

## Providing

reliable and up to date information to improve the understanding of arthritis and osteoporosis

## Promoting

healthy lifestyles and self-management to optimise health

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# **joinNTed** **Arthritis & Osteoporosis NT**

**October 2021**

## At the Seniors Expo

*Saturday 4<sup>th</sup> September at Marrara*

Hilary and Margaret ready to share information and materials:

a wide range of booklets produced by Arthritis Australia; osteoporosis information; various flyers and brochures relating to self management activities and community groups for fun activities!



## Palmerston Support Group news

The Group plans to celebrate their 25<sup>th</sup> Birthday with a public display of their regular meeting exercise routine, and then enjoy a special cake donated by MLA Marie-Clare Boothby whose Community Meeting Room we use for our meetings.

The goal of the Group is to support fellow arthritis sufferers, encouraging new members and supporting our friends as they age. These days, meetings start with a simple chair-based exercise routine using the AONT Stretch Breaks brochure, well received and fun. Regular raffles continue, with MLA Boothby donating a \$20 gift card at Target.

Among special events are Christmas lunches at a local venue and sometimes luncheons for members' birthdays.



*(continued on page 5)*

## Membership renewals



to those who have responded to earlier renewal notices, and of course to those who renewed before the end of the financial year. Continued support from members is much appreciated. Special thanks to all those who have kindly included a donation with their membership payment.

## Finding your way around Aged Care services with the Aged Care Navigator

COTA NT's Aged Care System Navigators, Janet Brown in Darwin and Debbie Pepper in Alice Springs, are available for individual meetings as well as group information sessions.

They are particularly reaching out to people who are having difficulty in accessing or understanding:

- ◇ the My Aged Care system,
- ◇ the My Aged Care website or
- ◇ using the 1800 phone number for any reason.

People who may be having difficulties include those unable to access or use a computer or 'smart' mobile phone, people from a multicultural background, indigenous people, people with hearing or seeing difficulties or disability, those who live rural or remote areas, are isolated, homeless (or at risk of), identify as LGBTI or Veterans.

For further information phone COTA on 8941 1004 during their office hours: Monday to Friday 9:00am to 2:30pm.

Thank you to the Northern Territory Government Community Benefit Fund - Minor Community Grants for much needed support.

Storage cupboard and two computers: essential for the efficient conduct of business, and appropriate storage for materials and records.



# Notice of Annual General Meeting

Saturday 6<sup>th</sup> November 2021

Commencing 2:30 pm

To be held at our office,

Shop 18 Rapid Creek Business Village

## AGM Order of business

1. Consideration of accounts and reports of the Board
2. Election of new Board members
3. Any other business requiring consideration by members.

All positions become vacant at the AGM and elections are held for the following positions:

### *Executive*

- ◇ President
- ◇ Vice President
- ◇ Secretary
- ◇ Treasurer



### *Board members - non-executive*

- ◇ A minimum of two and no more than ten 10 ordinary office holders.



Our Constitution provides for the Public Officer to be appointed from one of the serving Board members.

The Board now has three non-executive members, one having joined at the September Board meeting. A very warm welcome to Ruth Quinn!

While there has always been sufficient experience and skills on the board to ensure we meet all our Service Agreement and legal obligations, it would be wonderful to have more representation from our membership, to ensure we remain in touch with your needs and expectations. Currently, the Board meets on the third Wednesday of each month at 4:00pm, with days and times negotiable according to availability of genuinely interested prospective board members. Meetings usually finish by 5:30pm.

## News from Arthritis AUSTRALIA

Australians living with psoriatic arthritis can now become active and informed participants in their journey with the disease through a new online hub, launched 31<sup>st</sup> August by Arthritis Australia. Those engaging with the free hub **MyPsA** at the website [www.mypsoriaticarthritis.org.au](http://www.mypsoriaticarthritis.org.au), will be able to build individually tailored profiles, access customised information about their condition, and link with relevant support services.

Psoriatic arthritis is an autoimmune condition which causes pain and swelling in the joints. While not widely reported on, psoriatic arthritis affects around 200,000 Australians. Three out of every 10 people with the skin condition psoriasis develop psoriatic arthritis.

“MyPsA is a vital tool for helping those living with psoriatic arthritis to get a greater depth of knowledge on how to manage this complex condition,” said Arthritis Australia CEO Jonathan Smithers.

"Along with consulting regularly with their rheumatologist, people with psoriatic arthritis should also have easy access to reputable sources of information so they can learn more about their condition, and MyPsA can offer them just that," said Professor Susanna Proudman, a rheumatologist and Medical Director of Arthritis Australia.

## COVID-19 Vaccination message from Scleroderma Australia President Amanda Lawrie-Jones

“... the simplest advice around not only protecting yourself, but your family, friends and community is to speak to your rheumatologist or GP and book yourself in as soon as you can. I am very proud to say that I am fully vaccinated and that I have a sense of duty of care not only to protect myself but to protect others. Thank you to everyone who continues to support us in our scleroderma community, and we do hope to see you all soon.”

**- from Scleroderma Australia's September newsletter**



*Continued from front page*

## **Palmerston Arthritis Support Group - a bit of history**

The Group had its first meeting on 21<sup>st</sup> October 1996 with four members, soon increasing to 15, with Anne Jansen as the first convener. Anne held this position for 5 years. The meetings started with a joke from Greg Wilson and sometimes followed with a sing along. Doreen Walton stepped up as Group treasurer in 2007, doing a fantastic job for many years until her own health concerns took priority. Over the years, guest speakers included representatives from NT Health, Grow, Anglicare, podiatry, pharmacies, physiotherapists and natural therapy groups etc.

Having joined AONT in 2001, and the Support Group a few years later, Sylvia Bugg took over as Group convener in 2005. As a great letter writer and record keeper, Sylvia usually contacted potential guest speakers by mail, as was all her correspondence with AONT. Sylvia continued this work for 12 years until retiring in 2017. By the time of the Group's 20<sup>th</sup> birthday in October 2016, Sylvia was still sending out numerous get well cards to Group members and carefully documenting all the meetings. For her tireless support Sylvia had been awarded Honorary membership in 2010, as had Doreen.

Anne Coutts, a retired nurse specialising in aged care, joined the Group in 2015 at the invitation of then President Beth Harvey, tactfully assisting Sylvia as needed. At this stage there were 10 members but medical appointments etc often took priority. At times there were suggestions to close the Group, due to declining numbers, but members have always been adamant in continuing their friendship. As a tribute to her friend Beth, Anne remains committed to continue the good work in supporting the Group. It has continued with some members from the early 2000's and now thanks to Anne's networking and advocacy, there are new faces among the regular members.

In recent times guest speakers included representatives from Care Flight, Victims of Crime, Aged Care etc. Occasional craft mornings have been popular and High Teas hosted by Jeanette Shipp were a huge success - something really special. As well as now being the Support Group convenor, Anne is also a member of the Palmerston Senior Advisory Committee representing the Arthritis group and keeping the Support Group up to date with council events.

New faces are always welcome! The Group meets regularly at the Brennan Electorate Office, Palmerston Shopping Centre (opposite Target) on third Monday of each month at 10:00 am. Come along!!

*But no meetings in December or January, reconvening on 21st February.*

## **Be active: don't let a bladder or bowel problem hold you back.**

For optimum management of arthritis, osteoporosis and many other chronic health conditions, including chronic pain, we are encouraged to exercise and be physically active as possible. But sometimes this is not easy...

**Pelvic floor muscles tend to get weaker as we get older.**

***But the good news is***

**Pelvic floor muscle exercises can help strengthen them at any age.**



Find out how to get back in control

**1800 33 00 66**

**[www.continence.org.au](http://www.continence.org.au)**

An Australian Government Initiative managed by the Continence Foundation of Australia

## **How do I know if I have a pelvic floor problem?**

Common signs & symptoms of a problem with your pelvic floor include:

- ♦ accidentally leaking urine when you exercise, laugh, cough or sneeze
- ♦ needing to get to the toilet in a hurry or not making it there in time
- ♦ the need to go frequently go to the toilet
- ♦ finding it difficult to empty your bladder or bowel
- ♦ accidental loss of faeces or wind
- ♦ a prolapse
  - ⇒ in women, this may be felt as bulging in the vagina, or a feeling of pulling, dragging or drooping down
  - ⇒ in men, this may be noticed as a bulging coming out of the rectum, a feeling of needing to use your bowels but not needing to go
- ♦ pelvic pain
- ♦ pain during sexual intercourse
- ♦ poor sensation or loss of bladder control during sexual intercourse



*Adapted from [www.pelvicfloorfirst.org.au](http://www.pelvicfloorfirst.org.au)  
with thanks to the Continence Foundation of Australia:*

The following information is an extract only from the “Frequently Asked Questions” (FAQ) sheet developed by Arthritis Australia, on the current Tocilizumab (Actemra) shortage. 14 September 2021



## **Tocilizumab (Actemra®) shortage**

There is currently a global shortage of tocilizumab (Actemra®). As a result, the supply of tocilizumab products in Australia is currently limited.

*If you or someone you care for uses tocilizumab, contact your rheumatologist or prescriber as soon as possible about your treatment.*

### **Frequently asked questions**

#### **Why is there a shortage?**

The shortage is due to increased global demand for tocilizumab for use in people who are severely ill with COVID-19.

#### **Who is affected?**

Anyone who is taking tocilizumab is likely to be affected by the shortage. In Australia, tocilizumab is used to treat children and adults with the following conditions:

- ◇ rheumatoid arthritis (RA)
- ◇ systemic juvenile idiopathic arthritis (sJIA)
- ◇ polyarticular juvenile idiopathic arthritis (pJIA)
- ◇ giant cell arteritis (GCA)
- ◇ cytokine release syndrome (CRS).

*(continued over page)*

**Men's Health Pitstop - for a health check, information & advice to promote and encourage men's health and wellbeing.**

*Brought to you by Cancer Council NT*



**Thursday 4th November  
10:00am to 3:00pm**

**at  
Tennis NT  
1/9 Abala Road, Marrara  
0812**

For more information  
please contact Cancer  
Council NT on 8944 1800  
[nt.cancer.org.au](http://nt.cancer.org.au)

**The Arthritis  
Foundation of the  
Northern Territory Inc.**  
Trading as  
**Arthritis &  
Osteoporosis NT**  
ABN 67 099 326 608

*Patron:*  
Her Honour the Honourable  
Vicki O'Halloran AM  
Administrator of the NT

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*We are open:*  
9:30am – 2pm  
Monday to Thursday  
(excluding Public  
Holidays)

**Staff**  
*Administrative Assistant*  
Deirdre Moldenhauer

*Accounts*  
Natalie Valastro

**Board**  
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Vacant  
*Vice President*  
Margaret Murray  
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*Treasurer and Public  
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Ruth Garden  
*Non-executive  
Board Members*  
Anne Coutts  
Amin Islam  
&  
Ruth Quinn  
(Appointed 22 Sept 2021)

## Tocilizumab (Actemra®) shortage

(Arthritis Australia information sheet, continued  
from previous page)



Other questions & answers include:

- ◇ *How long is the shortage expected to last?*
- ◇ *Which products are affected by the shortage?*
- ◇ *What steps are being taken to manage the shortage?*
- ◇ *What will happen with my treatment?*
- ◇ *What alternative treatments are available?*
- ◇ *What if I have already tried 3 or 4 biologics that have not worked for me?*
- ◇ *What if my pharmacist doesn't have stock?*
- ◇ *If I need to change treatment, what will happen if I don't do as well on the new treatment?*
- ◇ *If I don't do well on the new treatment, will that affect my future eligibility for biologics?*
- ◇ *Will I be able to go back to tocilizumab when supply returns to normal?*
- ◇ *Will I be able to stay on the new treatment if that works for me?*

**The full FAQ sheet is available at the AONT office in Rapid Creek for those people affected by this shortage. Arthritis Australia will update this sheet as new information comes to hand.**



Margaret ready for visitors to our stand at the Seniors Expo.