

Arthritis Matters



In this issue

A moment with Lucy Evans
Focus on Behcet's Syndrome
Fatigue and arthritis

Plus

Kidsflix
Research
What's on
...and more

Autumn Winter
Edition 2021

Arthritis
SOUTH AUSTRALIA

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For information and support

Arthritis Infoline

1800 011 041

Country Free Call

Arthritis Foundation of South Australia

A: 111A Welland Avenue Welland SA 5007

T: (08) 8379 5711

www.arthritisau.org.au

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President's Message

2020 presented many challenges for our members and supporters and for SA community as a whole. For the Arthritis Foundation of South Australia, like many small organisations, 2020 similarly challenged us.

The Board and staff of AFSA have been working hard to continue to deliver services to our community through this time. It has been pleasing to see the benefits of our move to Welland with access to nearby facilities and the continuation of our services from this new location.

In this edition of our magazine we are pleased to be able to provide a focus on less well known areas of arthritis. We are privileged to have people willing to share their stories with us and develop our understanding of all aspects of the impact of arthritis on people's lives.

To enable us to continue our work and support research into aspects of arthritis like those highlighted in the magazine, we rely on our many supporters in the community for their assistance, especially through donations.

Many of you have responded to our Pain Appeal and this is greatly appreciated. Currently Arthritis SA is part of the Telethon Lottery with other charities.



I hope you will take up the opportunity to be part of this.

"My thanks to my fellow Board members and Arthritis SA staff for continuing to manage through these challenging times. And my thanks to all of you who continue to support our work for the SA community. It is much appreciated."

Kind Regards,

A handwritten signature in black ink that reads "David Waterford".

David Waterford
Board President

Arthritis
SOUTH AUSTRALIA

Make a lasting impact

Research holds the key to more effective treatments of Arthritis. By remembering Arthritis South Australia in your will, you can play a role in finding a cure for these debilitating diseases.

If you would like to leave a gift in your will, please contact us at

08 8379 5711 or
info@arthritissa.org.au

CEO's Message

Welcome to a new year with Arthritis SA.

In 2021 we are continuing to support people living with arthritis in South Australia. The past year was difficult for many of us at a personal level. It was also a difficult year for small organisations dependent on fundraising. Some of you would have received mail/emails from us asking for donations to support Kidsflix activities and our Pain Appeal.

Thank you so much for your support. Your generosity enables us to continue to provide education and information to the South Australian community and to enable families and their children to attend our Kidsflix events.

I am pleased that we have been able to continue to support people living with arthritis in South Australia through our Infoline.

This remains an important source of support and information for many people. We have been delighted to see so many people attending our Hydrotherapy Program at Welland.

People have also come to Welland to attend our Arthritis mini-seminars with our Health Educator Lyn.

The rollout of the COVID-19 vaccine in 2021 provides the opportunity for more South Australians to feel comfortable about engaging in a greater range of activities than they thought possible in 2020.

Kind Regards,

Vicki Toovey
Acting Chief Executive Officer

MAKE YOUR HEART SING

TICKETS STILL ONLY **\$10** NOW ON!

TelethonSA Melisi Projects Home Lottery at The Square at Woodville West is your chance to win great prizes while supporting 23 amazing charities who each has their heart in SA.

Tickets available now from participating charities and [telethon.com.au](https://www.telethon.com.au)

MELISI PROJECTS the sq at woodville west RenewalSA Government of South Australia NEWSLOT Taste furniture Telethon SA

Licence No. M13964. Photos for illustration purposes only. Prize details and Terms and Conditions at [telethon.com.au](https://www.telethon.com.au)

Tickets for the Telethon SA Melisi Projects Home Lottery at the Square available from Arthritis SA

Research

UniSA are seeking adults aged 50+ with painful knee osteoarthritis to respond to a survey and participate in a one-hour phone interview.

What is the study about?

'This study aims to explore and understand your thoughts and beliefs about the experience of knee osteoarthritis. We are also interested in determining if we can refine some of the questionnaires to reduce any overlap in order to reduce burden on participants involved in future studies.'

Additionally, it's important to get your feedback on these questionnaire items, so that our future research can be as effective as possible.

This research is funded by the National Health & Medical Research Council of Australia. It involves collaboration with researchers from the University of Adelaide, Flinders University, the University of Melbourne, and Stanford University (USA).'

– From the participant information Statement

This project has been approved by the University of South Australia's Human Research Ethics Committee (Ethics Protocol 202377)

Participants will receive a \$20 Coles/Myer voucher for participating.

If you are interested in participating or would like more information:



08 8302 1896



<https://redcap.link/9bs4zj63>



brian.pulling@mymail.unisa.edu.au



Arthritis SA out in the community

**Adelaide Petanque
invites friends
of Arthritis SA to their
annual Quiz night on
the 8th May.**

This will be a low key, fun night
with games and prizes.

\$15 per head and a basket supper.

**Get in early with
your tables of 8!**

**If you are interested in
attending or would like
more information
please contact
Tina on 0422082600**

On Thursday 18th of February, Arthritis SA presented to the Glenelg Probus Members. The presentation was to inform and create awareness about the work Arthritis SA provides to the people of South Australia.

The aim of the presentation was to communicate our services and promote our Health Education seminars and resources we have available to assist people living with arthritis.

This is a newly designed presentation that has been developed collaboratively by the Arthritis SA team. It was purely designed to engage with community groups, build stakeholder relationships, and drive membership.

Feedback was very positive with many members engaging with us after the presentation had concluded. The Glenelg Probus group were highly interested in the presentation with many questions being asked at the end.

The group took home a variety of Arthritis SA resources including copies of the Arthritis Matters magazine, promotional flyers, and information resources.

Please contact the Arthritis SA office if you would like to organise a talk or presentation to your organisation or community group.

National news

My Healthy Bones

At the beginning of the year Osteoporosis Australia launched their new name and website 'My Healthy Bones'. The new site is designed to help people with osteoporosis take control of their condition. It aims to improve the bone health of all Australians and help everyone lead a fit and active lifestyle throughout their life.

It offers online a self-assessment to review risk factors for poor bone health as well as information and resources on a range of areas including:

- Rheumatoid Arthritis and Bone Health
- Calcium and Bone Health
- Vitamin D and Bone Health
- Exercise and Bone Health
- Osteoporosis Treatment and Bone Health
- Medical Conditions, Medications & Bone Health
- Breaking a Bone and Bone Health
- Glucocorticoids and Bone Health
- Coeliac Disease and Bone Health
- and many more.

My Healthy Bones provides simple and easy, up to date information and support to Australians living with osteoporosis and related conditions.

healthybonesaustralia.com.au

Osteoporosis

Bones lose density becoming weak and fragile, increased risk of break.

Osteopenia

Bone mineral density is lower than normal but not yet classified as osteoporosis



**Over
1,000,000**

The number of people
living with osteoporosis in
Australia



173,000

The number of broken
bones each year due to
poor bone health

Fatigue and Arthritis

Fatigue: A common symptom of living with arthritis

'Fatigue is a feeling of both physical and mental tiredness. It's often described as exhaustion or lack of energy that doesn't change even after a good night's sleep or plenty of rest.

There are many possible causes of fatigue including: disease activity, pain, disturbed sleep, muscle weakness, anaemia (low red blood count), depression, and side effects of some medications.

Tips to Help Manage Fatigue

1. Talk to your doctor

Let your doctor or Rheumatologist know if you feel your medications may be a contributing factor, or if you are concerned you may be anaemic. Sometimes small changes in treatment can make a real difference to how you feel.

2. Exercise

It might sound odd but, being physically active has been shown to be one of the best things you can do to help manage fatigue. The key to a successful exercise program is to begin gradually, listen to your body and build slowly.

A physiotherapist or exercise physiologist can provide advice and support to get you started and help you progress.



3. Aim for Good Sleep

Getting a restful sleep can be important to help manage fatigue.

There are many simple steps to try such as: Limit tea, coffee, soft drinks and energy drinks after dinner (for some people from mid-afternoon).

Relaxation techniques. Try different relaxation techniques until you find one that works for you. For example, you could visualize a restful scene or focus on your breathing.

There are also many free relaxation apps you can download.

Visit the Sleep Health Foundation website for more ideas -

www.sleephealthfoundation.org.au



4. Conserve energy

Another important aspect of managing fatigue is learning how to conserve your energy.

Pace yourself!

Plan and organize your activities so you make the most of your energy. Plan your day so you can alternate periods of activity with periods of rest.

When you know you have a large task to do (eg. prepare a meal, clean a room), plan ahead, and break the job into smaller tasks.

5. Protect Your Joints

Try to simplify tasks. eg. buy pre-cut vegetables and meat to make cooking simpler.

There are many gadgets and aids that can make daily activities simpler and less tiring. These aids can help to protect your joints by reducing the effort you have to put in. eg. tap turners, jar openers.

An occupational therapist can provide advice for managing activities of daily living and help with modifying your home or work tasks.

Fatigue can have a significant impact on everyday life.

Please contact our Information Line at Arthritis SA if you would like more information on managing fatigue.

 1800 011 041



A moment with... Lucy Evans

Relapsing Polychondritis – Lucy's story of living with a rare and invisible condition.

The Department of Health defines a disease as rare if it affects less than 5 in 10,000 people. Approximately 2 million Australians are currently living with a rare disease, and diagnosis often takes time due to the complexity of the conditions and doctors not often seeing them. The federal government has programs and initiatives supporting the treatment and management of rare diseases including a National Strategic Action Plan.

Lucy Evans is an advocate for Relapsing Polychondritis (RP), having been diagnosed with the condition after a 15-month search for answers around her mystery illness. Lucy would like to utilize her experience to raise awareness of some of the issues that are part of living with a rare condition.

Lucy is an incredibly strong, smart woman. Having spent many years as a commercial lawyer she is not afraid of a challenge but becoming chronically unwell in the prime of her life was the biggest challenge she has ever experienced. The impact on her career, family and social life has been huge.

In 2018, Lucy saw a number of specialists including an Ophthalmologist, Cardiologist, Rheumatologists, Haematologist, Ear Nose Throat Specialist and Gastroenterologist, but a diagnosis was not forthcoming.

It was not until Lucy developed chronic pain in her ribs and inflamed ears that a diagnosis became possible. Lucy was at an Ophthalmologist appointment and her doctor said her symptoms were similar to another patient, who had Relapsing Polychondritis (RP).

Lucy's experiences had made her proficient in researching medical illnesses. Lucy discovered someone in the US, Nancy Linn, who has RP and has developed an awareness program online. This was a lightbulb moment for Lucy as she could relate to everything Nancy expressed.

<https://raceforrp.org/about/rp-the-ride-of-my-life/>

Seeking a definitive diagnosis, Lucy travelled to London to see Professor David D'Cruz, a specialist in RP. The moment he told her his findings Lucy felt a huge sense of relief that she finally had a diagnosis. As Lucy explains, to be told yes, you have this serious rare condition was a very surreal experience. Looking back, Lucy realizes 15 months is a short time for a diagnosis of this condition, and she is grateful to everyone who helped her to get to that point.

Lucy read into issues around chronic illness and life changing events and discovered literature that she found beneficial. In particular 'Unseen the Secret World of Chronic Illness' by Jacinta Parsons and 'Any Ordinary Day' by Leigh Sales.

Lucy, mother to two young teenagers and supportive loving wife to her busy husband had a successful career in law academia at Flinders University.

Lucy realized she could not manage her complex condition, maintain her high-profile career and her family life. In 2019, she made the heartbreaking decision to give up her career to concentrate on her health and family.

One of the biggest challenges is not just living with a rare condition, but an invisible one. Lucy has set out to shine a light on the many challenges faced not just by herself but other Australians in similar circumstances eg. accessing medications that are not subsidized on the PBS. Lucy connected with Rare Voices Australia which is the peak body for Australians living with rare disease.

In February 2020, the Minister for Health the Hon Greg Hunt MP launched the 'National Strategic Action Plan for Rare Disease'.

An important aspect of the plan is to promote equitable access to treatment for Australians living with rare conditions. Having a national action plan for rare diseases is a positive step for improving diagnosis, treatment and research.

The plan was launched on World Rare Disease Day 2020 (February 28th). Lucy hosted a high tea to raise awareness around relapsing polychondritis, rare diseases, and funds to implement the plan.



Living with a complex, rare and invisible condition can pose many challenges.

We asked Lucy what advice she would give to others:

- Find a way to ride the waves of uncertainty.
- Be prepared to advocate for yourself.
- Educate yourself. It is easy to be overwhelmed and confronted. Seek out reliable sources of information.
- Lucy recommends keeping a pre-diagnosis symptom diary and document everything, including photos of physical symptoms. This will assist in your diagnosis and treatment plan.
- Find a GP you feel comfortable communicating with as it takes time to build a team. Your relationship with your GP and specialists is critical as well as with allied health providers. It takes a multidisciplinary team to manage a rare disease like relapsing polychondritis.
- If your support is limited reach out to good friends and family, support groups and associations like Arthritis SA. Lucy's husband and her teenage children have been an amazing support to her. She is so proud of the way her children have adapted to the changes and challenges in their lives. Lucy's close friends and extended family have also been a great source of support and she is very grateful to them.
- But be prepared for social changes and challenges as Lucy has found constantly having to say "No" to friends, eventuates in less invitations to social events.
- As Lucy says 2018 was very hard and an enormous life change, but she now reflects that, "it's not what you do that matters it's who you are as a person".

- Having an invisible illness can reveal a lack of understanding, and empathy and this can be emotionally very hard to deal with. People get on with their lives, and interactions can become somewhat superficial as people who are well meaning don't know what to say.
- Lucy is a naturally optimistic person and throughout her journey, she has remained positive. Working on the emotion helps balance out the physical challenges, finding the positivity in everyday and it helps accepting things she cannot change. As Lucy says, 'you get a quicker outcome with less impact, by focusing on a positive mind frame'.
- Mindfulness has been a powerful tool to assist in maintaining a positive mindset.
- Being proactive about your plan and reaching out for support is essential.

For further information visit these websites:

Rare Voices Australia
www.rarevoices.org.au

Relapsing Polychondritis Foundation
www.polychondritis.org

Arthritis SA would like to thank Lucy for sharing her personal story. We thank all of our supporters for sharing their stories with us.

The opinions and experiences relate to their specific experiences and may not be everyone's. Always discuss your arthritis or arthritis related condition with your health care team.

What is Relapsing Polychondritis (RP)?

RP is a rare condition that affects approximately 3-5 individuals per million people. RP affects both men and women. It can affect individuals of all ages, but mostly occurs in midlife.

It is a systemic inflammatory disease which can be potentially fatal. RP affects multiple organs but particularly cartilage such as ears, nose, throat and ribs. It commonly affects the eyes and skin too.

References:

Relapsing Polychondritis Foundation
www.polychondritis.org



Kidsflix

Thank you to all of our wonderful Kidsflix supporters.



Kidsflix events have begun for 2021. It has been so great to welcome children from the Sydney South Coast, Bankstown, and Adelaide South to our mornings of fun and entertainment.

Our special friends Winnie the Pooh, and Piglet made everyone feel welcome as they entered the cinemas. The excitement on the children's faces was fantastic as they posed for selfies and danced along to the music.

As the US film distributors are still holding back some of the major blockbusters, we gave attendees the choice of movies, with everyone loving Raya and the Last Dragon.

The Noarlunga Kidsflix event welcomed back Belinda from Cool 4 Kids and Emma the Clown from WCH.

A big thank you to our partners Hoyts and Wallis cinemas, Nippy's for providing us with drinks and Jonny's popcorn for the delicious South Australian made popcorn.

A big thank you also to all our valued volunteers who help make Kidsflix events a magical experience for children, parents and carers.

Thank you to all the families that sent our donors letters of thanks - without donors we would not be able to host these wonderful events.



A message from an attendee

Thanks so much. This was the first time my daughter has been to the cinema and I was so happy with how it went. With the sound lowered and the lights on, she was able to enjoy the film and not be overwhelmed by the normal environment at the movies.'

Thanks again,

Benita.

Focus on

Behcet's Syndrome

As part of our focus on rare conditions in this issue, this article takes a closer look at the autoimmune condition Behcet's Syndrome.

Behcet's Syndrome is named after the Turkish dermatologist Hulusi Behcet who first defined the condition in 1924. The syndrome causes blood vessel inflammation throughout the body.

It most commonly occurs in people from Mediterranean countries, the Middle East, and South East Asia.

Behcet's Syndrome is a chronic condition. The cause is unknown, and currently there is no cure. Both men and women are affected, and it develops between 20 and 30 years of age but can occur at any age.

The condition can be difficult to diagnose as there are many and varied symptoms and these may come and go. (ie relapse).

As with some other autoimmune conditions there are no specific tests to confirm diagnosis. The most common symptom is recurring mouth ulcers.


Other symptoms can include:

- eye inflammation
- blood clots
- skin lesions
- joint pain and swelling
- fatigue and bowel problems.



The syndrome causes
**blood
vessel
inflammation**
throughout the body



Both

men and women
can be affected by the condition

 **20-30
years old**

The age where the condition
develops but it can occur at any age

Because Behcet's Syndrome can affect many different parts of the body a team of doctors from various specialties such as a Rheumatologist, Ophthalmologist, or Dermatologist may all be actively involved in treatment and management.

Living with a rare condition can present many challenges. Access to the internet has made it much easier for people to find information and support and connect with others living with the same condition from across the world.

But not all of us use the internet and it's not always easy to know what is reliable or even where to find information online.

If you or someone you know is living with a rare form of arthritis and you would like help to find reliable information contact us on the Information Line.

Information Line
1800 011 041
Or email info@arthritissa.org.au

Celebrating a milestone

Southern Arthritis Friendship and Support group celebrates 25th birthday

On Wednesday 27th of January, Arthritis SA was invited to celebrate the Southern Arthritis Friendship and Support group's 25th birthday.

It was a great afternoon, thank you to everyone who attended to share this amazing milestone, and a big thank you to Loretta who coordinated a beautiful afternoon tea.

Thank you to Katrine Hilyard MP who came to talk about how important support groups are in the community.

SAFS (Southern Arthritis Friendship and Support Group) Group meets every second month, on the last Wednesday of the month, at the Christies Beach Sailing Club, Esplanade, Christies Beach.



Health Services

Out and about in regional SA

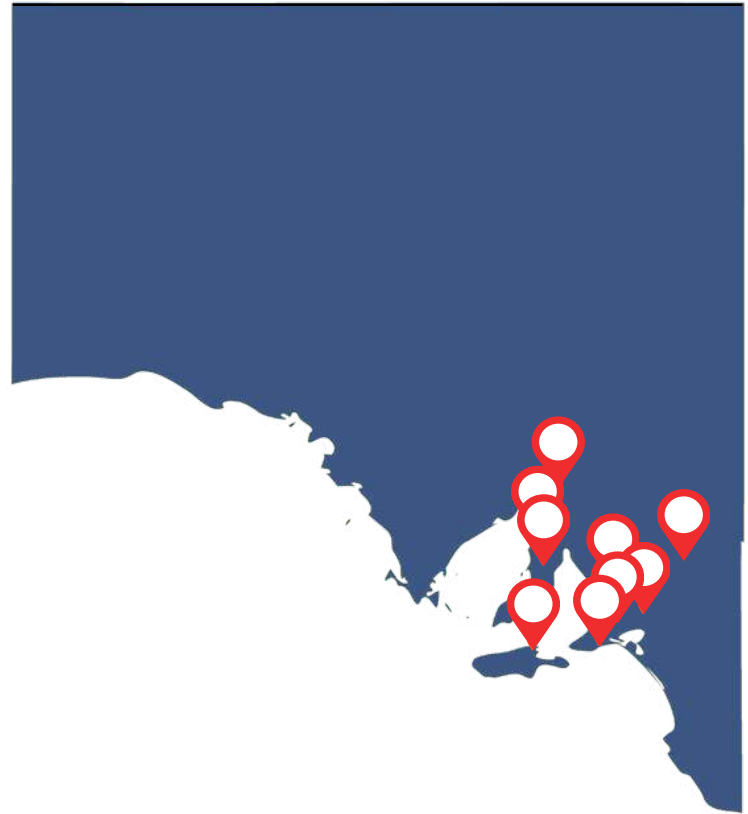
As part of recent grant funding from Country SA PHN, the Health Services team has been visiting a number of regional towns in South Australia.

In February, they ran a very successful workshop with the Mens Shed at the Maitland Community Centre. It was a great session and a fantastic way to kick off the 2021 regional workshops. We visited Port Pirie in March for another great session at the GP Plus, we will be in Waikerie in May.

In May and June we will be continuing our previously very successful association with the University of the Third Age, with talks planned for their groups in Gawler, Murray Bridge, Strathalbyn, and Victor Harbor.

We have also had the opportunity to provide workshops to a number of health care professionals including in Port Pirie, Wallaroo, Kangaroo Island, and the Riverland.

COVID has seen changes in attendances and operations for many community groups. While this has meant that some previously planned sessions have now been cancelled and many events rescheduled we would like to thank all of the individuals and groups involved with our events for their continued support.



We will be in the Riverland on the 18th-20th of May. Check our website for information on upcoming workshops.



What's on

Arthritis mini seminar series

Week 1 - 10 Steps for Living Well With Arthritis - An Introduction

Thursday 5th August - 10:00am - 12:30pm

A general introduction to the most common types of arthritis. Learn about what is recommended and resources available to support you.

Week 2 - Understanding Osteoarthritis & Staying Active

Thursday 12th August - 10:00am - 12:30pm

Learn about osteoarthritis, its causes, what is recommended. Come and hear about what types of exercise are beneficial for arthritis.

Week 3 - Maintain Your Well-being - Balancing Your Life & Making Food Choices That Count

Thursday 19th August - 10:00am - 12:30pm

The effects of arthritis are not just physical they can impact your mental wellbeing and how you live everyday life but there are strategies that can help.

Week 4 - Techniques For Coping With Ongoing Pain

Thursday 26th August - 10:00am - 12:30pm

An interactive workshop where you will learn about simple tips to help you cope with ongoing pain.

All sessions will be held at the Arthritis SA office at 111A Welland Avenue Welland SA 5033

Free for members - \$10 per session for non-members



Word Find

Frost	Leaves
Blanket	Yellow
Storm	Thunder
Fireplace	Hail
Rain	Chill
Tea	Orange
Lightning	Cold
Cozy	Autumn
Winter	

Words may be
backwards, forwards,
sideways, diagonal, or
up and down

HYDRO FOR ARTHRITIS

**IMPROVE YOUR STRENGTH,
FLEXIBILITY AND BALANCE**

Why hydro?

- Warm water helps muscles relax and makes movement easier and more comfortable
- Anti-gravity environment
- Provides natural resistance for strength building
- Provides natural compression to help decrease swelling and improve circulation

Call 8379 5711 for enquiries and to secure your place


How you can help others living with arthritis

You make a difference every time you donate. Please help by donating today.



Directly into our bank account using your Arthritis SA contact ID:
BSB: 035 212
Account: 220101



Online using our website:
 arthritis.org.au

To contribute by credit card, cheque or money order, please complete the form below and return.



My Contribution

\$

☐

\$50

☐

\$100

☐

\$500

☐

Monthly

☐

Annually

☐

One-off

Credit Card Number Expiry /

Card Holder Name

Signature

Contact ID:

☐

I would like my receipt via email
Saves money and paper!

☐

I would like my receipt via post

☐

I would like details about making a gift in will

Personal Details

Name

Address

Suburb

Postcode

Phone Number

Email



Arthritis SA is a registered charity (Licence No. CCP2463) all donations over \$2 are tax deductible



Your donation is
much appreciated!

Thank you David Waterford
Board President

Other ways to help:

- Fundraise for us at work
- Set up an online fundraiser
- Tell your friends and family
- Follow us on social media