

# Ankylosing Spondylitis Victoria Inc Annual Report 2021

## ***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*



## **Contents**

**Page 2** Presidents Report

**Page 3** Treasurers Report ,YWASG collaboration

**Page 4** Financial Statement

**Page 5** Committee Declaration

**Page 6** ASIF Report 2021, AS Vic Committee Meeting

**Page 7** Spondyloarthritis Awareness, MSK Survey 2020

**Page 8** Your Committee and our supporters

## Presidents' Report for 2021

Welcome to our annual report and financial report for 2020/2021.

We hope all our members, associates and musculoskeletal (MSK) community are keeping well and managing with the variously applied COVID-19 restrictions.

As with many patient organisations, 2020/2021 has been another challenging year.

Over the year we have welcomed numerous enquiries to our Web and Facebook sites and assisted many new members.

We have received great support from the Healthcare, MSK and patient organisations with links to webinars, forums and e-news that we have been able to send on to our AS Victoria members to keep them up-to-date. In collaboration with the AS Queensland group we have been able to continue with our AStretch national e-newsletter reporting on local and international AxSpA (Axial Spondyloarthritis) group activities and events.

We have been successful in holding online chat sessions with our members and guests over the year. Our social events have been curtailed by COVID-19 restrictions. In early May, during a break in Melbourne restrictions, a some members celebrated World AS Day at a lunch at the Berwick Inn. Over that weekend many members joined into the joint Axial Spondyloarthritis International Federation (ASIF) and Spondyloarthritis Association of America (SAA) 3 day online webinar and forum with a range of excellent speakers.

The Bendigo, Young Women's Arthritis Support Group (YWASG) led by our committee member, Dionne Lynch has been able to meet socially and online during the year. Dionne was recently featured in an article in The Bendigo Advertiser as a strong advocate for these groups and the MSK network providing peer support to others experiencing similar healthcare issues in regional Victoria.

During August, we were invited to participate in the Monash University, Department of General Practice, first year student "I am not my condition" patient experience talks with Professor Nadida Kachkouche. Along with the Rosemary Ainley and YWASG team, we were able to inform students about our personal experiences in the Healthcare sector.

Continuing with our objectives to provide informative MSK related articles, webinars, forums and exercise videos we have been well supported this year by Musculoskeletal Australia (MSK AU), Arthritis Australia, and Creaky Joints Australia.

During the year MSK AU, Consumer Advisory Committee, of which I am chair, and their staff worked together to produce a healthcare Consumer national Survey. The survey received over 3400 responses and provided a wealth of information on how people living with an MSK condition managed their lives, work, health and wellbeing. The consumer responses in this survey provided the basis for a landmark report, "*Making the invisible visible*. Australians share the impact of Musculoskeletal conditions on their lives". As a result, MSK AU has highlighted 6 areas for the organisation to focus on including lobbying for change and how to support these conditions, their funding and management in the Australian healthcare systems. During late 2020, the ASIF conducted 2 international online workshops on the Delay to Diagnosis focusing on the significant barriers in Health systems, for a person to obtain a correct diagnosis of AxSpA, currently an average of 7 years. Committee member Shayne van der Heide and I participated in this workshop and I provided my personal journey of delay to diagnosis of over 20 years as a case study. During June 2021, the ASIF published the subsequent report "*The unacceptable delay in AxSpA diagnosis: A Call to Action*". In July, this was followed by an online forum to discuss 6 recommendations from the report. These covered lack of awareness of AxSpA across both patient, medical and healthcare sectors.

I would like to personally thank all the committee members and volunteers for their commitment to continuing our Ankylosing Spondylitis (AS) peer support group and network. The support from our AS Victoria committee, members and volunteers has been outstanding in this difficult year and I would like to extend my appreciation and gratitude to them.



**Annie McPherson . President**  
**08/07/2021**

# Treasurers Report 2021

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 \$ 14,094 of total assets at 30 June 2021, comprising \$ 6,431 in cash at Bank, \$ 7,644 in term deposits and \$19 at PayPal. Our assets rose by \$ 434 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 the entire 12 months as compared to just three months last year when revenue and expenses were much higher. However, cost control was better in the latest year which enabled our surplus to grow from \$ 325 to \$ 434.

We have 56 registered members at the end of the year, including 25 complimentary members. Member numbers have increased significantly over the past year as have Facebook followers which rose from 670 to 776. Of the latter group, 73% are in Australia, with about half of them in Melbourne. There is a widespread range of other followers around Australia and the world, with USA (8%) and India (7%) being the largest groups.

No Government grant income was received during the 2020-21 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.

I look forward to another successful year in 2021-22 and hopefully an early end to COVID-19 disruption so we can meet again on a regular basis. Keep safe and healthy.



**Paul Fallon CPA Treasurer**  
06/07/2021

*Research:  
Patient advocacy*



## Bendigo Times

Saturday, May 15th, 2021

BENDIGO'S Young Women's Arthritis Support Group brings together an often-forgotten group of people with the condition.

Each month around 10 women of working age meet for a breakfast catch up and to hear of others' experience in the city's small world of professional arthritis treatment.

"We catch up once a month just for an informal chat and everyone's got different types of arthritis, some people might have had arthritis since they were children or might have recently been diagnosed as well," facilitator Dionne Lynch said.



Dionne Lynch - AS Victoria Inc Committee Member  
and North Central Region Representative

<b>AS Victoria Inc Financial Statements</b>	<b>2021 Year</b>	<b>2020 Year</b>
ACCOUNT Balance (previous year)	\$13,660	\$13,335
<b><u>Add Income</u></b>		
Membership fees	\$87	\$304
Donations From Membership	\$208	\$85
Donations from Events	\$490	\$813
Grants & Other DHHS	\$0	\$1,225
Seminar Income	\$123	\$0
Interest	\$0	\$159
DVD Sales	\$0	\$0
<b>Total</b>	<b>\$908</b>	<b>\$2,587</b>
<b><u>Less Expenditure</u></b>		
Postage	\$0	\$16
Printing	\$68	\$318
Ink Cartridges	\$0	\$185
Stationery	\$0	\$6
PO Box / Web Site	\$406	\$396
Meeting Costs	\$0	\$1,232
Meeting Costs/Catering	\$0	\$110
Subscriptions	\$0	\$0
Gifts	\$0	\$0
DVD/Booklet Purchases	\$0	\$0
Miscellaneous	\$0	\$0
<b>Total</b>	<b>\$474</b>	<b>\$2,262</b>
<b><u>BALANCE AT BANK</u></b>	<b>\$14,094</b>	<b>\$13,660</b>
<b><u>Bank Reconciliation</u></b>		
Cash at bank	\$6,431	\$6,120
Term Deposits	\$7,644	\$7,521
PayPal	\$19	\$19
Unprocessed payments	\$0	\$0
<b><u>BALANCE AS ABOVE</u></b>	<b>\$14,094</b>	<b>\$13,660</b>

*Coffee and Chat meetings*



*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, Adam Collard and Vicky Genius, 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 2021

Signed: ...

Adam Collard

Dated: 6/07/2021

Signed:

Vicky Genius

Dated: 6/07/2021



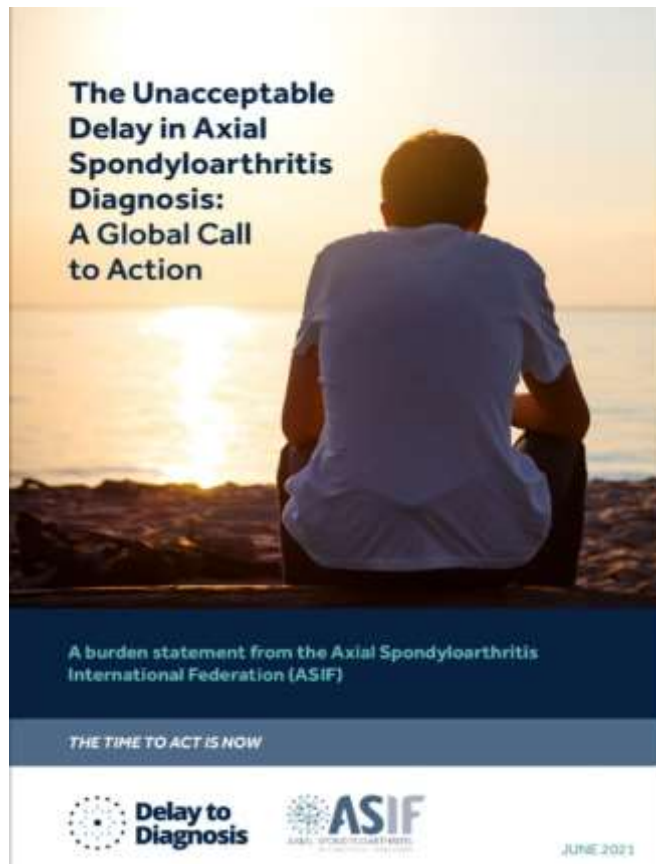
Social Dinners



Astretch Newsletter



## ASIF Report 2021



**AS Vic Committee Meeting February 2021**  
From top LHS Annie, Shayne, Dionne Olsen, Paul, Vicky, Dionne Lynch, Maria.



*Practical training for medical students*



**Spondyloarthritis Awareness May 2021 Berwick Inn**  
 Left to Right Angela , Paul –Treasurer, Charlotte ,Rosalind , Annie – President  
 and Vicky– Committee Member ( not pictured ).

## MAKING THE INVISIBLE VISIBLE

Results of our 2020 National Consumer Survey



## THE RESULTS ARE IN

Here are just some of what people shared...

- # 93% said their lives have been negatively impacted by their condition/s.
- # 66% said their condition/s had an impact on family and personal relationships.
- # 65% reported financial stress due to their condition/s.
- # 50% reported that their condition/s had a negative impact on their mental health.
- # 57% wanted affordable treatment options and services.
- # 46% wanted more government support specifically for the ongoing cost of treatment.



## Musculoskeletal Australia 2020 Results of National Consumer Survey



## Committee Members of AS Victoria Inc 30 June 2021 -

### **Adam Collard (Vice President & 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**

- 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
- Hydrohealth - Margaret Lewington (Physiotherapist)
- Janssen-Cilag Pty Ltd.
- MBE Printing Services Kew
- Melbourne Osteoporosis Support Group (MOSG)
- 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)**

