



# Ankylosing Spondylitis Victoria Inc Annual Report 2022

## ***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 information to the public about the condition, it's symptoms and management options through our website
4. Provide and co-ordinate educational information , events, seminars/webinars on Ankylosing Spondylitis .
5. Co-ordinate and interact with local, interstate and international Arthritis and peer support groups including participation in their events and activities .
6. Arrange social events and activities, for our group members family and friends.

*Webinars*



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## Presidents' Report for 2022

Over the year our membership has been steadily increasing as more adults are correctly diagnosed with Axial Spondyloarthritis (axSpA) and Ankylosing Spondylitis (AS) more frequently. Our social media likes and visits have increased significantly as we publish more information about consumer focused webinars, also online exercise classes, workshops and forums from our associated patient organisations, This has been very beneficial as many people living with AS have continued to work from their home.

This year 2022, we have been able to hold in-person social activities which were well attended in May and July. Additionally, we have continued with our bi-monthly online Sunday afternoon chats.

In August 2021, committee members provided lived experience speakers for the "I am not my condition" talks with the first year medical students in the Monash University, Department of General Practice with Dr. Nadida Kachkouche.

Young Womens Arthritis Support Group (Bendigo) have continued their social catch-ups our thanks to Dee Lynch in regional Victoria.

Our involvement with the MSK Australia Consumer Advisory Committee has continued and we have had several successful advocacy campaigns with the Australian Government, Pharmaceutical Benefits Advisory Committee, Pharmaceutical Benefits Scheme programs and listings of medications.

We continue to be represented in the MSK community research and clinical trials program with membership in the ANZMUSC Consumer Advisory Group, participating in the scientific meetings and presentations at the Australian Rheumatologists Association (ARA) conference and Neck and Back Pain Forum in 2021 and 2022.

During the year, the ARA have continued to provide clinical updates for Health Professionals and consumers on COVID-19 issues, Telehealth, medication management and vaccination information

Over 2021/2022 several of our committee members have been involved in projects with Arthritis Australia to develop and produce "MyAS" a new axial spondyloarthritis (including AS) focused consumer support and information website. These resources support newly diagnosed people living with AS and beginning their journey to manage the condition.

In February 2022 our committee members participated in Axial Spondyloarthritis International Federation (ASIF), "Talk to be Heard" social media program. This provided videos and pages encouraging people living with AS to talk and seek help, from their health professionals, family and friends about issues impacting them living with a chronic condition.

In May our team participated in the international "Walk Your AS Off" social media campaign, ASIF World AS Day and Spondylitis Association of America World AS online Summit (weekend) programs extensively followed on our social media.

Upon reflection, this year has provided many challenges for our team of volunteers. I would personally like to thank them for their involvement, efforts, and continuing support.

To all of our members and associates we thank you.



**Annie McPherson . President**  
**15/07/2022**



ASIF—Talk to be heard Workshop November 2021  
Annie McPherson Top LHS

## Treasurers Report 2022

I am pleased to present this report as Treasurer and wish to thank our previous Treasurer and now Secretary, Vicky Genius, for her valuable assistance during the year when she deputised for me on many occasions.

AS Victoria holds \$ 14,318 of total assets at 30 June 2022, comprising \$ 6,639 in cash at Bank, \$ 7,660 in term deposits and \$ 19 at PayPal. Our assets rose by \$ 224 over the year due to income exceeding revenues by that amount. Not surprisingly it was a very quiet year with the negative impact of COVID-19 felt throughout most of the year.

We have 58 registered members at the end of the year, an increase of two members over the past year. Our numbers include 21 complimentary members. Our Facebook followers have increased substantially over the past year from 776 to 930, an increase of 20%.

No Government grant income was received during the 2021-22 year although I am hopeful that this source of funding will become available in future years after difficulties with COVID-19 are out of the way.

Our main source of revenue continues to be Paypal donations which totalled \$ 845 last year. Our major expenses were PO Box and website related (\$ 402) and subscriptions (\$ 231).

I look forward to another successful year in 2022-23 and hopefully a final end to COVID-19 disruption so we can meet again on a regular basis. Keep safe and healthy.



**Paul Fallon CPA Treasurer**  
**11/08/2022**

*Research:  
Patient advocacy*



### AS Victoria Inc Collaborative Projects 2021/2022 Year

This year I took on the Vice President role. I also had the opportunity to be involved in a couple of projects both international and locally. The Delay 2 Diagnosis (D2D) ASIF a long with Annie McPherson we were grouped with other AS sufferers from around the world. The work shoo which were held during the middle of night in Australia, surprisingly most of the other countries had a similar story to Australia. The delay to diagnose and general knowledge on the condition was on average delay across the world 7 years.

I had the honour to trial Arthritis Australia's new Website to help people understand their AS condition. "MyAS" is a one stop support tool for people who suffer from AS. I was given the opportunity to test the website and give advice on content. This website when released will be game changer for sufferers of AS who need to know information on their condition.

I was able to attend the ASIF Annual Conference online which gave me another insight in conditions in other countries and how different Governments deal with medical conditions. Towards the end of the conference we were put into groups and discussed treatment and management of AS in our country. Australia is a little behind some countries but ahead of other when it comes to treatment and management of chronic illness.

Again this year I had the privilege along with Annie to lecture Monash Uni medical students. These young students had the opportunity to any questions they want about our condition, giving them an insight into a patients view of living with a medical condition.

**Shayne van der Heide Vice President**



<b>AS Victoria Inc Financial State-ments</b>	<b>2022 Year</b>	<b>2021 Year</b>
ACCOUNT Balance (previous year)	\$14,094	\$13,660
<b><u>Add Income</u></b>		
Membership fees	\$10	\$87
Donations From Membership	\$115	\$208
Donations from Events	\$845	\$490
Grants & Other DHHS	\$0	\$0
Seminar Income	\$0	\$0
Interest	\$16	\$123
DVD Sales	\$0	\$0
<b>Total</b>	<b>\$986</b>	<b>\$908</b>
<b><u>Less Expenditure</u></b>		
Postage	\$0	\$0
Printing	\$28	\$68
Ink Cartridges	\$0	\$0
Stationery	\$0	\$0
PO Box / Web Site	\$402	\$406
Meeting Costs	\$0	\$0
Meeting Costs/Catering	\$0	\$0
Subscriptions	\$231	\$0
Gifts	\$0	\$0
DVD/Booklet Purchases	\$0	\$0
Miscellaneous	\$100	\$0
<b>Total</b>	<b>\$762</b>	<b>\$474</b>
<b><u>BALANCE AT BANK</u></b>	<b>\$14,318</b>	<b>\$14,094</b>
<b><u>Bank Reconciliation</u></b>		
Cash at bank	\$6,639	\$6,431
Term Deposits	\$7,660	\$7,644
PayPal	\$19	\$19
Unprocessed payments	\$0	\$0
<b><u>BALANCE AS ABOVE</u></b>	<b>\$14,318</b>	<b>\$14,094</b>

*Coffee and Chat meetings  
joining with YWASG*



*Promotion of Warm Water Exercise*



**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 the Ankylosing Spondylitis Victoria Inc, certify that—

The statements attached to this certificate, give a true and fair view of the financial position of the Ankylosing Spondylitis Victoria Inc during and at the end of the financial year of the association ending on 30th June 2022

Signed: ...

Vicky Genius

Dated: 8/07/2022

Signed:

Adam Collard

Dated: 8/07/2022



Social Events



Astretch Newsletter



ASIF Zoom meeting July 2021



Spondyloarthritis Awareness May 2022 Berwick Inn  
From bottom LHS Vicky, Ros, Adam, Annie ,Paul and Charlotte



Practical training for  
medical students



**AS Vic Committee Meeting July 2021**  
 Left to Right from the top -Vicky , Annie, Tanya,  
 Shayne , Ellen , Goopy ,Maria and Rosemary



MSK.ORG.AU

**Embracing happiness - Musculoskeletal Australia (MSK)**

Feeling a bit meh? Us too! Here are some things we've been doing recently...



**Back pain, arthritis or fibromyalgia making it hard to work? Join us for our free online Koadlow lecture.**

Sponsored by



**MSK Australia  
 Helpful Articles**

**Online Lectures  
 and webinars**

**Peer Support  
 Group Host.**

**Supporter of  
 Research**



**Musculoskeletal Australia**



## Committee Members of AS Victoria Inc 30 June 2022 -

### **Adam Collard (Gippsland Region Representative)**

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

### **Annie McPherson (President)**

- AS Victoria Inc Co-Founder and member from 2005, lives in Kew
- Retired IT- Business Analyst
- Patient advocate and 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
- Secondary Teacher –retired

### **Paul Fallon (Treasurer)**

- Member from 2013, lives in Wheelers Hill
- Part-time financial and due diligence consultant to Government

### **Shayne van der Heide (Vice President)**

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

### **Vicky Genius (Secretary)**

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



*Peer Support Meetings*

## **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)
- Caulfield Community Health Services (CCHS) - Belinda Coulter (Physiotherapist)
- Creaky Joints Australia (CJA)
- Chronic Illness Alliance (CIA)
- Collective of Self Help Groups
- Donegan's Accountants
- Health Issues Centre
- Janssen-Cilag Pty Ltd.
- MBE Printing Services Kew
- Musculoskeletal Australia
- Young Womens Arthritis Support Group (YWASG)



*Promotion of exercise such as Nordic Walking*

### **International Bodies**

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

**Ankylosing Spondylitis Victoria Inc**  
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**[www.facebook.com/asgroupvic](http://www.facebook.com/asgroupvic)**

