective treatments for the condition.

Source: https://medicalxpress.com/news/2023-08-genetic-raynaud-phenomenon.html



Simple steps for reducing hip fractures

We usually consider hip fractures as being a risk for people with osteoporosis, however, studies show that the majority happen in people who don't have the condition - 60% of women who sustain a hip fracture and 70% of men won't have bone mineral density loss in the osteoporotic range.

This has significant implications for all of us as individuals, and as a community if we wish to lower the risk of these painful and potentially life-limiting injuries.

A new Australian study, published in the Journal of Bone and Mineral Research, suggests that a populationwide strategy aimed at enhancing Bone Mineral Density could lead to a substantial decrease in the incidence of hip fractures.

Researchers compared two groups of study participants and found that in those who increased their bone mineral density by a 'very modest' 3%, there was a 45% reduction in hip fractures across the group. The good news is that such an increase can be achieved through making small lifestyle changes.

"Bone mineral density is about 50% modifiable, and even small improvements reduce the fracture risk," Professor Tuan Nguyen, Distinguished Professor of Predictive Medicine at the University of Technology in Sydney, said.

Bone mineral density loss doesn't have to be an inevitable part of the ageing process, if we simply make lifestyle changes sooner rather than later and take steps to reduce the risk of sustaining a fall.

Source: https://www.uts.edu.au/news/healthscience/study-reveals-how-little-things-canreduce-hip-fractures

research news

One baby's trash

What if we could find an alternative to joint replacement surgery for people with worn cartilage? A new study shows the answer could be in the medical waste bin!

New parents often say that all they wish for is a newborn who is healthy and has 'ten fingers and toes.' But one baby in a thousand will have a condition called polydactyly, meaning that they have an additional digit which is usually surgically removed later on. It is cartilage extracted from these healthy but surplus 'bits' that has researchers from the Tokai University in Tokyo, excited. The team extracted cartilage cells from the discarded fingers of babies and grew them into 'sheets' in their lab. These were then implanted into the knee joints of volunteers with arthritis.

Scans taken at twelve months showed that the new cartilage had continued to grow in all of the volunteers, replacing their own worn-out cartilage. All reported being largely pain-free with no adverse effects. "This has the potential to allow people to walk their entire lives on their own knees, without requiring artificial joints" said researcher Professor Masato Sato. The study, published in the journal npj Regenerative Medicine, demonstrates the merits of recycling!



Source: https://www.msn.com/en-au/health/ other/how-cartilage-from-youngsters-isnow-being-used-to-ease-arthritis-pain / arAA19HdEF#:~:text=Researchers%20are%20 taking%20cartilage%20%E2%80%94%20 the%20tough%2C%20flexible,surgically%20 removed%20from%20people%20born%20with%20extra%20digits.

Shedding Light on Hypermobility

People who have very flexible joints were once said to be 'double-jointed.' We now refer to their joints as being 'hypermobile' or having a greater range of movement. For some people this doesn't cause any real problems, for others, including those with conditions such as Ehlers-Danlos, it can cause pain and joint traumas including sprains and dislocations. The specific cause of hypermobility has remained elusive.



Now, researchers from Louisiana, USA have found a link between hypermobility and a deficiency of folate caused by a variation of the MTHFR gene (which is involved in how the body uses this vitamin). People with the genetic variant can't metabolise folate. The resulting deficiency prevents key proteins from binding collagen to the extracellular matrix, resulting in more elastic connective tissue.

This discovery has the potential to assist with the diagnosis and treatment of hypermobility. Describing the findings, published in the journal *Heliyon*, as 'a big deal' is Dr Gregory Bix, Director of the Tulane University Clinical Neuroscience Research Centre. "It's a vitamin that could improve people's lives. That's the biggest thing: we know what's going on here, and we can treat it."

Whilst more laboratory research and clinical testing needs to be completed, this work has the potential to offer millions of people relief from pain and other symptoms associated with hypermobility syndromes.

Kudos to the Victorian Government

In the first study of its kind in Australia, and potentially in the world, the Victorian Government is conducting an inquiry into services for women and girls who live with chronic pain. Persistent pain is much more common in females, and studies show that their pain is more severe and longer lasting. We also know that the care response is sadly lacking.

The Government is now calling for input from women and girls (12 years and older) who live with pain (and health workers who care for them), to better understand the challenges they face trying to access adequate treatment for their pain.

The *Inquiry into Women's Pain* will provide recommendations to inform improved models of care and service delivery for Victorian girls and women in the future. The final report will be delivered in December 2024. Congratulations to the Victorian Government for leading the world in this important area. We will watch this space with interest. <u>https://</u> www.health.vic.gov.au/inquiry-intowomens-pain

other news

Hidden but Not Ignored

When you live in Tasmania, airports often mean the start of something, whether it is an adventure, for retail therapy, seeing family and friends, or traveling to have a specialist medical appointment or procedure. No matter what your reason for being there, they can be extremely overwhelming places.

Airline passengers need to navigate their way through a maze of often unfamiliar and sometimes stressful processes, negotiate what seems like miles of concourses dragging little cases, and battle crowds of other travelers - swimming against the tide as they flow along in their masses.

Whilst most airports have a welldesigned and accessible built environment with ramps and lifts, and systems in place that cater for and assist people with easily recognisable physical disabilities such as those in wheelchairs or with mobility aids, what about people whose disability is not as obvious or is actually hidden?

In 2016, staff at Gatwick in the UK identified that their airport (with its two massive terminals, sixty-five departure gates, serving nearly forty million passengers per year) could pose significant problems for people with conditions/disabilities that were hidden to an observer but posed a challenge for the individual in that environment.

These types of 'hidden' disabilities include sensory deficits (eg. sight or hearing difficulties), anxiety or



mental health issues, communication disorders, autism spectrum disorder, types of dementia, those with bowel and bladder issues, and those that would be specifically relevant to our consumers - arthritis, osteoporosis and/ or chronic pain syndromes including fibromyalgia.

To improve the traveler's experience, the Gatwick authorities worked with charities and groups associated with a wide range of health conditions and came up with a mechanism whereby people with 'hidden' conditions could indicate to airport employees that they may need assistance or support - so the sunflower lanyard was born.

By wearing a sunflower lanyard (and now a sunflower badge or wrist band), passengers who live with a 'hidden' disability or those who are caring for/assisting someone with one, can indicate to airport personnel (who are trained to look for the symbol) that they may benefit from special care and consideration. Those wearing the sunflower can be assisted in navigating their way through the airport and making their way through special assistance lanes. It does not, however, fast-track people through security or passport control areas (for international flights).

Some airlines also acknowledge the program and those wearing a sunflower (lanyard, wrist band or badge) will be assisted by counter and onboard staff to have extra time getting on (preboarding) and off aircraft, and having support in the event of travel changes eg as the result of a departure gate change.

The sunflower lanyard initiative has now gone global, being adopted in thirty-nine countries. It is in place in major Australian airports including Hobart and Launceston. It is also available on NSW and Victorian rail services, in some large supermarkets and shopping malls, and is





acknowledged by emergency services in some jurisdictions. The program was even in evidence at the recent FIFA Women's World Cup hosted by Australia and NZ.

Lanyards can be obtained free from participating airports and public transport services, please note that they may need to be applied for ahead of travel, see the relevant Airport or Service's website for details.

For more information on the Program, or how it operates at the Hobart or Launceston Airports see:

https://hdsunflower.com/au/

https://hobartairport.com.au/travellers/ airport-guide/accessibility/hiddendisabilities/

https://launcestonairport.com.au/flights/ hidden-disability-program

https://upload.wikimedia.org/wikipedia/ commons/f/f3/Crowded_terminal_at_ Cairo_Airport_during_the_2011_Egyptian_ Protests_%285%29.jpg

https://upload.wikimedia.org/ wikipedia/commons/a/a1/Brisbane_ Airport_Domestic_Terminal%2C_ May_2021%2C_05.jpg

members stories

Flying into a Storm (on the ground)

Diana has always adored travelling, particularly by air. It is, therefore, extremely sad that a recent incident has taken the shine off her love of flying. When returning to Tasmania, after time spent with family on the mainland, Diana approached the airport security screening checkpoint, placed her bag on the conveyer belt and stepped towards the screening officer. As recommended, she informed him that she had 'metal onboard' (in the form of joint replacements in both hips, both knees, and 'hardware' in both ankles) as a result of living with rheumatoid arthritis. It was then that things became 'turbulent.'

First, the screening officer took Diana's (metal) walking stick, which she requires for safe mobility, and passed it to a colleague so that it could undergo Explosive Trace Detection testing. He then indicated for her to walk into the Body Scanner and place her feet on the 'footprints' provided. Feeling very unsafe and 'wobbling badly' Diana made her way into the scanner, where she was directed to lift her arms, which she did with great difficulty (due to her condition). The officer then indicated that he was not able to get a clear scanned image, saying the results appeared 'smudgy' around her lower torso area.

Diana was then directed to walk through an adjacent metal detector frame, after which a female officer commenced using a hand wand over this area and the whole body, repeatedly. Only after commencing the process did the officer mention the option of having this search conducted in a more private area. Eventually, cleared to go, Diana looked around to locate her walking stick. She saw it five metres away, leaning against the counter of the swab testing area, and had to ask for it to be returned to her.

In addition to the above, Diana found aspects of communication with the security personnel to be challenging. The general environment was noisy and hearing commands was very difficult. Rather than approach her, the screening officer had instead raised his voice and 'barked' directions at her. In her complaint to the airport, Diana stated "I found this experience so distressing and traumatic, that my long-time pleasure and delight in flying has been crushed, completely."



The specific airport involved contracts its Border Control and security screening processes to an external contractor, Certis. As a result of Diana's complaint, the airport's Customer Experience Team stated that they "have undertaken to work with the team at Certis to ensure that their staff are adequately trained to assist customers in differing circumstances, and to deliver a positive customer experience to all passengers."

Subsequently, Diana was informed by a friend that she should have been offered a wooden walking stick to replace her metal one for the screening process. Diana has raised this issue with the airport concerned, who have indicated that they are in the process of acquiring more wooden walking sticks.

To be clear, Diana has absolutely no issue with aviation security screening requirements. She wholeheartedly supports these processes being in place to keep herself, and all travellers, safe and is grateful that Australia takes passenger security seriously. It is the manner in which the processes (briefly touched on above) were facilitated that was less than ideal.

Diana needs to travel to the mainland again very soon. She is aware of the Sunflower Lanyard project (see page 8) and is intending to wear her lanyard as she proceeds through each airport and their screening checkpoints. Hopefully, screening staff will know about the project and offer her some additional time and assistance, and Diana can once again experience the 'delight' of flying.

https://en.wikipedia.org/wiki/ Full_body_scanner#/media/File:NRW-Verkehrsminister_Hendrik_W%C3%BCst_-_ Vorstellung_Easy_Security-6294.jpg

programs & events



BLACKMANS BAY

Blackmans Bay Hall Tuesday 2:15pm - 3.15pm Wednesday 10.30am - 11.30am Wednesday 12.00pm - 1.00pm

BRIGHTON

Pontville Hall Thursday 12.00pm - 1.00pm

CAMBRIDGE

Cambridge Hall Thursday 11:30am - 12:30pm

CLARENCE Clarence Integrated Care Centre

Monday 11:30am - 12:30pm

GLENORCHY

Glenorchy Scout Hall Tuesday 10.00am - 11.00am 11.30am - 12.30pm

LENAH VALLEY

Pat Murnane Memorial Hall Wednesday 11.45am - 12.45pm

LINDISFARNE

Lindisfarne Citizens Activity Centre Tuesday 10.30am - 11.30am

MIDWAY POINT Midway Point Hall Tuesday 10.30am – 11.30am

SNUG

Snug Community Hall Monday 9.30am – 10.30am 11.00am - 12.00pm

SOUTH HOBART

South Hobart Community Centre Tuesday 12.30pm - 1.30pm Wednesday 1.30pm - 2.30pm

TRANMERE

Tranmere Hall Wednesday 1.00pm - 2.00pm

ULVERSTONE Gawler Room, Civic Centre Thursday 9.30am – 10.30am

Living Well with Arthritis

Do you, or someone you care about, have arthritis?

Then this session is just for you!

Come along and let us:

- bust some myths about arthritis
- explore what hurts and why
- Look at a few types of arthritis
- see what you can do to live well with arthritis

If you have any queries, please contact us: on **1800 011 041** or **info@arthritistas.org.au**

We thank the staff of the Campbell Town Community Health Service for their assistance in planning and supporting this session. This is a FREE Community Information Session.

> Thursday, 29th Feb 2024

1pm – 2.30pm Campbell Town Community Health Service

> 70 High Street, Campbell Town

new resources

Free Community Webinars and Podcasts Enhance your understanding of your condition and how best to manage it with these podcasts, webinars and documents.

New Pain in Arthritis Booklet

One universal fact about arthritis is that it is a pain in the ... joint/s. In recognition of this, Arthritis Australia recently convened an expert group to develop a new resource on the subject.

The new Taking Control of Your Pain in Arthritis booklet discusses different types of pain, acknowledges the impacts that pain can have on a person's life, explains who can help (from your GP to the range of specialists and allied health practitioners who work with people in pain), and offers strategies that a person in pain can utilise to 'dial down the volume' of their pain.

For a copy of this new booklet, call your Arthritis Tas InfoLine on 1800 011 041 or visit: <u>https://arthritistas.org.au/</u> wp-content/uploads/2023/07/Pain-in-<u>Arthritis-2023.pdf</u>



New Fibromyalgia Booklet

In recognition of the prevalence and impact of Fibromyalgia, Arthritis Australia has added a new booklet on this condition to its suite of resources. *Taking Control of Your Fibromyalgia* explores what Fibromyalgia is (and what it is not), discusses how it can affect an individual and who can help them, and offers suggestions about positive steps to take in enhancing function and quality of life.

For a copy of this new booklet, call your Arthritis Tas InfoLine on 1800 011 041 or visit: <u>https://arthritistas.org.au/wp-</u> <u>content/uploads/2023/10/Fibromyalgia-</u> <u>Booklet-A5-web-v.2023.pdf</u>

Reminder About Not So Welcome Summer Visitors

We are heading into that time of the year when a particular seasonal guest can drop by. No, we are not referring to Santa, but mosquitoes!

If you live in or are visiting the East Coast of Tasmania, from the eastern Bass Strait Islands to the very south of the state, it is important to protect yourself from mosquitos that may carry the Ross River or Barmah Forest viruses.

While most people who are exposed to these viruses from a mosquito bite will have mild or no symptoms, a third will develop symptoms including a rash, fever, chills, headaches and/or fatigue. They may also develop swelling, pain, and stiffness in their joints.

For more information, see our Ross River and Barmah Forest Virus Information Sheet or call your Arthritis Tas InfoLine on 1800 011 041 for a copy: <u>https://arthritistas.org.</u> <u>au/wp-content/uploads/2022/11/</u> <u>RossRiverBarmahForest-2017.pdf</u>



Staying Safe in the Sun

It is very tempting to want to spend lots of time outdoors in the sunshine at this time of the year, however, people with inflammatory types of arthritis such as Rheumatoid, Lupus and Ankylosing Spondylitis may be taking medications that make them susceptible to sunburn (even with limited sun exposure) and skin rashes.

Photosensitivity (sensitivity to ultraviolet rays from the sun) is a side effect of medicines including Methotrexate, Plaquenil (Hydroxychloroquine), Leflunomide and even Non-Steroidal Anti-Inflammatories such as Ibuprofen and Naproxen. If you are taking any of these medications, or if you want to know if your medicine/s cause photosensitivity, check the Consumer Product Information Sheet for the specific medication or ask your pharmacist.

For more information, visit the Arthritis Foundation (USA): <u>https://www.</u> <u>arthritis.org/drug-guide/medication-</u> <u>topics/sun-sensitivity</u>

Connecting Kids with Juvenile Arthritis

Living with JIA can be isolating. To bridge the gap, our friends at JAFA, Juvenile Arthritis Foundation of Australia, have developed KidsConnect, a fun and interactive digital platform that links kids (aged 7 – 17 years) with arthritis. The website offers kids a secure space to play games, connect and chat with their peers, and navigate some of the issues associated with living with this challenging condition.

To learn more about KidsConnect visit: <u>https://www.jafa.org.au/kidsconnect/</u>

get involved

New Juvenile Arthritis Registry

It is estimated that some thirty thousand young Australians live with juvenile arthritis, and yet, awareness of this and other childhood rheumatic conditions is seriously lacking, and paediatric rheumatology is a grossly under-resourced area in our health care system.

An effective way to represent the needs of these children and young people is through the collection and analysis of data that allows us to better understand who lives with these conditions, where they reside, and what services/treatment they need.

To this end, the Juvenile Arthritis Foundation of Australia, Australian Paediatric Rheumatology Association, Arthritis Australia, and the Australian Arthritis and Autoimmune Biobanking Collaborative (A3BC) have partnered to establish the *Australian Juvenile Arthritis Registry* (AJAR).

The Registry is a national project that aims to gather key information on Australian children and young adults with juvenile arthritis (JIA) and other rheumatic diseases for the purpose of better and understanding the extent and impacts of these conditions on their lives. It will allow researchers and consumer groups to use survey responses to raise awareness and lobby for better services, more support and research. It is hoped that these efforts could improve the lives of children with these conditions now and in the future.

Individuals who sign up for the Register may also opt to participate in the A3BC Biobank-Registry study which will collect additional health information, biospecimens (e.g. blood samples), clinical assessments, and online questionnaires.

Participation in the Registry is open to individuals aged under 25 years, who have been diagnosed with a juvenile rheumatic condition before the age of 16 years.

> JAFA Juvenile Arthritis Foundation Australia

For more information on the above, go to The Australian Juvenile Arthritis Registry - Frequently Asked Questions page at <u>https://a3bc.org.au/ajar-faqs/</u>



Australian Juvenile Arthritis Registry (AJAR)

Do you, your child, or a relative have juvenile arthritis or another childhood rheumatic disease?

Do you want to help make a difference?

The Juvenile Arthritis Foundation Australia (JAFA) has partnered with the Australian Paediatric Rheumatology Group (APRG) and the Australian Arthritis and Autoimmune Biobanking Collaborative (A3BC) to develop the first national registry for juvenile arthritis and related childhood rheumatic diseases.

This will enable a more consistent approach to information, diagnosis and treatment for juvenile arthritis and childhood rheumatic diseases across Australia.

• We are looking for people under the age of 25 to join the registry – basic information will be collected to help us better understand juvenile arthritis, other childhood rheumatic diseases and current treatments.



 You can also join additional research studies (optional) to help improve our collective knowledge and treatments – e.g. surveys, trials, specimen collections and data links.



Please visit <u>a3bc.org.au/ajar-faqs</u> to find out more and scan the QR code or click the link to register your details.



Link: bit.ly/3YGxEOe

Data custodian organisation: The University of Sydney This study has been approved by the Northern Sydney Local Health District Human Research Ethics Committee (HREC) – 2019/ETH10386 AJAR Flyer V1. 127-Feb-2023