

# **2017 Annual Report**





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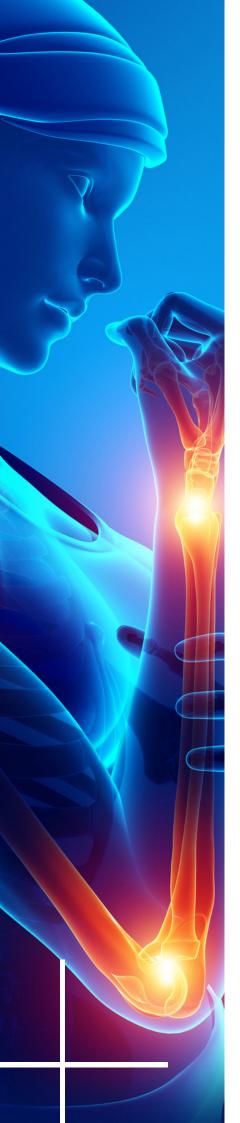
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## **ARTHRITIS**

Arthritis is a common condition in Australia that affects one in five people of all ages and from all walks of life.

Arthritis affects people in different ways but the most common symptoms include swelling, pain, stiffness and decreased range of joint motion.

Living with arthritis is a daily struggle that impacts on every facet of daily life. People with arthritis cannot take simple things like going to work, shopping or socialising with family and friends for granted.

The pain and suffering that people with arthritis endure because of their condition not only decreases the quality of life for them but also for their families and carers.

The number of people with arthritis is expected to increase nationally by 38% from 3.9 million to 5.4 million by 2030.

In total health care costs, West Australian costs are predicted to rise by 55% from \$515.48 million to \$799.05 million.

## **OSTEOPOROSIS**

Osteoporosis is a common disease affecting over one million Australians and it is estimated that a further 6.3 million have low bone density (or osteopenia).

Osteoporosis occurs when bones lose minerals, such as calcium, more quickly than the body can replace them, causing a loss of bone thickness (bone density or mass).

This disease makes bones become brittle leading to a higher risk of breaks than in normal bone.

In 2017, the total direct costs of osteoporosis and osteopenia in Western Australian adults aged 50 years and over will be \$307 million, of which \$211 million (69%) relates to the treatment of fractures.

Osteoporosis is often called the silent disease because there are usually no symptoms evident until a fracture occurs.



## PRESIDENT'S REPORT

Dr Jack Edelman AM MBBS FRACP

It is my pleasure to report another very successful year for the Foundation. A substantial trading surplus of \$798,000 was achieved on an income of over \$3.5 million whilst delivering high-quality evidence-based programs.

Arthritis is one of the most common, disabling and costly chronic conditions in Australia and the incidence is growing, emulating worldwide epidemiological trends.

Already the burden of musculoskeletal disorders in Australia is profound, and musculoskeletal conditions; specifically osteoarthritis, rheumatoid arthritis, juvenile arthritis and osteoporosis are recognised as National Health Priority Areas.

By 2050, arthritis in Australia is projected to affect seven million people due to population ageing and increasing levels of obesity.

As life expectancy continues to increase, so do chronic diseases, with more people living with long term health conditions, intensifying the importance of providing best practice musculoskeletal health care. Although the mortality rates for arthritis appear low, this is probably a contradiction as arthritis increases and contributes to life threating co-morbidities: depression, cardio-vascular diseases, cancer and obesity, adding to the ever increasing diseases burden.

The psychosocial and financial cost of arthritis to the individual and family cannot be underestimated, neither should the escalating health care costs. Strategies must be set in place to accommodate and provide the right musculoskeletal health care in the right place to avoid a tsunami of health and disability costs over the next decades.

Arthritis & Osteoporosis WA, working closely with rheumatologists, endeavours to provide statewide, best practice rheumatology services. We continue to provide evidence-based, disease-specific self-management programs to consumers and train health professionals to deliver these programs. Our programs are designed to help prevent and manage musculoskeletal conditions and one day to hopefully find a cure.

Furthermore, our commitment to research is as strong as ever as we continue to fund the Professorial position at UWA, and now a PhD scholarship as well. The scholarship for a PhD student was made possible by a substantial and generous bequest from the late Mr John Donald Stewart.

Of course, the success of the Foundation would not be possible without the enormous contribution made by our volunteers and staff. I would also like to thank the Mal Atwell Leisure Group for organising bingo, which is a substantial income earner for the Foundation.

My sincere thanks to Dr John Quintner for his work with pain management for both the consumers and Health Professionals, and to the Board of Management and Committee Members who also give their time.

# Arthritis & Osteoporosis BURDEN OF DISEASE

**Arthritis will affect** 



Arthritis affects one in 1,000 children



two out of every three people with arthritis are between 15 - 60 years of age

\$7.6 Billion
Arthritis health
system costs
by 2030

West Australians aged 50 years and above with poor bone health or osteoporosis



**\$2** BILLION

Cost of joint replacement surgery for Osteoarthritis per year

## HEALTH SERVICE PROGRAMS DELIVERED

## **Rural Rheumatology Clinics**

The Rural Rheumatology Clinic Service has been delivering best practise rheumatology in rural and remote areas of WA since 1974, enabling early identification and treatment for people with arthritis.

Arthritis & Osteoporosis WA (AOWA) coordinated 134 rheumatology day clinics in:

- 13 locations across the state of Western Australia plus 18 Telehealth consultations.
- 2070 patients were seen of which 393 were new patients; 1677 were review patients.
- **752** (36%) patients attending the clinics have Rheumatoid Arthritis which is a serious inflammatory condition requiring constant monitoring and necessitating specialist visits 6/12 or more frequent specialist visits, reinforcing the importance of this rural program.

Other serious inflammatory arthritis conditions seen include:

- 181 patients with Psoriatic Arthritis
- 86 with Ankylosing Spondylitis
- 33 with Systemic Lupus Erythematous
- 31 with Gout

Rheumatologists travel from Perth regularly to provide this rheumatology service to people living in rural Western Australia. These rural areas include Kimberly, Esperance, Port Headland, Carnarvon, Karratha, Geraldton, Kalgoorlie, Manjimup and Albany.

These clinics are the lifeline for all people living with arthritis in rural WA and without this service, their quality of life would diminish. People would have to travel to Perth to visit their specialist, increasing the financial and psychological burden to their families and to the Health Department of WA.

This service reduces hospital bed occupancy and Patient Assistance Travel Scheme (PATS) costs relating to rheumatology conditions, allowing treatment closer to home and improving 'Quality of Life' for the individual and family.

## **Building Workforce Capacity**

Arthritis & Osteoporosis WA builds on the increasing capacity of GPs, nurses and allied health staff by offering best practice rheumatology education to all health professionals, practising within WA.

In 2017, AOWA delivered the following Clinical Updates and Training for Health Professionals to metro and rural areas in WA.

## Clinical Updates:

- Inflammatory Arthritis Update for GPs and HPs
- Bone & Mineral Disease Update for GPs
- Inflammatory Arthritis Update for GPs and Nurses

## Training for Health Professionals:

- OAK Facilitator Training
- RAP Facilitator Training

AOWA is committed to teaching people with arthritis the knowledge and skills to enable them to manage their diseases, which empowers them to make informed choices in partnership with their health care providers.

AOWA provides Disease-Specific, Self-Management Education Programs for people with arthritis that have been developed, tested and peer-reviewed; thus providing consumers with evidence-based information on how to understand and manage their disease. The programs available for consumers are Osteoarthritis of the Knee, Rheumatoid/Psoriatic Arthritis and Ankylosing Spondylitis.

In 2017, AOWA delivered 17 evidence-based education and self-management programs to 219 people with these above-mentioned conditions:

- Programs were held throughout the metro area from Willetton and Leeming south of the river to North Beach and Dianella in the north.
- Rural education and self-management programs were offered in Narrogin and Albany.

## **Public Seminars**

In 2017, 16 seminars given by specialist presenters were held for the general public. The seminars covered a diverse range of topics such as; The Impact of Lupus, Feet and Arthritis Talk as well as Estate Planning and a Joint Replacement Q&A.

A total of 700 people attended the public seminars that were held within the metro area as well as the rural areas of Kalamunda, Kalgoorlie, Geraldton and Dunsborough.

# **Community Speakers**

Trained volunteers delivered 63 talks to 1,332 members of various groups including service and seniors clubs, business clubs, community groups and multi-cultural groups of diverse ethnicity.

# **Exercise and Physical Activity Programs**

Research has found that regular exercise is one of the most effective treatments for Arthritis and for maintaining bone health to prevent Osteoporosis. Regular exercise increases mobility, muscle strength, flexibility and reduces joint pain.

Exercise forms such as Yoga and Pilates for Arthritis are an acceptable modality in the treatment for musculoskeletal conditions when delivered by specially trained practitioners.

AOWA offered Tai Chi for Arthritis, Yoga, Pilates for Arthritis and Osteoporosis exercise classes, complementing our existing Hydrotherapy classes.

A Hydrotherapy program for children with Juvenile Idiopathic Arthritis (JIA) was introduced at our premise in Shenton Park which proved to be very successful.



# **Support Groups**

A number of Support Groups are held within the metropolitan and regional areas and provide those with living with arthritis, an opportunity to talk freely about their experiences in a safe and non-judgemental environment.

## **Telephone Advisory Service**

Our Telephone Advisory Service is a valuable resource for people living with arthritis, osteoporosis and other related conditions. This free service provides information and advice for those newly diagnosed, or for those who may require further help to manage their condition.

# **Camp Freedom**

Camp Freedom is held annually during the Sept/Oct school holidays and is designed for children aged between 7 - 17 years with Juvenile Idiopathic Arthritis (JIA). The camp provides children an opportunity to meet others like themselves and participate in numerous activities, as well as providing parents respite from their caring roles.

Educational workshops and self-management techniques included in the camp, equip the children with knowledge to help them manage their arthritis. A total of 42 children attended the camp which was held at the Forest Edge Recreation Camp in Waroona.

Camp Stretch is a new camp commencing in March 2018 and will be a fun filled 3 day weekend camp specifically designed for children between 7-17 years old with Elhers Danlos and other Hypermobility conditions.







## RESEARCH

Our commitment to research continues under the direction of Prof Hans Nossent as Chair of Rheumatology and Musculoskeletal Medicine at the University of Western Australia. Research provides the key to further our knowledge of musculoskeletal conditions, improve treatments and management, and ultimately search for cures.

The scholarship for a PhD student was made possible by a substantial and generous bequest by the late Mr John Donald Stewart. Warren Raymond was awarded the scholarship and his PhD research plan was recently approved by the Research Board of UWA. His thesis planned for 2020 will investigate in detail six specific aspects of Systemic Lupus Erythematosus (SLE) based on WARDER data and report these findings in peer-reviewed journals.

## Prof Nossent's activities in 2017

### **WARDER**

A WA Health approved project on the epidemiological characteristic of rheumatic disease in WA. The project contains statewide linked data for all patients with rheumatic disease who were in hospital contact over the period 1980 - 2015.

- In 2017, these data sets have been synchronised to include statewide cancer, ED and mortality registries and the resulting data sets have undergone extensive quality control checking. With the data set now complete, the stage is set for investigations into a number of research questions. Preliminary findings were presented in 2017 at the International Lupus Meeting in Melbourne and EULAR 2017.
- Ms Milica Ognjenovich is a master of Public Health and has taken over the role of Rheumatology Research Officer at UWA. She is investigating the WARDER data for frequency and severity of spinal fractures in patients with Ankylosing Spondylitis.

## **Perth Lupus Registry**

Prof Nossent is founder and chairman of the Systemic Lupus Erythematosus Working Party which is a collaboration between QEII campus-based rheumatologists, clinical and basic immunologists and renal physicians. Its aim is to increase research activity into this disease and coordinate local services to SLE patients.

- The online database has been populated with clinical data for 102 patients and will be regularly updated with new data for included and newly recruited patients.

## **Busselton Health Study**

- In collaboration with Prof Matthew Knuiman at the School of Population Health, two papers were published regarding rheumatic disease markers as a predictor of cardiovascular disease in the Busselton Health Study.

## **Biopsy Proven Lupus Nephritis**

- -This local collaborative investigation with Drs B Wong and A Chakera to evaluate the frequency, severity and outcome of renal disease in patients with SLE at SCGH over the period 2000 2015 reached the final stage of a closed complete database in 2017.
- -Preliminary findings for this project were presented at the 2017 International Lupus Meeting in Melbourne and EULAR 2017.
- A connected investigation into Lupus Nephritis in Aboriginal patients and into rare presentation of Lupus Nephritis have led to two papers in 2017.

## **PUBLICATIONS**

We endeavour to provide high quality publications and educational resources to inform those living with musculoskeletal conditions.

#### ARTHRITIS TODAY MAGAZINE

A high quality magazine published three times per year with a circulation of over 10,000 per issue. The magazine includes contributions from leading health professionals, the latest research news, information on diet and nutrition, medications and treatments and upcoming seminars and special events.

#### ARTHRITIS E-NEWSLETTER

A digital newsletter emailed monthly to 6,000 subscribers containing research updates, self-management and education programs, exercise classes, seminars and events.

#### **WEBSITE**

Our website provides an overview of our programs and services and is a valuable resource of information that receives over 16,000 visitors per month.

## INFORMATION BOOKLETS AND FACT SHEETS

Our printed resources are freely available to the community and cover most of the 100 types of bone and joint disease.

#### SOCIAL MEDIA

Our Facebook page has an engaging community of 7,500 followers.

## PROMOTIONAL CAMPAIGNS

A range of health promotional campaigns for bone and joint disease are disseminated in the print media.

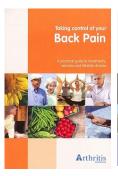
A PRACTICAL GUIDE TO LIVING WITH RHEUMATOID ARTHRITIS A uniquely Australian book for people with Rheumatoid Arthritis and their families. Each chapter is written by medical and health professionals who have expert knowledge of the condition.

## **FUNDRAISING**

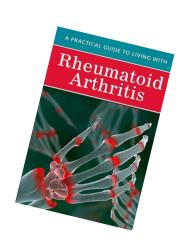
A number of fundraising initiatives are held throughout the year including:

- Weekly Bingo held at the Mal Atwell Leisure Group
- Direct Mail
- Fremantle International Portrait Prize
- Bequest Income
- HBF Run for a Reason
- City 2 Surf
- Rottnest Channel Swim
- Entertainment Book Memberships











# Snapshots of 2017





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# In our world of James Bond, MI5 and undercover agents, their code was simple....... 'If my window blind is up, I'm OK!'



Two ladies, decades ago, started a friendship that blossomed and lasted for reasons more than mere enjoyment of each

other's company. They'd developed a bond, they cared and watched out for each other. Losing husbands, they chose to live alongside each other to help hold fast to what was now three decades of 'a caring friendship'.

These two elderly ladies even had a 'secret' code. Each morning, on rising, a 'raised blind' on a front window said... 'I'm up and I am OK!". In times of smart phones, their ability to watch over each other was both simple and effective.

Until one day, one blind wasn't raised and the neighbor made entry to find her lifetime friend on the floor, rendered immobile with a broken hip. Her fall and fractured hip was followed a short while later by a stroke. She died aged 98.

And I retell this story for good reasons...First is the generosity expressed in her Will. This dear lady had left us an amount of \$158,000 which we are using to help advance research into arthritis. Bless her.

Second, was the effectiveness of their code, their private pact to "watch out" for each other by adjusting a window blind. If only all things in life were as simple!

Yes, these two ladies were organized, each had written a Will and each had an unwritten pact to look out for the other, but these days, there is more, much more...

After preparing your Will, next is to prepare an EPA, or Enduring Power of Attorney, which provides for others to manage your finances in the event you are incapacitated.

Then, there is an Enduring Power of Guardianship or EPG that while similar to an EPA, takes care of the where, with whom and how you might live.

Next is to write an Advanced Health Directive or AHD that in the event you are seriously ill, tells others the extent to which you want medical intervention to be used.

And if you have funds in a Superannuation Fund, you will almost certainly need to sign a Binding Death Benefit Nomination or BDBN instruction. This directs the Fund Trustee as to how to deal with your Fund assets that are expressly not covered by your Will.

Here at Arthritis & Osteoporosis WA, we have a wallet of information expanding on the above issues, ready to send you if you call. The wallet of information is free, as is our FREE Wills writing service. We can also put you in touch with legal or financial professionals to help you deal with those more complicated issues that surround our last years.

### Here's how to get your pack of information:

Phone: 9388 2199 I Email: general@arthritiswa.org.au I Website: www.arthritiswa.org.au

AOWA: 17 Lemnos St, Shenton Park



## **Wyllie Arthritis Centre**

17 Lemnos Street, Shenton Park WA 6008 Post Office Box 34, Wembley WA 6913

**Telephone:** 9388 2199 **Country (Free Call):** 1800 011 041

**Email:** general@arthritiswa.org.au **Website:** www.arthritiswa.org.au

ABN: 43 390 598 024



