



This Annual Review provides an overview of the performance of Arthritis & Osteoporosis NSW for the 2015/16 financial year and an outlook for the year ahead. Performance is tracked against the principal activities of health promotions, fundraising and the provision of support across NSW. Complete audited financial statements are published in our Financial Report for the year ended 30 June 2016. To obtain a copy of the Financial Report, please call **9857 3300** or email **info@arthritisnsw.org.au**. This Annual Review has not been audited, but it contains extracts from the audited financial statements. It is also available online at <http://arthritisnsw.org.au/about-us/annual-reports/annual-report-2015-16/>

*Cover photo: Paul Looyen, Stonemeadow Photography*

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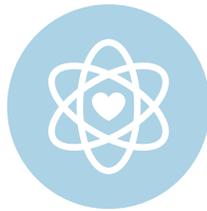
# Arthritis & Osteoporosis NSW

**Arthritis & Osteoporosis NSW is a for-purpose charitable organisation seeking to improve the quality of life of people affected by arthritis, osteoporosis and other musculoskeletal conditions. We develop and provide information, support and evidence-based services and programs; build community awareness; engage with consumers and health professionals and aid research into causes and treatment.**



## **Our Vision**

A community free from Arthritis



## **Our Values**

- Compassion
- Support
- Integrity
- Respect
- Communication
- Commitment
- Positive Attitude



## **Our Priorities**

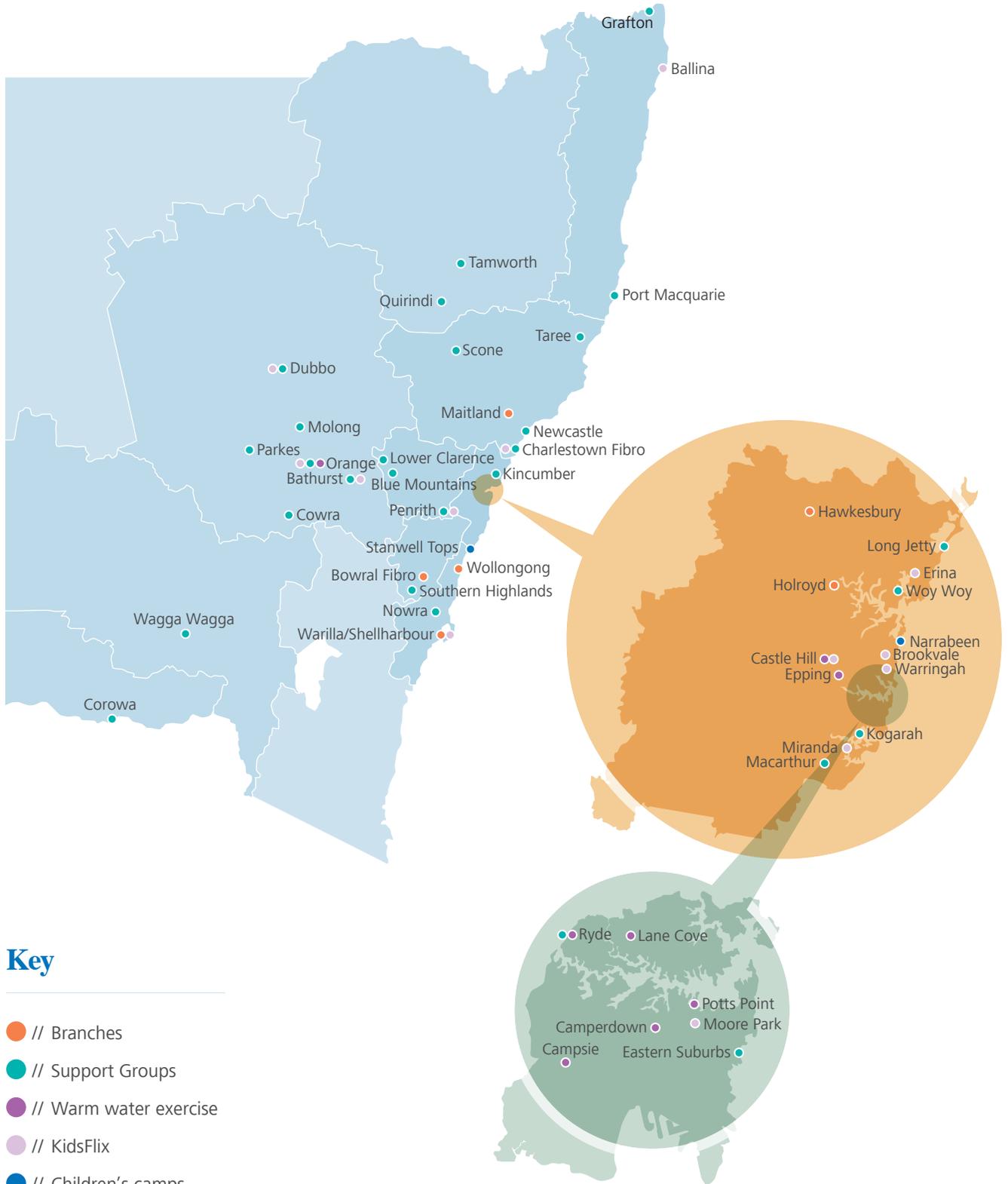
- Empower people to manage their health
- Strengthen and enhance research contribution
- Maintain a network of support groups
- Build awareness of Arthritis & Osteoporosis NSW to support fundraising initiatives and fund service provision



## **Our Mission**

Excellence in services that promote the prevention and treatment of arthritis & osteoporosis in NSW.

# Our reach



# President's Report

Arthritis & Osteoporosis NSW (AONSW) experienced significant challenges and change during 2016, with cancellation of some major events and Chief Executive Officer, Jannine Jackson, departing in April.

We were fortunate to have former Chief Executive, Karen Filocamo assist in an acting capacity for a period of three months while the Board identified a suitable successor.

## Our executive

The Board was pleased to appoint Sandra Vincent as Chief Executive Officer before the end of the financial year. Sandra brings to AONSW a wealth of experience in the health, community and aged care sectors. Since joining the organisation, Sandra has commenced rebuilding the team and re-establishing relationships with our key stakeholders.

As a consequence of leadership changes and unrelated circumstances, we also experienced a high level of staff turnover during the year. This added further challenges to the Board, remaining staff and new employees and hampered capacity to meet member and stakeholder expectations in the short-term.

To ensure we return to the right path, the Board approved an independent strategic review of stakeholder perceptions. We look forward to considering this review and working with Sandra to implement its recommendations in the year ahead.

## Warm-water exercise

Early in 2016, the Board made a decision to cease offering volunteer-led warm water exercise classes across the state because of risks identified. We regret the lack of communication about this decision and the fact that many classes were closed without alternative arrangements first being put in place.

While later than ideal from our community's perspective, the new AONSW management team has commenced actively working with relevant organisations in order to

develop positive and sustainable plans for the future of warm water exercise classes in the state.

The Board accepts responsibility for the inconvenience and distress caused. The feedback we have received from warm water participants set in motion significant deliberations at the Board. As such, we have changed our director renewal process and board composition.

## Thank you

Thank you to everyone who has donated to, or fundraised for us. As a society, we are constantly made aware of worthy causes, more than any one individual has the capacity to support. Thank you for your commitment to our cause and also for your understanding as we have conducted regular appeals. We have heard and acted on your feedback that appeals to donate have been too frequent.

I would also like to thank all members of the Board for their contribution. Greg Monaghan, our former President, retired from the Board in November 2015 after eight years of service, while Judith Cantor retired as Vice President and director after five years. We acknowledge the significant input of the directors who retire at this year's Annual General Meeting, including branches representative, Doris Carrall. We look forward to welcoming our new directors, working more closely with the membership and also facilitating greater member-input into our strategic decision-making and service provision.



*Allan Ryan*

**Allan Ryan**

// President

Arthritis & Osteoporosis NSW

# Message from CEO Sandra Vincent

I am delighted to have been appointed as CEO of Arthritis & Osteoporosis NSW in July 2016 as I thrive on challenges and opportunity. This is the situation we find ourselves in, given changes not only within our organisation, but also the external environment impacting the arthritis and musculoskeletal community.

Arthritis is still understood incorrectly as a condition afflicting only the ageing population. The impact of poor bone and joint health is vastly underestimated. Children and adults in mid-life still suffer judgement and discrimination in silence because pain prevents full and active participation in school activities, the workplace and everyday life.

It is clear to everyone close to AONSW that there are many issues needing to be addressed quickly. As we solve current problems, we will also be refining our strategy with a view to improving our financial position, member experience, stakeholder relationships and back office functions. Our strategic review will include exploring opportunities to remove the duplication that exists among arthritis organisations operating in Australia. This may involve our team taking on a leadership role in delivering some national member services from NSW.

I believe the successful achievement of a strategic turnaround will require an initial year of rebuilding foundations. We will then have established a stronger base to provide more meaningful and valuable services and support to the citizens and health professionals of NSW.

As an affiliate of Arthritis Australia, we have continued to provide local input into, and support for, National initiatives, including information distribution, research and advocacy (see page 20 for an advocacy update). We have also promoted awareness campaigns such as *Time to Move* and *Kids Get Arthritis Too*.

## Financial result

Our financial result for 2015-16 was a surplus of \$784,483. This result was achieved largely due to more than \$2 million earned in bequest income. After closely

reviewing our financial position, we have prioritised cost reduction and the generation of alternate revenue streams.

We are incredibly grateful to all who have bequeathed funds. These funds have sustained support services and children's camps. Future bequests can and will fund much-needed research. In this report, you will find more information on our activities.

Once again, I stress that as competition among charities for funding intensifies, new revenue streams must be developed to enable us to continue pursuing our vision while simultaneously providing relief from the physical and mental pain of arthritis and osteoporosis. A proportion of previously donated funds will be carefully invested to open up new revenue-generating opportunities.

## Thank you

I would like to echo the President's thanks to our major benefactors, corporate supporters (including Pfizer and Eli Lilly) and those who have contributed to our appeals. We acknowledge the loyalty of all members who have renewed membership year-on-year. I thank the Board for their support and for encouraging us to make the changes that need to be made.

Thank you also to our enthusiastic and dedicated team of volunteers and employees for continuing to deliver our valued services.

We look forward to better supporting you with your current needs while also increasing our contribution to the longer-term priorities of prevention, improved diagnosis, treatment and research into a cure.



*Sandra Vincent*

**Sandra Vincent**

// CEO

Arthritis & Osteoporosis NSW

# Board members



**Allan Ryan** // President

BSc (Hons), MEng. Sci, MAICD

Allan Ryan is the Director of Managed Innovation International, founder and Executive Director of the Hargraves Institute and an Adjunct Professor at UTS Business School. An expert facilitator, he enables organisations to deliver competitive advantage through innovation. He is a member of the Arthritis & Osteoporosis NSW CEO selection committee and the finance and investment committee.



**Peter Ricketts** // Honorary Treasurer

B. Com., MBA, CA, FGIA, FCIS, FAICD, CFTP (Snr)

Peter Ricketts is a consultant and non-executive director.

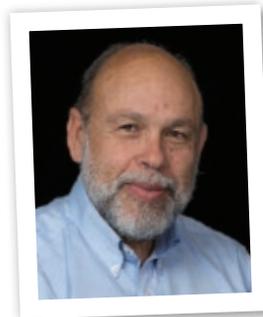
He is chair of the Arthritis & Osteoporosis NSW finance and investment committee.



**Amanda Harvey** // Vice President

BA/LLB (Social Psychology), Grad Dip Psych, MLLR

Amanda is a director of AJ Harvey Consulting Pty Ltd, Pixiu Pty Ltd and Weir Consulting Pty Ltd. She is an experienced employment lawyer, workplace investigator and consultant to the public and private sector. Amanda's understanding of musculoskeletal and autoimmune conditions has arisen through personal experience with scleroderma. Amanda chairs the Arthritis & Osteoporosis NSW HR committee and she is a member of the finance and investment committee.



**Prof. Nicholas Manolios** // Director

MD BS, PhD, FRACP, FRCPA

Professor Manolios is Director of Rheumatology at Westmead Hospital and Professor in Medicine, University of Sydney.

He is chair of the Arthritis & Osteoporosis NSW Research Committee.



**Cosimina Pupo** // Director

Cert (Mgt), Dip (Counselling)

Cosi is a senior probate paralegal and former director of the Independent Living Centre. She is involved in the Tutor Patient Partner Program, chairs the Arthritis & Osteoporosis NSW Education Committee which she first joined in the 1980s, and is also a member of the National Arthritis Consumer Reference Group (NACRG). Cosi applies her experience of living with chronic pain to assist others, especially working adults.



**Doris Carrall**

Doris Carrall, the branches representative, resigned from the Board in September 2016.

**Director information is current as at October 2016. Directors' appointment and retirement dates are provided in the Financial Report.**

**The Board is supported by four sub-committees including finance, research, education and fundraising. These committees support the Board and management team to oversee and implement principal activities.**

As at September 2016, Arthritis & Osteoporosis NSW employed eight full time and three part-time staff.

**Organisation chart**

*As at September 2016*



# Performance overview

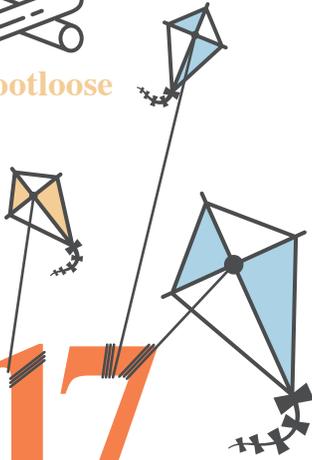
**2,938** 

**Memberships**  
INCLUDING 200 FAMILIES

**34**  BRANCHES & SUPPORT GROUPS

## Children's camps

**35**  CHILDREN @ **Camp Footloose**

**17**  FAMILIES @ **Camp Twinkletoes**

## Health promotion



**1213**  
COMMUNITY EDUCATION PARTICIPANTS

ACROSS **63** SESSIONS



**124**  
SEMINAR PARTICIPANTS ACROSS 5 SESSIONS

 **20** HEALTH PROFESSIONAL PROGRAM PARTICIPANTS

**55**  WEBINAR PARTICIPANTS IN 3 WEBINARS

## Our office



## Financial result

Revenue 2015/16:

**\$2.67m**

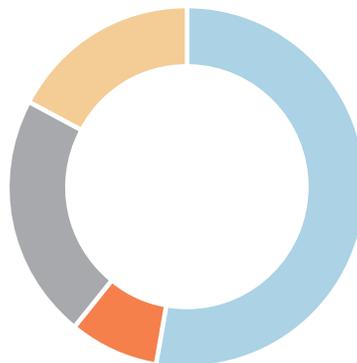
(2014/15: \$2.28M)

Net result 2015/16:

**\$784,484**

(2014/15: \$752,766)

## How resources were used



### Key

-  // Salaries and wages
-  // Health Promotion
-  // Fundraising & Marketing
-  // General administration



# Supporting community

**Arthritis & Osteoporosis NSW organises children's camps to facilitate connections between families living with juvenile arthritis (JIA). These camps are supported by AONSW members and donors, with many branches and support groups choosing to direct funds raised towards these programs.**

According to 2011–12 National Health Survey, one in 1,000 children aged under 15 have juvenile arthritis. This equates to as many as 6,000 children and young people in NSW currently diagnosed with JIA (*ACI: Model of Care for the NSW Paediatric Rheumatology Network, 2013*).

Juvenile arthritis can affect joints in the knees, elbows, wrists and ankles, with some children also affected in the eyes, skin or other body tissues. JIA can be so severe that children can have difficulty moving or be unable to move at all. If not properly treated, juvenile arthritis can result in joint damage, growth abnormalities and/or permanent disability.

*See page 18 for a report on juvenile arthritis.*

## Camp Twinkletoes

Camp Twinkletoes for children aged one to eight years, was held over three days in February at Stanwell Park, north of Wollongong. Seventeen (17) families, including 18 children with JIA, their parents and 17 siblings found connection with one another by sharing their experiences in a social setting.

In addition to building a support network, the aim of Camp Twinkletoes is to provide an opportunity for families to learn about JIA, while enjoying a fun family weekend away. The formal program included arts & crafts, kite making, swimming, games, a kids' party entertainer and an information session from Carers NSW. Five volunteers assisted staff to run the program and answer family questions about JIA. Volunteers attend training programs prior to camp.

Almost all attendees who completed the evaluation (12 out of 13) rated Camp Twinkletoes as excellent value for money. We extend our gratitude to all supporters for enabling us to keep this program affordable for families living with JIA.

**“We are not alone, there is always help out there.”**

## Camp Footloose

Camp Footloose is an annual week away organised for children and teens aged 8 to 18 years. Held in the September school holidays, this Camp is about giving children the opportunity to have fun in a non-judgemental setting and feel a sense of belonging.

Children and teenagers attending Camp Footloose meet others who understand their challenges. Between leisure time and enjoying sporting activities, campers learn life skills and coping strategies. We see campers' confidence in managing life with arthritis grow and their self-esteem increases.

Thirty-five (35) children attended our 2015 camp at the Sydney Academy of Sport and Recreation in Narrabeen on Sydney's northern beaches. The campers were supported by a registered nurse and team of 14 volunteer leaders, all who attended a mandatory leader training day. Camp leaders attend the entire week to help create a comfortable environment, support participation in activities and ensure medical needs are attended to.

**“I love Arthritis NSW. Keep up the great work and support.”**

### CAMP EVALUATION

Organising a week-long residential camp requires intensive preparation, as programs are developed, risks identified and mitigated, safety procedures established and information is exchanged between staff, volunteers, parents and guardians. We are working to secure additional funding to ensure the long-term sustainability of camp.

## Future direction

One camp per age group during the year is not enough. We are exploring options to create more opportunities for parents and children living with JIA to connect with one another more often.

## Kidsflix

Kidsflix is a program enabling children with Juvenile Idiopathic Arthritis (JIA) and other disabilities to have an 'out of the ordinary day' with their families at the movies. In addition to the film screening, family entertainment includes costumed performers, face and hand painting, balloon twisting – and in December 2015, children received a visit from Santa.

Kidsflix sessions were held in Shellharbour, Miranda, Erina, Castle Hill, Ballina, Orange, Bathurst, Dubbo, Penrith, Charlestown, Moore Park and Brookvale during the year. Some participating moviegoers were featured in the local press, including the *Daily Liberal* (Dubbo).





Sheila Morris and Jill Majkowycz of Warilla-Shellharbour Branch, 14 August 2015 Picture: Georgia Matts. <http://www.kiamaindependent.com.au>

## Branches & support groups

Arthritis & Osteoporosis NSW branches and support groups operate throughout the state (see page 5). Most groups meet at least one morning or afternoon a month (mid-week).

As well as providing a forum for understanding and friendship, support group activities include information-sharing and fundraising. Some groups organise guest speakers and promote local seminars and events. The Warilla-Shellharbour branch, led by Sheila Morris, celebrated its 30th anniversary in August 2015. In this year's review, we profile the Long Jetty support group (see opposite).

## Warm water exercise

Arthritis & Osteoporosis NSW operates physiotherapist and fitness instructor-led warm water exercise programs in eight locations across NSW (see map page 5). These locations are connected with AONSW support groups. Volunteer-led warm water exercise classes ceased to operate across the state in 2016 due to risk issues identified. We are continuing to work with Local Health Districts and private companies to facilitate sustainable access to these valued programs.

## Telephone Support

Arthritis & Osteoporosis NSW operated a Helpline between the hours of 9am – 5pm Monday to Friday. This service is provided in agreement with Arthritis Australia and its network of affiliates. Staff are authorised to provide general information and support, referral options and details regarding AONSW services.

## Online support groups

Arthritis & Osteoporosis NSW moderated three online support groups on Facebook throughout the year:

- Juvenile Arthritis Support – Arthritis NSW (149 members)
- Young Adults with Arthritis – Arthritis NSW (85 members)
- Arthritis & Osteoporosis NSW (70 members)

These closed groups comprise people living with arthritis and osteoporosis in NSW. Maintaining these closed forums enables people to freely ask questions and share experiences.



## Arthritis Matters

Two editions of *Arthritis Matters* were distributed during the financial year:

- November 2015
- February 2016



## Webinars

In response to feedback and suggestions, we hosted webinars on biosimilars and biologics, nutrition and mindful eating, as well as stress and pain management. Webinars organised by Sydney Medical School's Institute of Bone and Joint Health were also promoted via our website and social media channels.

# Long Jetty support group



*Back row L to R Gillian Willis, Robyn Blom, Carol Noakes. Middle row L to R June Taylor, Sue Perdriau, Gladys Hampson, Marlene Midda. Front row L to R Sheila Wood, Mary Power, Jean Slaughter, Linda Nash, Liz Balean*

The Long Jetty Support Group celebrated its 20th anniversary in 2016. Since its first meeting on 6 June 1996, the group has been a place of mutual support and friendship. Residents in suburbs surrounding Long Jetty have found the motivation to leave the house and live well with chronic pain.

According to the group's current convenor, Liz Balean, a retired nurse, there is nothing quite like talking to people with the same problems. In the case of Long Jetty, the most common link is osteoarthritis.

Since joining the group at her physiotherapist's recommendation, Liz has learnt to live well with osteoarthritis by engaging in hydrotherapy and other exercises such as Tai Chi.

Long Jetty members share a belief in building community knowledge, which is reflected in the group's diligently-maintained meeting records. These records have been preserved largely thanks to former chair, Beryl Evans, who liked to run disciplined meetings. Fellow co-founder, Enid Monaghan, who sadly passed away earlier this year, was also "formidable" at branch AGMs, Liz recalled.

"If nobody put their hand up for a position, Enid would 'encourage firmly' some hapless victim into a position of responsibility... it was in this way that I ended up as chairperson when Beryl finally retired. I admit that I was reluctant at first and only agreed to take it on for a year, but having accepted it, and in the absence of dear Enid

to bully somebody into taking over, I find that I have now had charge of the group for nine years and I freely admit that I still enjoy it," Liz said.

The first guest speaker at Long Jetty, Dr Robert Baume, a local rheumatologist, has been followed by pharmacists, a podiatrist, physiotherapist, local shire councillor, nutritionist, police officers, occupational therapist and many others. The group has also canvassed a range of medical and social topics, including fire safety, hearing, wildlife rescue, dementia and ageing with disability.

For group treasurer, Linda Nash, joining the support group has meant finding invaluable support for her daughter, Kellie.

**"I was blessed to be the camp [Footloose] nurse for almost 20 years. I have met and watched so many amazing young children grow into adults, especially my daughter Kellie who started me in this journey when she was 8."**

LINDA NASH

During its 20 years, the group has moved venues three times and changed structure from branch to support group, but the purpose, friendship and support given and received has remained a constant. In the early days, many married couples attended the group together. These days, Long Jetty is comprised of 15 regular members aged between 55 and 97, three of whom are trained nurses. Members share personal experience while seeking professional medical advice for individual circumstances.

## Thank you

We thank all group members of Long Jetty, as well as all other branches and support groups in NSW, for devoting their time, skills and resources to help others, whether that be through conversation, craft, operating stalls, selling raffle tickets, attending camps, ushering at Kidsflix and/or donating funds to AONSW.

# Research

**The arthritis research laboratories at Westmead Hospital were established in 1997 with the financial aid of Arthritis NSW to promote teaching and research into the cause and treatment of arthritis. The Rheumatology Unit at Westmead is indebted to the AONSW Board and its members for their vision, support and encouragement to find a better solution for arthritic sufferers. The following is an outline of the different projects in progress.**

## **Determining the mechanism and scope of novel anti-arthritic compounds**

Rheumatoid arthritis (RA) is a multifactorial autoimmune disease caused by a combination of genetic and environmental factors. RA leads to an altered immune response that drives inflammation relentlessly. A particular immune cell called a T-cell predominantly drives this aberrant immune response. Under normal conditions, this cell has the ability to recognise something "foreign" and eliminate it from the body. However, there is nothing foreign in rheumatoid; T-cells recognise "self" as foreign and starts attacking itself. What results is painful chronic inflammation involving hands, feet, and large joints of the body.

**(a) Linear peptide:** We have identified a short peptide called 'core peptide' (CP) corresponding to a critical region of the T-cell that acts as an effective inhibitor of T-cell function. When we tested this compound in animal models of arthritis we noted a marked improvement in the animals' symptoms and signs of inflammation. We are extending this work to identify the underlying mechanism of action. We believe that the peptide interferes with the transmission of

information from the cell surface to the nucleus. Since this compound is a peptide, it has the potential to be used for gene therapy. A future project planned for our laboratory is to place this product into a virus that can be used to infect cells and then used for gene therapy in rheumatoid arthritis.

- (b) Cyclic Peptides.** In trying to improve the solubility and half-life of the linear peptide, we cyclized the original peptide, and developed a new compound. This new compound has similar anti-arthritic effects to the original compound but very different features in terms of action. A current focus of research is looking at its effect on pain.
- (c) Computer modeling.** This project focuses on implementing high performance computing to investigate and establish the physico-chemical characteristics of the interaction sites within the T-cell that can then be used to design and examine new targets. So far we have screened 25 million candidates and have narrowed these to 200. Further work in the laboratory will determine which of these possible compounds may be useful in arthritis.

## **Targeted drug delivery for the treatment of arthritis**

Our current paradigm for the treatment of chronic inflammatory arthropathies (joint diseases) is to prevent inflammation, subsequent joint damage and later bone destruction. We are developing new methods of drug delivery that provide specificity and decrease systemic side effects. There are two projects in progress:

- (d)** The search for new synovial biomarker in the lining cells of the joints that could be used for targeting drugs to joints.
- (e)** Cannabinoid-based drugs targeting arthritis. In collaboration with CSIRO, we are examining the ability of synthetic cannabinoid (marijuana) oils to self-assemble and form nanoparticles that can then be targeted to joints. Current experiments are looking at the potential anti-inflammatory and pain relieving



effects of these cannabinoid oils alone without any drugs loaded in them. The potential clinical application is for patients with inflammatory arthritis such as rheumatoid or psoriatic arthritis, as well as degenerative conditions such as osteoarthritis. Use in fibromyalgia patients is another possibility worth investigating at a later stage.

*Pacing and avoidance in chronic pain.* This study, being conducted within the School of Psychology at The University of Sydney, is continuing to invite participants to respond to a questionnaire on activity levels and chronic pain. The study is expected to be completed in late 2017. For further information, please go to <http://tinyurl.com/usydpain>.



**Dr. N Manolios**  
Director of Rheumatology  
Westmead Hospital  
Professor Rheumatology  
Sydney University

## Connecting consumers to research studies

AONSW invited consumers to participate in relevant research studies including:

*Impact of Cane Use in people with medial knee osteoarthritis.* This study, led by Professor Kim Bennell and Dr Ans Van Ginckel of The University of Melbourne (in collaboration with Royal North Shore Hospital Sydney), aims to evaluate the effect of daily cane use on knee joint structure as well as knee pain and function in people with knee osteoarthritis. The research team is still seeking additional participants.

## NSW Arthritis Research Committee

*The aim of this committee is to provide guidance and promote both quantitative and qualitative research. The committee, which reports into the Board, plays an important role in maintaining a research profile. Updates shared via the AONSW website and Arthritis Matters enable members to keep up-to-date with developments and directions of research. In the last financial year there were no grants in aid distributed.*

### Membership

Prof Tanya Meade (Psychologist, UWS), Dr Justin McNab (Epidemiologist, Sydney University), Prof Kevin Pile (Rheumatologist, UWS), Matthew Jennings (Allied Health Director, Physiotherapist, Liverpool Hospital) and Prof Nicholas Manolios (Rheumatologist, Westmead Hospital).

# Juvenile Arthritis

**Dr Davinder Singh-Grewal**



NSW continues to fall well behind national and international standards for service provision in paediatric rheumatology. An analysis published in February 2016 showed a major shortfall in access to service nationally<sup>1</sup>. NSW is also known to have the poorest access to care in public hospitals across all states of Australia. This issue was further highlighted by a NSW patient parent survey published later in the year which showed that:

- more than 40% of children and young people with JIA suffered symptoms for five or more months before the diagnosis was made; and
- more than 40% were seen by four or more health professionals about their symptoms before a diagnosis was made.

In this study, families highlighted the need for improved access to patient educational materials, paediatric rheumatology nurses as part of coordinated care and better education of health professionals to streamline care (including those working in primary care) and prevent delays in diagnosis<sup>2</sup>.

In order to address these concerns, AONSW has worked with the Sydney Children's Hospital Network's (SCHN) Paediatric Rheumatology Network (PRN) through representation on the Network's Steering Committee. This relationship follows on from AONSW's input into the development of The NSW Health's Agency for Clinical Innovation (ACI) Model of Care (MOC) for Paediatric Rheumatology (released in 2013). The Steering Committee has overseen the work of a project officer, jointly funded by the ACI and SCHN, who has mapped the available services, and worked at developing a plan for implementation of some aspects of the MOC.

Furthermore, AONSW in partnership with SCHN, has secured a \$35,000 grant from The Newcastle Permanent Building Society to develop a patient support website for children with JIA and their families. This work is underway and will be completed by early 2017.

While there is still a significant amount of work to be done in improving access to care and services for children and young people with JIA, AONSW and health professionals working within the field are continuing their education, research and advocacy to achieve this outcome.

The PRN was pleased to see children and families participating again in the recreational camps organised by AONSW (see pages 12-13).

<sup>1</sup> Cox, A., Piper, S. and Singh-Grewal, D. (2016), Pediatric rheumatology consultant workforce in Australia and New Zealand: the current state of play and challenges for the future. *Int J Rheum Dis*. doi:10.1111/1756-185X.12802

<sup>2</sup> Coda A, Jones J, Grech D, Grewal DS. *Aust Health Rev*. Survey of parent and carer experiences and expectations of paediatric rheumatology care in New South Wales. 2016 Jul 29. doi: 10.1071/AH16061.

# Fundraising

**Arthritis & Osteoporosis NSW relies on donations and gifts generously given to fund services, which include education programs, support group administration, warm water exercise, stakeholder engagement and advocacy.**

## Bequests

We received \$2,003,973 income in bequests from six individual estates. More than 70 per cent of total bequest income was donated from the estate of Kay Stubbs. A scholarship program has been established in memorium.

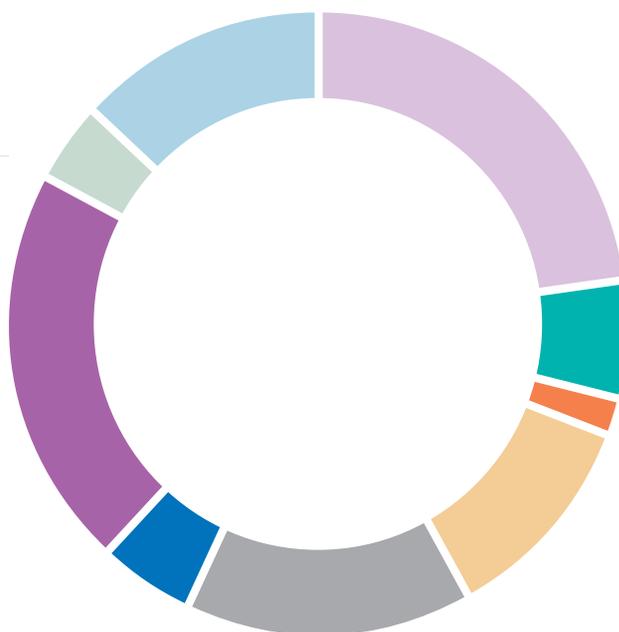
## Appeals and events

In 2015/16, we conducted four appeals which raised \$132,078. Two fundraising events were cancelled during the year because of limited resources.

## Fundraising & Marketing income

### Key

- // Appeals
- // Branch fundraising
- // Advertising
- // Donations
- // Trusts, foundations, grants
- // Workplace giving
- // Kidsflix
- // Community fundraising
- // Merchandise



# Arthritis Australia advocacy update

## Advocating for improved care

Arthritis Australia has continued to advocate strongly to the Australian Government for improved care programs for people with arthritis, based on the recommendations of the *Time to Move: Arthritis strategy* which was launched in 2014. Arthritis Australia's three priority areas for action are: better non-surgical management for people with osteoarthritis; building the rheumatology nurse workforce to provide patient education, support and care coordination and boosting arthritis research funding.

## Input to government inquiries

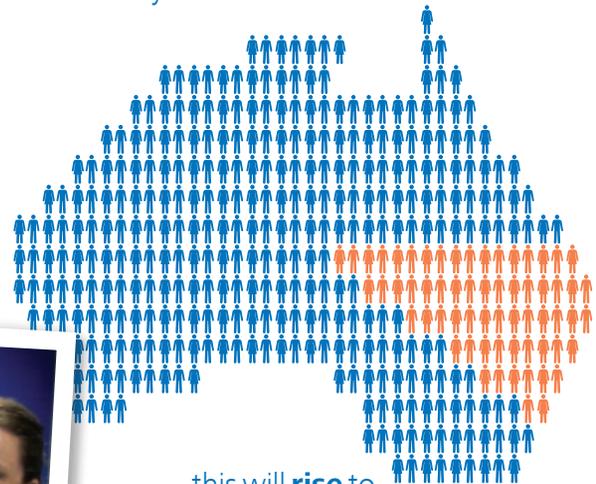
Input was provided to a number of government consultations and inquiries relating to chronic disease prevention and management. Submissions highlighted the importance of providing timely, team-based, patient-centred and coordinated care for people with arthritis, in line with the recommendations of the *Time to Move: Arthritis strategy*.

It was pleasing to hear a trial for a new model of care for people with chronic and complex conditions announced by the Australian Government in March. This aligned closely with many of our recommendations for the provision of improved care for people with arthritis.

## Launch of *Counting the cost: the current and future burden of arthritis*

The report *Counting the cost: the current and future burden of arthritis* was launched during Arthritis Awareness Week in May 2016. This report highlights the personal, social and economic costs of arthritis and supports the case for implementing better programs and policies to support people with the condition. The report, which was sent to all parliamentarians and key policymakers in health, received good media coverage in the lead up to the Federal Election.

**4 million**  
**Australians**  
currently live with arthritis



this will rise to  
**5.4 million**  
by 2030



## #Speakup4arthritis campaign

Arthritis NSW supported the grassroots campaign conducted by Arthritis Australia in the lead-up to the Federal Election in order to raise awareness among politicians of the personal impact of arthritis and why better programs are needed. As part of the #Speakup4arthritis campaign, people with arthritis were encouraged to email their local MP to describe their personal experience of living with arthritis and to seek their support for action on key priorities. Copies of the email were also sent to the Minister for Health and the health spokespeople for Labor and the Greens.

Approximately 450 people sent emails to their local MP and to the Minister for Health as part of the campaign. The campaign received positive feedback, with a number of people commenting that they had not realised that there were so many different forms of arthritis or that it affected so many younger people.

## Supporting consumer education on biosimilars

An information sheet for people with arthritis taking infliximab was developed following the introduction to the Australian market of a biosimilar version of this medicine. Biosimilars are copies of biologic medicines that are similar, but not identical to, the original medicine. This information sheet highlighted the importance of people making an informed decision, in consultation with their rheumatologist.

Arthritis Australia is also participating in a Reference Group for the Australian Government's Biosimilars Awareness Initiative, with the aim of supporting safe and effective use of biosimilars for people with arthritis. This Initiative is developing an education program for consumers, prescribers and pharmacists to support the uptake of biosimilars.

## Project effectiveness

Advocacy by Arthritis Australia and other stakeholders in the area of chronic disease management is starting to lead to significant reforms to the way in which people with chronic conditions are managed in primary care. Under major reforms announced by the Australian government in March 2016, a new model of care for people with chronic and complex conditions will be trialled, based on the concept of a Health Care Home.

Under this model, eligible people can enrol with a participating medical practice (usually a GP) that will provide a home base for developing and delivering a tailored, coordinated, integrated team care plan to help the person to manage their condition. This model aligns closely with key recommendations from the *Time to Move: Arthritis strategy* and ongoing advocacy representations.

## Future outlook

In the year ahead, Arthritis Australia will continue to work with government, health professionals and other stakeholders to promote and implement key elements of the *Time to Move: Arthritis strategy*.

It will also:

- engage with Primary Health Networks implementing the Australian Government's Health Care Homes trial;
- engage with stakeholders to further develop the proposal to build the rheumatology nurse workforce to provide education and support for people with inflammatory arthritis; and
- assess geographical access to specialist rheumatology services across Australia.

# Our stakeholders

People living with arthritis, osteoporosis and other musculoskeletal conditions in NSW



**AONSW members**



**Corporate foundations**



**Volunteers**



**Hospitals**



**Branches and support groups**



**Retirement villages**



**Donors**



**University medical schools**



**General practitioners**



**Community groups**



**Allied health professionals**



**Arthritis Australia and affiliates**



**NSW Local Health Districts**



**Osteoporosis Australia**



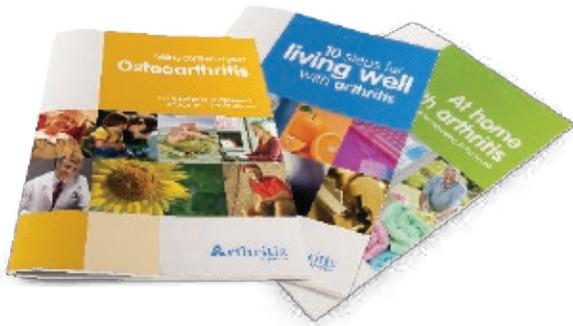
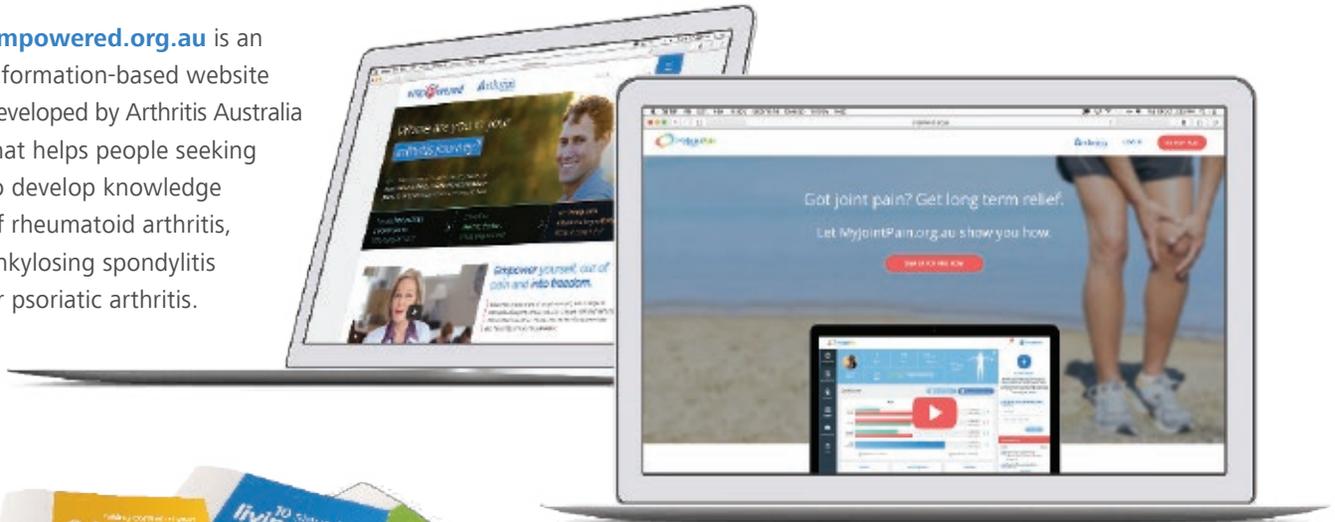
**Pharmaceutical companies**



**Professional associations**

# Arthritis information

**Empowered.org.au** is an information-based website developed by Arthritis Australia that helps people seeking to develop knowledge of rheumatoid arthritis, ankylosing spondylitis or psoriatic arthritis.



Developed by Arthritis Australia and medical experts, **myjointpain.org.au** features a range of on-line tools and information. It is easy and free to use.

## Information Booklets

The following information booklets are available as PDFs on [arthritisaustralia.com.au](http://arthritisaustralia.com.au).

- 10 steps for living well with arthritis
- Taking control of your Ankylosing spondylitis
- Taking control of your Back pain
- Taking control of your Gout
- Joint replacement – *A practical guide to understanding joint replacement surgery*
- Taking control of your Osteoarthritis
- Taking control of your Psoriatic arthritis
- Taking control of your Rheumatoid arthritis
- Stepping out – *A guide for young adults with arthritis*
- At home with arthritis – *Simple steps for managing in the home Juvenile arthritis*
- Juvenile arthritis – *A teacher's guide*

## Information Sheets

Arthritis Australia has developed a series of information sheets. These can be accessed online or by calling AONSW on **9857 3300**.

- Arthritis in specific areas of the body;
- Complementary therapies/supplements;
- Condition specific;
- General management:
- Juvenile idiopathic arthritis (JIA);
- JIA medicines; and
- Medical management.

A series of fact sheets are available in **Arabic, Chinese, Croatian, Greek, Italian, Korean, Macedonian, Persian, Spanish and Vietnamese**.

# Statement of Profit or Loss

and other comprehensive income  
for the year ended 30 June 2016

	2016 \$	2015 \$
Revenue	2,671,839	2,283,391
Other income	209,047	205,621
Employee benefits expense	(997,870)	(957,713)
Depreciation and amortisation expense	(49,398)	(47,626)
Education expenses	(102,234)	(91,566)
Marketing and fundraising expenses	(458,467)	(359,976)
Other expenses	(488,433)	(279,365)
<b>Profit before income tax</b>	<b>784,484</b>	<b>752,766</b>
Income tax expense	-	-
<b>Profit for the year</b>	<b>784,484</b>	<b>752,766</b>
<b>Other comprehensive income:</b>		
Changes in fair value of available-for-sale financial assets	(32,648)	(83,835)
<b>Other comprehensive income for the year, net of tax</b>	<b>(32,648)</b>	<b>(83,835)</b>
<b>Total comprehensive income for the year</b>	<b>751,836</b>	<b>668,931</b>

# Statement of financial position

as at 30 June 2016

	2016 \$	2015 \$
<b>ASSETS</b>		
<b>CURRENT ASSETS</b>		
Cash and cash equivalents	1,746,088	2,354,006
Trade and other receivables	30,440	115,721
Inventories	627	-
Financial assets	-	1,846,025
Other assets	11,650	5,907
<b>TOTAL CURRENT ASSETS</b>	<b>1,788,805</b>	<b>4,321,659</b>
<b>NON-CURRENT ASSETS</b>		
Financial assets	4,006,677	755,718
Property, plant and equipment	1,177,962	1,198,973
<b>TOTAL NON-CURRENT ASSETS</b>	<b>5,184,639</b>	<b>1,954,691</b>
<b>TOTAL ASSETS</b>	<b>6,973,444</b>	<b>6,276,350</b>
<b>LIABILITIES</b>		
<b>CURRENT LIABILITIES</b>		
Trade and other payables	122,545	175,303
Employee benefits	17,428	19,412
<b>TOTAL CURRENT LIABILITIES</b>	<b>139,973</b>	<b>194,715</b>
<b>NON-CURRENT LIABILITIES</b>		
Employee benefits	-	-
<b>TOTAL NON-CURRENT LIABILITIES</b>	<b>-</b>	<b>-</b>
<b>TOTAL LIABILITIES</b>	<b>139,973</b>	<b>194,715</b>
<b>NET ASSETS</b>	<b>6,833,471</b>	<b>6,081,635</b>

# Statement of changes in equity

For the year ended 30 June 2016

	2016 \$	2015 \$
<b>EQUITY</b>		
<b>Reserves</b>	(12,885)	19,763
Retained earnings	6,846,356	6,061,872
<b>TOTAL EQUITY</b>	<b>6,833,471</b>	<b>6,081,635</b>

	Retained Earnings \$	Fair Value Reserve \$	Total \$
<b>2016</b>			
<b>Balance at 1 July 2015</b>	6,061,872	19,763	6,081,635
Profit attributable to members of the entity	784,484	-	784,484
Net change in fair value of available for sale financial assets	-	(32,648)	(32,648)
<b>Balance at 30 June 2016</b>	<b>6,846,356</b>	<b>(12,885)</b>	<b>6,833,471</b>
<b>2015</b>			
<b>Balance at 1 July 2014</b>	5,309,106	103,598	5,412,704
Profit attributable to members of the entity	752,766	-	752,766
Net Change in fair value of available for sale financial assets	-	(83,835)	(83,835)
<b>Balance at 30 June 2015</b>	<b>6,061,872</b>	<b>19,763</b>	<b>6,081,635</b>

# Statement of cash flows

For the year ended 30 June 2016

	2016 \$	2015 \$
<b>CASH FLOWS FROM OPERATING ACTIVITIES:</b>		
Receipts	2,785,494	2,748,245
Payments to suppliers and employees	(2,108,117)	(1,689,966)
Interest received	61,950	75,975
Dividends received	118,724	117,045
Net cash provided by (used by) operating activities	858,051	1,251,299
<b>CASH FLOWS FROM INVESTING ACTIVITIES:</b>		
Purchase of property, plant and equipment	(28,387)	(25,341)
Purchase of available-for-sale investments	(1,437,582)	(154,887)
Net cash provided by (used by) investing activities	(1,465,969)	(180,228)
Net increase (decrease) in cash and cash equivalents held	(607,918)	1,071,071
Cash and cash equivalents at beginning of year	2,354,006	1,282,935
Cash and cash equivalents at end of financial year	1,746,088	2,354,006



 **Arthritis &  
Osteoporosis**  
NEW SOUTH WALES

**Arthritis &  
Osteoporosis NSW**

Locked Bag 2216  
North Ryde NSW 1670

Phone: 02 9857 3300

Fax: 02 9857 3399

Helpline: 1800 011 041

[www.arthritisnsw.org.au](http://www.arthritisnsw.org.au)

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