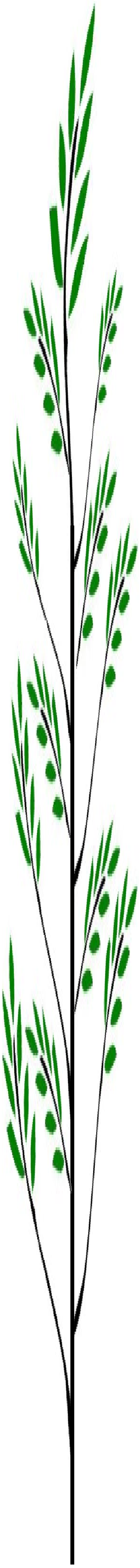
Ankylosing Spondylitis Victoria Inc

20th Anniversary

2005 - 2025



Dear AS Victoria Inc. Members and Supporters,

Welcome to our 20th year of operations supporting the Ankylosing Spondylitis community. We continue into our 21st year with a great team of volunteers at the helm and with all of you our wonderful Ankylosing Spondylitis community.

When we began in May 2005, we were a small team of volunteers, since then we have been fortunate to grow and have had over 19 people volunteer as committee members. Our membership of approximately 84 in 2010 has evolved into 62 members and 1206 Facebook followers. This pattern has repeated for many Peer Support groups with the ascendance of social media.

Since the pandemic we have waived membership fees in line with other groups. We have focused on providing social lunches, online chat sessions, e-newsletters, and social media posts to keep our community informed. In our musculoskeletal community we provide support to patients, social workers, physiotherapists and exercise physiologists with patient resources and rheumatology clinics.

Our associations with Musculoskeletal Health Australia and Arthritis Australia continue, regular webinars, e-newsletters, and events. Our team members are directly involved with their research and advocacy in the health community.

We have representatives actively involved with the international community through the Axial Spondyloarthritis International Federation, where they provide valuable community and consumer resources online, webinars, and advocacy in the healthcare professional community. Importantly, ASIF consumer lead research work continues to be a well-resourced joint effort by many member nations and persons with lived experience of Axial Spondyloarthritis.

We have increased our consumer involvement in musculoskeletal research in Australia through our representatives in the ANZMUSC Musculoskeletal clinical trials network and their Consumer Advisory Group and Australian Rheumatology Association.

An ongoing activity, medical student education, where we have provided persons with lived experience of ankylosing spondylitis in various educational settings, including Monash, LaTrobe and Melbourne Universities. We have also provided with lived experience speakers and presenters for various musculoskeletal clinics, medical professional conferences, forums, and annual scientific meetings.

Our team members have contributed to various consumer focused guidelines, calls to action studies, pain studies and scientific musculoskeletal publications by

Musculoskeletal Health Australia, Arthritis Australia, and ANZMUSC Musculoskeletal clinical trials network.

Our strong connection with the Ankylosing Spondylitis Group of Queensland enables production of our e-newsletter, AStretch. This e-newsletter contains patient stories, exercises, research, events and activities reports across Australia.

Our long-standing Committee members have added comments below on their years activities and involvement with our group.

We look forward to the next 10 years with you and our AS community.

Annie McPherson – President

Dee Lynch- Committee Member /North Central Region Representative:

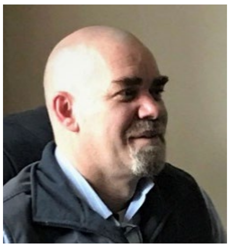
I was in my late 30's when I was diagnosed with Ankylosing Spondylitis (AS) and I immediately sought valuable advice from AS Victoria Inc. President Annie gave me so much of her time to explain the condition, how to live a normal life following diagnoses and even how to self-inject biologics which became important in significantly reducing my symptoms.

I felt isolated being diagnosed with a strange sounding arthritis and it was so valuable for my mental and physical health to join this peer support group. Members are so diverse and at different stages in their AS journey and treatments so we can celebrate small achievements and can empathise together. Being in regional Victoria, I have the option to travel to Melbourne to catch up face to face for social events with other members while attending meetings online, often from the comfort of my couch with my pug who also likes to make an appearance.

The group is very involved in current AS research, participating in international conferences and educating health professionals on the condition. This allows the peer support group to share valuable information and provides opportunity for members to participate in research.

Soon after joining AS Victoria as a member, I enquired about joining the Committee to increase my involvement with the peer support group. I also became a regional representative of AS Victoria and Young Woman's Arthritis Support Group (YWASG) as it's so important for me that I can offer the same important and beneficial support I received following my diagnosis.

Shayne van der Heide - Vice President:



In my twenties, I began experiencing significant pain in my lower back and hip area. Despite numerous visits to doctors and specialists, no clear diagnosis was made. At the time, I was living in a small rural town on the NSW/Victoria border, with limited access to specialist care. It wasn't until my early thirties—more than seven years later—that I was finally diagnosed with Ankylosing

Spondylitis (AS). Prior to this, I had never heard of the disease and had to rely entirely on my own research to understand it.

I continued managing the condition as best I could for several years. In my early forties, I moved to Melbourne and was introduced to AS Victoria Inc, a peer support group for individuals living with AS. This was a pivotal moment in my journey. For the first time, I met others who understood what I was going through. Before that, I The support and information I received from the group were life changing.

Shortly after my first meeting, I joined the AS Victoria committee, and 14 years later, I now serve as Vice President. I provide support and guidance to newly diagnosed patients and am passionate about helping others navigate their journey with AS.

In recent years, I've been fortunate to participate in several research projects and case studies with the Axial Spondyloarthritis International Federation (ASIF), contributing to global efforts to improve diagnosis and understanding of the condition. As an AS patient representative, I often take part in international discussions—frequently joining online meetings in the early hours of the morning to accommodate global time zones.

Today, I manage my AS with a combination of biologic medications and regular exercise. I'm especially passionate about cycling. Through AS Victoria, I had the opportunity to ride the first two legs of an AS awareness and fundraising ride from Melbourne to Darwin—a deeply rewarding experience.

Xmas in July Lunch at Rosstown Hotel
From the LHS Mark Creaney,
Ellen Makridis, Vicky, Annie and Shayne

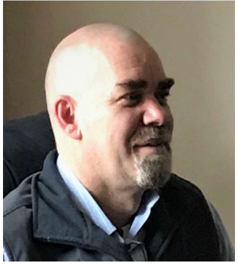
Annie and
Rosemary Ainley (CreakyJoints Aust)
Representing
GHLF at Patient Showcase
Parliament House Canberra

Committee Meeting at Ringwood Training
Maria, Shayne, Annie and Dee

Student lectures at Monash University our speakers -Annie , Shane and Rasul Family

Adam Collard
(Gippsland Region Representative)
Member from 2006, Korumburra

Dionne Lynch
(North Central Region Representative)
Member from 2014,Bendigo



Shayne van der Heide (Vice President)
Member from 2015, Boronia

Annie McPherson
(President)
AS Victoria Inc Co-Founder and member from 2005, Kew

Maria Makris
Founding member from 2005,
Doncaster East

Vicky Genius
(Secretary/Treasurer)
Member from 2011,
Northcote