

Ankylosing Spondylitis Victoria Inc

Annual Report 2025

Our Purpose

Ankylosing Spondylitis Victoria Inc peer support group is an organisation of people who wish to improve knowledge of AS and the ability to manage the condition. Our group embraces the goals and objectives of people and families living with Ankylosing Spondylitis.

Our Mission

1. Provide a forum for the exchange of information, ideas and experiences.
2. Distribute information to patients and healthcare professionals on Ankylosing Spondylitis.
3. Provide educational events, workshops and seminars on Ankylosing Spondylitis.
4. Co-ordinate and interact with local, interstate and international Arthritis and peer support groups including participation in their events and activities.
5. Arrange social events and activities, for our group members, family and friends.



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Presidents report 2025

Welcome to the 2025 annual report, our twentieth year of operations.

Online sessions have been well attended by members and general public with queries on all things Ankylosing Spondylitis (AS).

On May 10th we held World AS day lunch at Ringwood RSL with new and current members we joined the online International Spondyloarthritis Summit webinar, provided by ASIF and Spondyloarthritis Association of America, over two days in early May.

During July, we held our Annual social meet up at Rosstown Hotel in Carnegie which was well attended by members.

Rasul Family (AS Vic member/volunteer), Shayne van der Heide (vice President) and I presented AS patient lived experience "I am not a condition" talks at Monash University for first year Medical students. In addition, Rosemary Ainley (AS Vic member, YWASG and CreakyJoints Australia leader) presented discussion on "Soft Skills are the hardest" about communication with our health professionals and clinicians. Our thanks to Dr Nadida Kachkouche in arranging these talks with first year General Practice students.

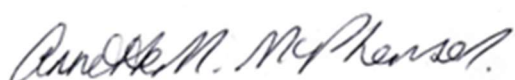
Young Women's Arthritis Support Group coffee and chat sessions in Bendigo continue with the support of Dee Lynch (AS Vic Bendigo Area Committee Member) with new members joining over the past year.

Our involvement in MSK community research, via ANZMUSC musculoskeletal (MSK) clinical trials network and now includes involvement in MSK clinical trials. Throughout the year we participated in research and projects as part of MSK Health Australia, Arthritis Australia, and Australian Frailty network.

Shayne van der Heide and I have been involved with ASIF during the year, with interviews articles and workshops. ASIF have updated their online resources AS and axial spondyloarthritis(axSpA) patient organisations.. During the year Shayne van der Heide was involved in a series of podcasts "Patient PrepRheum" with our colleague, Naomi Creek at CreakyJoints Australia. Along with rheumatologist Dr Arupam Raman and other MSK patients, the discussions were centred around management of co-morbidities along with their axSpA.

Lastly, I thank our team of Committee members and volunteers, who have been very active over the year.

The Committee thanks our members and associates for their ongoing support.



Annie McPherson. President 15/07/2025

*Research:
Patient advocacy*



Treasurers report 2025

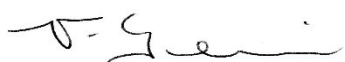
AS Victoria holds \$16,212 total assets at 30 June 2025, comprising

\$2,939 in cash at Bank, \$13,273 in term deposits.

We have 62 registered members, 22 are complimentary being Health Professionals,

Volunteers and former Committee members. Our Facebook followers now number 1206.

We look forward to another successful year for 2025-26.



Vicky Genius Secretary / Treasurer 13/07/2025

SCHEDULE 1

(Regulation 15)

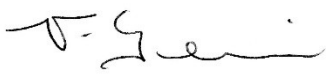
FORM 1

Associations Incorporation Act 1981 Sections 94(2)(b), 97(2)(b) and 100(2)(b)

ANNUAL STATEMENTS GIVE TRUE AND FAIR VIEW OF FINANCIAL POSITION OF INCORPORATED ASSOCIATION

We, Vicky Genius, and Adam Collard, being members of the Committee of “Ankylosing Spondylitis Victoria Inc”, certify that –

The statements attached to this certificate give a true and fair view of the financial position of “Ankylosing Spondylitis Victoria Inc” during and at the end of the financial year of the association ending on 30th June 2025

Signed: 

Vicky Genius
Dated: 10/07/2025

Signed: 

Adam Collard
Dated: 10/07/2025



Social Events



The immune system protects us from all sorts of nasties – bad. Our genetic studies highlighted the importance of the cytokines (tiny, invisible, though immune to some but a few) in order to do IL-23 and IL-17 in AS. Inhibition of IL-17 has proven so effective that the immune system has developed really complex and so time therapy is early clinical trials, demonstrating that this is not the worst way of distinguishing good from bad, or harmless from important drivers of inflammation in AS. Tissue studies have been helpful. Obviously this works well but in the case of infection taught us lots about the cells producing and responding to these or causes or widespread inflammation and subsequently the cytokines. But we still don't understand why they are produced immune system goes wrong. In AS, the immune system attacks in the first place. To investigate this we've based our focus on the body's own cells and tissue. We know that cytokines can travel the gut.

ponents of the immune system called cytokines. Cytokines are like messengers of the immune system, they allow one White, at first glance, investigating the role the gut plays in AS cell to communicate with other cells to thousands or millions of cells. It's a bit like a network of tiny messengers that's not just a local boss of other cells. It's a bit like if you stand in front of a very and scientific logic to justify it. The co-existence of AS and gut bugs and every group of people and try to speak to them, you inflammation has been known for some time and between 5 could either talk to each other individually and robustly (10% of AS patients develop clinically diagnosed inflammatory and probably more not on speaking to any, or you could use a whole disease (IBD), and a further 70% of AS patients develop irritable bowel to every your message a long way with little effort, subclinical gut inflammation. In reactive arthritis (ReA), a type of immune cell sense something is wrong it can release members of the SpA family, inflammatory arthritis sometimes lots of cytokine molecules that float through the blood system develops following gastrointestinal infection with particular to influence of other cells and then to what's happening, bacteria, indicating that inflammation in the gut may influence

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Astretch Newsletter

AS Victoria Inc Financial Statements	2025 Year	2024 Year
ACCOUNT Balance (previous year)	\$16,469	\$16,563
Add Income		
Membership fees	\$0	\$0
Donations From Membership	\$20	\$40
Donations from Events	\$119	\$87
Grants & Other DHHS	\$50	\$0
Seminar Income	\$0	\$0
Interest	\$407	\$191
DVD Sales	\$0	\$0
Total	\$596	\$318
Less Expenditure		
Postage	\$0	\$0
Printing	\$0	\$0
Ink Cartridges	\$0	\$0
Stationery	\$0	\$0
PO Box / Web Site	\$607	\$174
Meeting Costs	\$0	\$0
Meeting Costs/Catering	\$0	\$0
Subscriptions	\$246	\$238
Gifts	\$0	\$0
DVD/Booklet Purchases	\$0	\$0
Miscellaneous	\$0	\$94
Total	\$853	\$412
BALANCE AT BANK	\$16,212	\$16,469
Bank Reconciliation		
Cash at bank	\$2939	\$8,583
Term Deposits	\$13,273	\$7,867
PayPal	\$0	\$19
Unprocessed payments	\$0	\$0
BALANCE AS ABOVE	\$16,212	\$16,469

*Coffee and Chat meetings
joining with YWASG*



Promotion of Warm Water Exercise



Welcome to our 20th Year

Read the full text at - www.asvictoria.org
(Bottom Left hand side of the page)



Over 20 years of operation supporting the Ankylosing Spondylitis community. Ankylosing Spondylitis (AS) is a chronic inflammatory disease of the spine and other joints. It is a rare condition, affecting approximately 1 in 1,000 people. AS is a chronic inflammatory disease of the spine and other joints. It is a rare condition, affecting approximately 1 in 1,000 people. AS is a chronic inflammatory disease of the spine and other joints. It is a rare condition, affecting approximately 1 in 1,000 people.

Annie McPherson – President



We celebrate 20 years supporting the Ankylosing Spondylitis (AS) community and move into our 21st with a dedicated team of volunteers and all of you—our wonderful members. When we began in May 2005, we were a small team. Since then, more than 19 people have served as committee members. Membership has shifted from 84 in 2010 to 62 today, while our online reach has grown to 1,206 Facebook followers. This reflects a wider trend across peer support groups as social media becomes central. Since the pandemic, we have waived membership fees in line with other organisations. We now focus on social lunches, online chats, e-newsletters, and social media posts to keep our community connected. We also provide support and resources to patients, social workers, physiotherapists, and rheumatology clinics. A key activity remains medical education. Our members with lived experience of AS regularly contribute at Monash, La Trobe, and Melbourne Universities, as well as at professional conferences and scientific meetings. We also contribute to consumer guidelines, pain studies, and musculoskeletal publications with Musculoskeletal Health Australia, Arthritis Australia, and ANZMUSC. Our strong link with the Ankylosing Spondylitis Group of Queensland enables production of our e-newsletter AStretch, which shares patient stories, exercises, research, events, and activity reports nationwide. Finally, our long-standing committee members have added reflections on their involvement below. We look forward to the next 10 years with you and our AS community.

Dee Lynch – Committee Member / North Central Region Representative



I was in my late 30s when diagnosed with Ankylosing Spondylitis (AS). I sought advice from AS Victoria's President, Annie, who explained the condition, shared ways to live well, and even taught me to self-inject biologics, which helped reduce symptoms. Being diagnosed with a strange-sounding arthritis felt isolating, but joining a peer support group was vital for my physical and mental health. Members are diverse and at different stages in their AS journey, so we celebrate small wins and empathise together. Living in regional Victoria, I often attend meetings online—usually from my couch with my pug by my side—while also travelling to Melbourne for social events. The group participates in international research, conferences, and education for health professionals, which provides us with valuable information and chances to contribute to studies. Soon after joining, I asked to become more involved. I joined the Committee and later became a regional representative for both AS Victoria and the Young Women's Arthritis Support Group, so I can provide the same support I once received.

Shayne van der Heide – Vice President



In my twenties, I had severe pain in my lower back and hips. Despite years of medical visits, no diagnosis was made. Living in a small rural town limited access to specialists, and it wasn't until my early thirties—seven years later—that I was finally diagnosed with AS. I had never heard of the disease, so I relied on my own research. For years I managed alone, but moving to Melbourne in my forties changed everything. I discovered AS Victoria Inc. and, for the first time, met others who truly understood. The support was life changing. Not long after, I joined the Committee, and 14 years later I now serve as Vice President. I support newly diagnosed patients and am passionate about helping others navigate their AS journey. In recent years, I've taken part in international research and projects with the Axial Spondyloarthritis International Federation (ASIF), often joining global meetings at odd hours. Today, I manage AS with biologics and regular exercise, especially cycling. Through AS Victoria, I was able to ride the first two legs of an awareness and fundraising ride from Melbourne to Darwin—a deeply rewarding experience.



World AS Day Lunch Ringwood RSL in May – Michael Feehan, Annie, Shayne and Rasul



Consumer Advisory Group

The CAG is composed of volunteers with lived experience of MSK disorders and a keen interest in shaping research. The group provides a mechanism for consumer input on ANZMUSC clinical trials and other activities undertaken by the network.



Ms Annie McPherson
Chair - CAG



Mr. Geoff Ryan AM



Dr. Danielle Berkovic



Mr. Gary Cantwell



Helpful Articles- Online Lectures
Webinars- Peer Support Group Host
Supporter of Research

Committee Members of AS Victoria Inc 30 June 2025

Adam Collard (Gippsland Region Representative)

- Member from 2006, lives in Korumburra
- SGASG convener and Community representative
- Community Volunteer

Annie McPherson (President)

- AS Victoria Inc Co-Founder and member from 2005, lives in Kew
- Retired IT- Business Analyst
- Patient advocate and MSK research Consumer representative

Dionne Lynch (North Central Region Representative)

- Member from 2014, lives in Bendigo
- Local Government employee
- Community volunteer

Maria Makris

- Founding member from 2005, lives in Doncaster East
- Retired Secondary Teacher
- Community Volunteer

Shayne van der Heide (Vice President)

- Member from 2015, lives in Boronia
- Tertiary Educator/ Manager
- SES & St John Ambulance Volunteer

Vicky Genius (Secretary/Treasurer)

- Member from 2011, lives in Northcote
- Retired Finance employee
- Community Volunteer

AS Victoria Inc has support from and interaction with many organisations and individuals these are our main connections

- ARA – Rheumatology Health Professional Special Interest Group
- Ankylosing Spondylitis Group of Queensland
- Arthritis Australia
- Austin Health Spondylitis Clinic - Dr Lionel Schachna (Rheumatologist)
- Australia New & Zealand Musculoskeletal Clinical Trials Network (ANZMUSC)
- CreakyJoints Australia (CJA)
- Donegan's Accountants
- MBE Printing Services Kew
- Musculoskeletal Health Australia
- Young Womens Arthritis Support Group (YWASG)

International Bodies

- Axial Spondyloarthritis International Federation (ASIF)
- National Axial Spondyloarthritis Society (NASS) UK
- Spondylitis Association of America (SAA) US



Peer Support Meetings



Practical training for medical students

Ankylosing Spondylitis Victoria Inc

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