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ARTHRITIS ACT E-NEWSLETTER

Issue 10 – October 2019

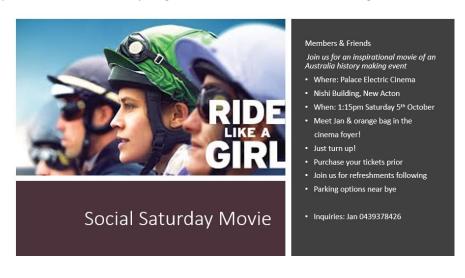
Hello members

Isn't it wonderful to finally have some warmth from the sun! I think everyone starts to feel better in themselves once the days start to get longer and brighter.

I know many of you are wondering where we are up to with the pool issues. I have been doing a lot of running around for ACT Health trying to locate other options for hydrotherapy on the southside and also working out how to implement the Nous report's recommendation that pool sessions have a higher level of supervision. As you can imagine the total costs of both these items was very hefty and I think came as quite a shock to ACT Health and the Minister. At present we are trying to work through to find an affordable solution, whatever that may be. I will continue to represent our case for needing to maintain the amount of capacity we have on the Southside. I think it's been important to point out to Government as well that structure changes such as the removal of codeine from the market and the ever growing population of Canberra have had a big impact in the need for hydrotherapy. Arthritis ACT is still contractually obliged to operate the same number of pool sessions as it was decades ago, when Canberra was a much smaller town, and the demographic of our city was very different. We hope that Government will continue to understand that hydrotherapy is a primary preventative health strategy, and should it become harder to access the ramifications on the health budget are enormous. At present the pool is slated to close at the end of November but as we well know this may yet change.

It is with sadness that I inform you all that our Office Manager of 10 years, Michael, has retired. For many of you Michael was synonymous with Arthritis ACT. We have greatly valued both his lived experience and his utter professionalism. He isn't going far – we'll still be seeing him at the pool. As part of the AGM we will be having a presentation to Michael in appreciation of all his has given to our organisation, and we hope as many of you as possible can be there.

AGM: Friday 18 October 12 Midday. Light lunch served. RSVP for catering 6251 2055







STRENGTH & BALANCE 2019

Registration for Term 4 now open!

Mondays	Balance 30	Strength & Balance	14th Oct—16th Dec
Kaleen	9.30am to 10.00am	10.30am to 11.30am	
Tuesdays	Balance 30	Strength & Balance	15th Oct— 17th Dec
Weston Creek	9.30am to 1/0.00am	10.30am to 11.30am	
Thursdays Tuggeranong		Strength & Balance *10.00am to 11.00am	17th Oct—19th Dec

Keep up your exercise and try our Strength & Balance Maintenance Classes. Enroll and attend for an extra 10 sessions throughout the term. Bookings essential.

Wednesday	Strength and Balance	
Bruce	8.30am - 9.30am NEW TIME!!!	
	11.00am – 12.00noon (FULL)	

To Register:

Please contact Arthritis ACT on info@arthritisact.org.au or phone 1800 011 041. Registrations are essential.

Prices:

Members: \$120 New Starter OR \$100 Continuing Non-Members: \$149 New Starter OR \$129 Continuing Balance30 Members: \$50 OR Non-Members \$79 Peer mentors are volunteers of Arthritis ACT and the ACT ME/CFS Society who have undergone training in how to support people who are living with chronic conditions. Mentors may be able to assist you in finding services and supports, or they may be a friend who can walk beside you as you walk your own journey with chronic illness.

If you would like to be able to meet up with someone who is more like your age, or has had similar difficulties, let us know and we can assist you to meet up with someone. Ph 6251 2055 to register your interest or email jan@arthritisact.org.au

Term 4 Yoga Class Dates

Arthritis ACT offers Yoga to improve muscle tone, better breathing habits, reduction of stress, better sleep, and a sense of well-being.

14 th October Bruce - Floor Yoga	16 th December	Monday 9:30 to 10:15 am	
14 th October Bruce - Chair Yoga	16 th December	Monday 11:00 to 11:45 am	
17 th October Pearce - Chair Yoga	19 th December	Thursday 2:30 to 3:30 pm	

Cost: Members: \$10 per session Non-Members: \$15 per session

Venues: Monday @ Building 18, 170 Hayden Drive, Bruce Thursday, @ SHOUT Offices, Collet Place Pearce

To register: Contact Arthritis ACT on info@arthritisact.org.au or phone 1800 011 041

A conversation for everyone: Advance Care Planning

An Advance Care Health Plan ensures your values and preferences are respected when you can't voice your decisions. This could be due to a stroke, a car accident or other health issue. Learn the steps to make a plan, tips for having the conversation about your wishes and find out who can help to get your plan in place.

Date: 10:00am – 12:00pm, Thursday 3 October 2019 **Venue:** Building 1, Pearce Community Centre, Collett Place, Pearce

Cost: FREE

RSVP: by Monday 30 September to karenjames@hcca.org.au or phone: 6230 7800. Light refreshments provided.

AIN REDUCING 'KMINA CRUTCHES' are available to trial at the Arthritis ACT office in Bruce.



These crutches remove pressure from the hands and wrists and distribute pressure evenly along the forearm. These are a comfortable alternative to normal crutches or walking sticks if you experience arthritis in your hands.

Call the office to come and trial these. You can also purchase the produce online or read more about them at: https://gonglcs.com.au/collections/products/products/kmina-crutches

Social Connections

Our peer mentors are very concerned about the lack of social connections and isolation that many of our community suffer. As a result they are looking into a number of initiatives including organising some movie catch ups, because many of us love to get out to a movie, but it's not always fun doing this alone!

When: Saturday 5th October (Final details to be emailed and posted on Facebook in the days before)

Where: Palace Electric Theatre
Acton (in the Nishi building)

Everyone is responsible for purchase of their own tickets

If there is interest, a catch up coffee or drink will occur after the movie.

No need to RSVP – just turn up and look for the crowd in the foyer!

Please contact Jan for more information jan@arthritisact.org.au

Tai Chi For Health and Falls Prevention 2019

Tai chi for Health and Falls Prevention is an 8 -week beginners program, designed to improve strength, flexibility and balance. This program aims to assist in reducing falls.

Venue: Kaleen Community Hall - 28 Georgina Cres, Kaleen

When: Monday 21st October-Monday 9th December

Time: 11.45 am-12.30pm

Members: \$40 per term Non Members: \$80

Venue: Building 18, 170 Haydon Drive, Bruce

When: Saturday 26th October—Saturday 14th December

Time: 9.30am-10.15am

Members: \$50 per term Non Members: \$90

Hydro Tai Chi

Venue: The Canberra Hospital- Yamba Drive, Garren

When: Wednesdays

Time: 9.00 am-9.45am

Cost: \$10 per class (WWX registration essential)



To Register: contact Arthritis ACT on

info@arthritisact.org.au or phone 1800 011 041



Arthritis ACT Facebook Groups Parenthood With Autoimmune Disease Support Group Hypermobile ACT JIA Parents Support Group Young Women's Autoimmune Friendship Group Request to join via Facebook or email AACT at info@arthritisact.org.au







GLA:D 2019 UPCOMING DATES

GLA:D°, or Good Life with Arthritis: Denmark, is an education and exercise program developed by researchers in Denmark for people with hip or knee osteoarthritis symptoms. It is run only by physiotherapists. The GLA:D website for further information is https://gladaustralia.com.au/.

GLA:D^o uses education and exercise to help with daily activities. You will work on strengthening your body, as well as learning to move correctly and manage symptoms to improve pain.

Where:

170 Haydon Drive Bruce ACT 2617

About the sessions:

- Twice a week for 6 weeks recommended for best results- please enquire for flexible options such as once weekly or a home based program.
- · Small group classes will run on Monday, Tuesday and Thursdays.
- There are 14 sessions in total, including two education sessions teaching you about Osteoarthritis and Exercise
- · Education session 1 is free for members to come and see what the program is about
- · An initial assessment is required with the Physiotherapist prior to commencing the program

Class	Dates	Time	Cost	
Initial Assessment	To be booked	To be booked	\$95	
Education 1	Monday 21 st October	1pm-2:30pm	Free	
Education 2	Monday 28 th October	1pm-2:30pm	\$40	
Education 1	Tuesday 12 th November	1pm-2:30pm	Free	
Education 2	Tuesday 19 th November	1pm-2:30pm	\$40	
	Mondays	10am – 11am	\$30 per class	
		11:30 am - 12: 30 pm		
Group Classes	Tuesdays	9am – 10 am	\$30- Member	
		8:30am-9:30am	620 Member	
	Thursdays	10:00- 11:00am	\$30- Member	
		11:30 am -12:30 pm		

If you have any further questions, please call 02 6251 2055 or email info@arthritisact.org.au For Non- Member prices, please contact the office on 02 6251 2055

ME/Chronic Fatigue Syndrome and Fibromyalgia Self Help Course



Learn practical skills for dealing with common problems of ME/CFS and Fibromyalgia in a supportive environment

Build skills and a support network in seven sessions over eight weeks

Tuesdays: 15 October - 3 December 2019 (includes a rest week)

10:30am - 12:30pm

170 Haydon Drive, Bruce

This course has been shown to improve health and wellbeing using scientifically proven self-management techniques

Pace yourself Minimise relapses Set realistic short term goals

Reduce stress Manage emotions Improve relationships

Hosted by trained facilitators with lived experience of these conditions

Cost is \$75/\$50 (society members), including book and refreshments



Peer Mentors are available to assist you!

Contact us now

ph: 6290 1984

email: admin@mecfscanberra.org.au

7

Syndra - Drop-in Meditation

Our next drop-in meditation night is on this Tuesday 20th August 2019. As usual we will be starting promptly at 7.00pm.

The meditations go for an hour. There are refreshments afterwards.

The venue is: The Tuggeranong Business Centre, 12 Kett Street Kambah. That's the first building on the right after the speed hump.

No need to book. \$15 at the door.

Future dates for your diary:

Tuesday 1st October 2019 Tuesday 19th November 2019 Tuesday 3rd December 2019

For all enquiries, please call or email me:
Ph. 02 6287 1710
michael@syandra.com.au
www.syandra.com.au

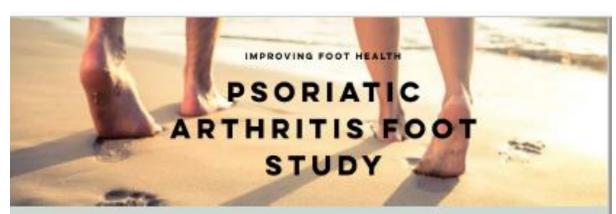
Looking for an exercise program tailored to your needs? Small Group Exercise Physiology Classes

Small group (groups up to 4 people) Exercise Physiology classes are offered on Monday's at SHOUT in Pearce and Wednesday's at Bruce with one of our EP's. These classes allow you the flexibility to come and go but also to have a tailored program that is just for you. They can include seated exercise, standing/balance exercise, and a quiet and calming atmosphere. Your program will also be regularly monitored and updated as you need.

Individual Exercise Physiology Programs

Individual assessments and planning for hydrotherapy programs can be undertaken at either our SHOUT Pearce location or Bruce office. These sessions can be claimed under the GP Management Plans or on Private Health insurance. An assessment is essential before a hydrotherapy session with your EP so that we can make sure all factors are taken into account when planning hydrotherapy. If going to a gym or exercising in another location is an important part of your health program, our EP's can assist you with this and can accompany you to your gym of choice.

For all Exercise Physiology support, please call 6251 2055 or email info@arthritisact.org.au for an appointment



INVITATION TO TAKE PART IN A NATIONAL SURVEY

TO FIND OUT ABOUT FOOT PROBLEMS IN PEOPLE WITH PSORIATIC ARTHRITIS



This research project is led by Kate Carter at Western Sydney University and is part of her PhD in podiatry.



Our research has shown that foot problems are common in people with psoriatic arthritis. Pain and swelling in the feet and ankles can make walking difficult and can greatly limit daily activities.



Little is known about the impact of foot problems from the perspective of people with psoriatic arthritis.



We need a better understanding of foot problems related to psoriatic arthritis so that we can help to treat it better in the future.



It is essential that we seek information from people with psoriatic arthritis to identify the most important and relevant concerns.



The survey asks how foot problems impact on daily life, footwear choice and the foot care needs of people living with psoriatic arthritis



TO TAKE PART, YOU SHOULD:

Be aged 18 or over
Have psoriatic arthritis
Have past or present foot problems
Live in Australia or New Zealand

Complete the survey online on www.psoriaticfootarthritis.com



or

Complete the paper survey, please contact Kate Carter at info@psoriaticfootarthritis.com to be sent a paper copy



This study has been approved by the Western Sydney University Human Research Ethics Committee. The approval number is H12973.

Research Survey — Foot problems among people with psoriatic arthritis

Considerable improvement in the assessment and treatment of foot problems related to psoriatic arthritis is needed and little evidence exists in this area. Keeping people on their feet is important for maintaining a normal daily routine, work, family and social life.

Western Sydney University researchers are seeking your help with new research into foot problems in psoriatic arthritis. With the right management, people with psoriatic arthritis might have the opportunity to minimise disabling foot pain and joint damage and this research will seek to identify what are the important issues.

The study is a survey to better understand the experiences of people with psoriatic arthritis related foot problems. By helping with this survey, you will be directly influencing the research agenda and raising issues that are important to people with psoriatic arthritis.

Help us to promote your views by completing our online survey!

To learn more about the study please visit our website: www.psoriaticfootarthritis.com

To participate in the survey click below:

Complete the survey



To be sent a paper copy of the survey, please contact Kate Carter at: info@psoriaticfootarthritis.com

WESTERN SYDNEY UNIVERSITY



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ACT Aged Care Navigators Trial: Supporting Access to Aged Care Services

The Aged Care Navigators Trial is funded by the Older Persons Advocacy Network (OPAN) to test different types of services and activities aiming to support older people learn more about Government supported aged care programs through the My Aged Care service system.

The ACT Disability and Aged Care Advocacy Service (ADACAS) is one of thirty organisations across Australia taking part in the Aged Care Navigators Trial.

Who is ADACAS?

ADACAS is a non-government human rights organisation providing free advocacy and information to:

- people with disability
- people experiencing mental ill health
- older people
- carers

How do the Information and Support Hubs work?

ADACAS Aged care expert staff and trained volunteers are available to provide support, and educate and assist people 65 years and over, by providing information and linkages with suitable aged care services in the ACT and surrounds. The purpose is to build knowledge and personal capacity by helping navigate the My Aged Care system; from information to assessment, through to receiving care.

Information and Support Hubs offer a range of activities including:

- workshops and information
- assistance accessing and navigating the My Aged Care website
- assistance filling My Aged Care registration forms
- outreach Drop- In
- group sessions & individual support sessions

Drop-in service - All Welcome!

When: Every Thursday 10:00am to 12:00am

Where: Multicultural Centre-Theo Notaris Room (180 London Circuit, Canberra City)

Cost: Free

Next Outreach- Queanbeyan

Venue: Country Heir Cafe

Dates: Thursday 3 October 2019-Thursday 10 October 2019 11:00am to 12:00am 2:00pm to 3:00pm

Cost: Free

Please make sure to check the ADACAS website <u>www.adacas.org.au</u> for upcoming activities in your area

More information

If you would like more information or book a group information session, workshop, or an individual session please call us at ADACAS on 02 **6242 5060** or email: adacas@acacas.org.au

You can also go to the Council of the Ageing website by following the link below https://www.cota.org.au/information/aged-care-navigators/

October Pool Update

Labour Day Monday 7th October – All Pools will be closed on this day due to the Public Holiday – TCH Users please speak to your supervisor to see if your session will be running.

Pool sessions remain very busy, especially at the University of Canberra Hospital Pool.

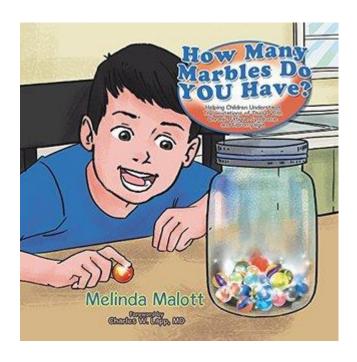
Some availability for midday sessions remains on Tuesday and Thursday's sessions in October but Wednesday, Friday sessions are fully booked. We ask that if you are booked into one of the popular sessions cannot attend you telephone the office to notify us ASAP to allow others to attend in your place. For those wishing to try and gain a spot in these sessions, we recommend that you telephone the office **on the day** to see if there have been any cancellations.

Space still remains at the Club MMM! Pool in Belconnen, with two sessions running, for those wanting to gain midday access to a pool on a Wednesday

Change to Tuesday and Thursday Sessions at TCH

Sessions held at TCH Pool on Tuesday and Thursday at TCH at 5pm – 5.45pm are now **Self-led** sessions.

Tuesday and Thursday Hydro Motion sessions are now held from 5:45pm-6:30pm.



How Many Marbles Do YOU Have?: Helping Children Understand The limitations of Those With Chronic Fatigue Syndrome and Fibromyalgia

by

Melinda Malott

"This is the book we've been waiting for—a story for children of parents with Fibromyalgia or Chronic Fatigue Syndrome. In fact, I plan to buy a copy for all my loved ones, so they'll better understand what my life is like. It all depends on how many marbles are in my jar each day—the perfect metaphor for explaining the unpredictability and the ups and downs of Fibromyalgia and CFS. At the end of the book, Malott writes, "a heart full of love is better than a jar full of marbles any day." Not only is this book informative and insightful, it's a heart full of love in itself.

—Toni Bernhard, author of How to Be Sick

A mom uses a brilliant jar-and-marble analogy to teach her son about her limitations related to chronic fatigue syndrome (CFS) and fibromyalgia. The book uses marbles, a toy all children are familiar with, as a measure of the mother's limited energy. Using a jar and some marbles, the author conveys difficult concepts in terms that children can understand. These concepts include taking preemptive rests to have more energy later, finding alternate ways to perform tasks that use less energy, and postexertional malaise. The concepts in the book are relevant to someone with one or both illnesses, and it can be applied to other physically limiting conditions as well. The book reminds the reader that although illness may limit a mother's activities, it never diminishes a mother's love for her children. The book is fun and yet realistic and will capture your child's heart."

This book appears to be only available as an ebook – check your favourite ebook seller.





The Therapeutic Goods Administration (TGA) is consulting with the public about increasing online access to medicine ingredient information. HCCA believes this is important information for consumers and we are preparing a submission to this consultation.

Background on TGA Consultation

Consumers need access to information about the ingredients in their medicines to make informed choices and avoid medicines that may not be suitable. These could be ingredients where allergies are an issue, or where consumers want or need to avoid particular ingredients.

In this consultation, the TGA is proposing to display the names of excipient, or 'inactive', ingredients present in a medicine in the public view of the Australian Register of Therapeutic Goods, which is available on the TGA website. This proposal is in response to consumer frustrations that they cannot easily access information about ingredients in their medicines through existing mechanisms (e.g. labels, consumer medicine leaflets or from companies supplying the medicines).

By making this information available online, the TGA hopes to give people with allergies better access to information about ingredients in a medicine anytime, even before they buy it. Access to this information could also help people compare different medicines and identify if a specific ingredient may have contributed to an adverse reaction.

<u>The TGA have provided a detailed proposal – click here to find out more.</u> The TGA are looking for feedback on their proposal and on how much ingredient information should be made public on the online Australia Register of Therapeutic Goods.

Next Steps – please consider providing your input!

If you would like to provide feedback to HCCA as part of our submission to the consultation process, please get in touch! You can contact Kathryn Briant at HCCA on (02) 6230 7800 or kathryn.briant@hcca.org.au by midday Tuesday 8 October.

Or, if you would prefer to give feedback directly to the TGA, there is also a quick <u>consumer survey</u> available.

Gut Health for Overall Health

FREE HEALTH SEMINAR

Find out:

- How good gut health affects your diseases and general health
- · What affects our gut health
- What to feed your gut bacteria for healthy outcomes

Time

7pm-9pm, Thursday 17 October 2019

Place

Building 1, Pearce Community Centre, Collett Place, Pearce

RSVP by Monday 14 October to 6230 7800 or karenjames@hcca.org.au







To RSVP or for more information on these seminars please contact Health Care Consumers' Association on 6230 7800 | karenjames@hcca.org.au