# **ANNUAL REPORT 2019**







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# **ARTHRITIS NSW**

Arthritis NSW is a charitable and membership-based organisation that works to improve the lives of those affected by arthritis, osteoporosis and other musculoskeletal conditions. We work to empower the individual to manage their own condition and health, to achieve their personal meaning of our vision, *Freedom from arthritis*.

The organisation is a trusted source of evidence-based and up-to-date information on arthritis and its treatment, with education programs delivered via community awareness sessions and webinars. Our health services team develops and delivers exercise programs tailored to the needs of people affected by arthritis, such as the popular Warm Water Classes and Strength & Balance Classes. We deliver two annual camps for children affected by juvenile arthritis: Camp Twinkletoes for children under 8 years old and their families, and Camp Footloose for children and young people aged 9 to 18 years.

We engage with the community through our membership program, publications such as *Arthritis Matters*, eNewsletter subscriptions, and social media such as Facebook, Instagram, Twitter and LinkedIn. We also have our toll-free Arthritis Infoline which connects callers with health professionals via a call-back service.

#### **Our vision**

Freedom from Arthritis

#### **Our priorities**

- Provide support, advice and information for people with arthritis or other musculoskeletal conditions and their families
- Provide programs to raise awareness of issues associated with arthritis for the community and health professionals
- Empower people to develop skills to manage their own health
- Work with health professionals to improve management of arthritis and early diagnosis
- Support and conduct research into the effective management of arthritis and other musculoskeletal conditions.

#### **Our mission**

To provide excellence in services that promote the prevention and management of arthritis and osteoporosis in NSW.

#### **Our values**

- Collaboration
- Courage
- Commitment and Passion
- Teamwork and Co-operation
- Authenticity
- Compassion
- Respect for people
- Support



## Warm water classes

- Campsie
- Castle Hill
- Epping
- Lane Cove
- Potts Point
- Ryde/Putney
- Wollongong

## KidsFlix

- Ballina
- Bankstown
- Blacktown
- Bondi Junction
- Brookvale
- Erina Fair
- Newcastle
- Orange
- Penrith
- Warrawong

## Children's camps

- Narrabeen
- Lane Cove

## Rural health events

- Albury
- Bathurst
- Henty
- Macksville
- Parkes

# PRESIDENT'S REPORT

My task as President is to expand the very good foundations introduced by former President, Allan Ryan, to establish a Board culture that takes us forward, structured to face the challenges presented for not for profit organisations.

#### **Shared objectives**

Our Board has changed substantially over recent years and has an excellent representation of qualified Directors, businesspeople and health specialists. Our focus has not only been on financial stability and sustainability, but also on ensuring that our objectives are shared by all stakeholders including staff, consumers, members and suppliers. This has been achieved by improving communication, largely through our magazine, eNews and expanding our community health programs which have been so well received. In this respect, our support groups play an important role by sharing information and providing a social connection to others living with arthritis and related conditions.

Of particular note is our Rural Health Initiative which expanded our reach into many more rural communities who embraced our presence to help them live well with arthritis and osteoporosis. We have also doubled the number of our successful children's camps this coming year, offering young people a safe, supervised environment to explore their capabilities and share experiences with others who understand.

#### New three-year strategy

The Board always keeps in mind that the purpose of the organisation is to deliver health services to people who live with arthritis to help improve their lifestyle. In early 2020, the Board will develop the next three-year strategy to build on our established health services and community relationships and explore new horizons to create opportunities.

Our financial statements highlight our dependency on the generosity of people in the form of bequests and donations. There is strong competition among charities for a share of these funds and in these uncertain economic times, there is less available to go around. This is a priority for the Board as it develops the new strategy so Arthritis NSW can continue to enhance the services that it delivers to benefit the community.

#### Thank you

We thank all our supporters and want them to know they are making a substantial difference to the lives of many people with their generosity.

Thank you to our CEO Sandra Vincent and her dedicated team for creating and delivering the valuable programs and promoting the services that are offered to our varied communities.



Late

**Nigel Corne** // President Arthritis NSW

## Farewell and thank you

Allan Ryan served as President of the Arthritis NSW (ANSW) Board from November 2015 – 2018 and will resign his position as Director later in 2019. He shares below the achievements that he believes steered ANSW to become the practical health services organisation it is today.

Arthritis NSW is a strong, focused organisation dedicated to providing health services and education across all ages and areas impacted by arthritis in NSW. While President of the Board and with all Directors, I was privileged to set this agenda, which was achieved thanks to our CEO Sandra Vincent and her team.

We began with the decision to take ANSW back to basics: to deliver evidence-based health information, education and exercise programs to people living with arthritis.

To widen our reach geographically, we addressed the lack of health information and services in rural areas by trialling and adopting the Rural Program. To date, the Health Team has visited five rural centres and delivered the presentation *Living Well with Arthritis* to warmly appreciative audiences.

We expanded ANSW's health services with the Strong Program, which paired the warm water exercise classes with a new land-based exercise program, researched and developed for ANSW by a health professional from a leading Sydney hospital. This marked our decision to increase funding to practical research and clinical governance to improve the quality of our health services. The ANSW Clinical Governance Framework, developed in 2017, ensures that all our programs and services are safe,

efficient, effective, appropriate, personcentred and equitable.

Finally, the introduction of the social media program hugely increased our engagement with people who look online for information on arthritis. Their interaction with ANSW and each other enriches our understanding of this community and their needs.



# CEO'S REPORT

Welcome and thank you to all our members, existing and new. I would like to take this opportunity to thank those people who have donated so generously to support the programs at Arthritis NSW.

Our support groups continue to play an integral role helping each other and providing opportunities for friendship. Some have been extremely active in their fundraising efforts to support the camps for children. Thank you.

Arthritis NSW has been a hive of activity in 2018-19 and the team has worked hard to reach more people across NSW through our Rural Heath Initiative. Thank you to those people who generously donated to this program. Without you, it would not have been possible.

#### Strategy and business update

We have had a very productive year and I am very proud of the achievements that are continuing to support people to live well with arthritis. We have continued to focus on the individual to provide more services and support, reach and engage more people through digital platforms, education events, business events and face-to-face.

Key achievements include:

- Development of the model for data capture to enable us to continue to review the impact of our service and which commenced with Camp Footloose
- Growth of our land-based and therapeutic warm water exercise classes
- Our Rural Health Initiative, providing information to more people through community education seminars across four rural districts
- Application of our revised and approved Clinical Governance Framework principles across all services to ensure that we meet National Quality Health Care Service Standards
- Growth in our online communities
- Development and implementation of our Business Continuity Plan (cyber security)
- Development and implementation of our Incident Management Plan (cyber security)
- Development and Go Live of our website, including web host services
- Increased presence and solid relationships built at retirement villages, and with community groups and clubs across NSW
- Development of targeted bequest campaigns
- Increased PR and media presence across print, digital, and radio for rural health and children's services.

#### **Financial result**

Our financial result for 2018/19 was a shortfall of just \$140,010. This result occurred across a landscape of spending to enhance our services and expand our community reach.

We continue to face challenges in raising funds through donations. Competition for donor dollars remains competitive with more than 55,000 charities in the country. Economic uncertainty reported in last year's report remains a constant that continues to affects giving.

The 2018/19 Financial Report shows that bequests remain our single biggest source of income. These very generous donations have supported the shortfall in funds needed to provide services such as community education, camps for children, warm water exercises, and strength and balance classes. Some of these funds were allocated to advocacy activities through public relations and by engaging the media to give a voice to children with arthritis. Currently, there is a serious shortfall in funding provided by Government for children in need of rheumatology services in NSW, which currently fall well short of international guidelines. We are seeking to improve this by raising public awareness because it's important that we advocate for our kids.

#### Thank you

I would like to thank our major benefactors, corporate sponsors and those who have contributed to the organisation. Thank you also to the members for their support and loyalty in continuation of their membership.

Thank you to the Arthritis NSW team, whose enthusiasm, resilience and support is inspiring and unwavering, and to those who volunteer their time to assist us deliver our services to help people live well with arthritis.

Sandra Vincent // CEO

Sancta Vincent

Arthritis NSW



# BOARD MEMBERS: 1 JULY 2018 - 30 JUNE 2019



Nigel Corne
President
BE, FCIA, GAICD
Appointed: 26 October 2016

Nigel is an experience and qualified Chairman and Director of listed public, unlisted public and private

companies. Past roles include National Chair of the Australian Hotel Association (Accom), Vice President of AHA NSW, Director of Sydney Convention & Visitors Bureau and Managing Director of Tourism, Hotels and Leisure Limited. Nigel has extensive non-executive committee and management experience in the industries of tourism and hospitality, franchising and trade and investment, together with community service organisations and not for profits, Nigel is President of Arthritis NSW and Chair of the Governance and Strategy Committee.



**Allan Ryan**Director (immediate past President)

BSc (Hons), MEng. Sci., MAICD Appointed: 28 March 2012

Allan Ryan is a leading researcher and consultant who provides expert advice

to businesses to improve performance and be sustainable in today's rapidly changing world. He is an Adjunct Professor at the UTS Business School, founder and Executive Director of Hargraves Institute and Director at Managed Innovation International. Before starting research at the Australian Graduate School of Management he spent 13 years in senior executive roles in a leading not for profit organisation.



Murray Smith
Vice President/Honorary
Treasurer
BA Bus, CA, GAICD, FAPI
Appointed: 26 October 2016

Murray is a non-executive company director and chartered accountant

with specialist restructuring and insolvency skills. Murray was previously a partner at McGrath Nicol and KPMG, having spent over 30 years working with troubled and impaired businesses, and advising banks, corporations and Government. After retiring from professional practice in 2014, Murray commenced non-executive director roles with Slattery Auctions Australia and the Independent Liquor & Gaming Authority. Murray has both personal and family experience with osteoarthritis.



Peter Stewart
Company Secretary
MA MBA Bachelor of Laws LLB
Appointed: 31 July 2018

Peter is an accomplished commercial lawyer who brings broad-ranging legal expertise, extensive senior management

experience, and a high level of commercial acumen to his role as Company Secretary. Peter also has extensive experience in advising within the for-profit and not-for-profit sectors.



Anne Carroll
Director
BHSc (N), Masters in Public Health
(MHP), MAICD
Appointed: 3 December 2018

Anne is a qualified registered nurse who has held many senior management

positions within the profession, including health management consultant and hospital director.

Anne is committed to aligning organisational missions and values with strategy, focusing on ethically responsible action principles, and promoting positive and sustainable outcomes for members, staff and the wider community. She holds a Masters Degree in Public Health.



**Dr Davinder Singh-Grewal** Director

MBBS FRACP MMedSci PhD MAICD Appointed: 15 May 2018

Dr Davinder Singh-Grewal is a paediatric rheumatologist. He is appointed at The Children's Hospital

at Westmead, The Sydney Children's Hospital at Randwick and The John Hunter Children's Hospital in Newcastle. Davinder is a Clinical Associate Professor at both The University of Sydney and The University of New South Wales. He has completed a PhD in the field of Juvenile Arthritis and also a Masters in Medical Science.



Lynn Garlick

Director (former)

BA Social Work, MA Journalism Appointed: 30 November 2016 Resigned: 21 July 2018

Lynn is an experienced communication,

engagement and consultation professional. She has a depth of expertise in the health, corporate communication and education industries and she has lectured at university in the fields of writing and social work. She is also an International Yoga Teachers Association (IYTA) qualified yoga teacher.



Robert Lagaida
Director

BEc, MCom, Grad Dip Information Systems, FCPA, GAICD Appointed: 15 May 2018

Robert is a former Executive Director of Finance, Commercial and corporate

Services of HealthShare NSW and eHealth NSW. He retired in late 2017 and was recognised in the 2018 Australia Day Honours list and awarded the Public Service Medal for outstanding public service to financial management in the health care sector in NSW.



**Rebecca Partington**Company Secretary (former)

LLB

Appointed: 15 May 2018 Resigned: 31 July 2018

Rebecca was appointed Company Secretary on a temporary basis after

Andrew Mok resigned due to ill health in February 2018. She resigned on 31 July when the permanent Company Secretary Peter Stewart was appointed. We thank her for her time and expertise.



Cosimina Pupo
Director (former)

Cert (Mgt), Dip (Counselling) Appointed: 19 December 2007 Resigned: 26 November 2018

Cosi is a senior probate paralegal and former director of the Independent

Living Centre. She is involved in the Tutor Patient Partner Program, 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. The Board is currently supported by three committees, the Clinical Governance and Research Committee, the Finance Risk and Audit Committee and the Governance and Strategy Committee. These committees support the Board and management team to oversee and implement principal activities.

Director information is current as at October 2019.

# PERFORMANCE OVERVIEW

The first priority of Arthritis NSW is to deliver our health and education services, such as our gentle exercise classes, children's camps, and rural seminars to people living with arthritis. Our yearly performance also includes running fundraising appeals, developing business partnerships, raising our online profile and lobbying government for improved funding and services to treat juvenile arthritis. We achieved all of these objectives, and have planned many more, thanks to our donors in 2018/19.

## Memberships



2,446

Memberships including 144 families



18

Branches and support groups

## Children's camps



28

Children @ Camp Footloose



9

Families @ Camp Twinkletoes

#### **Publications**



3

Issues of *Arthritis Matters* magazine published and sent to members



2,725

Subscribers to monthly eNewsletters

# **Health promotion**



1,032

Community education participants across 45 sessions



178

Participants in warm water classes across 6 locations



413

Arthritis Infoline callers



13

Strength and Balance class participants



536

Rural Program participants across 9 sessions

## Social media



4.688



1,579



1228



189

## **Our office**



11 Staff

### Regular volunteers



4 regular, 18 for camps and 44 Kidsflix.

## Partnership development



Bowls NSW CSR Gyprock Nurses & Midwives Association Riverside Business Chamber

#### **Professional committees**

Musculoskeletal Advisory Committee: Agency for Clinical Innovation

Stream Health: Clinical Academic Group Paediatric Rheumatology Network GAP Standing Committee on Productive Ageing Transport Advisory Group

## Fundraising appeals



Christmas Appeal 2018: **\$27,045** Tax appeal 2018: **\$10,422** 

### Support groups



Support group fundraising: **\$3,150** 

### Financial result

Revenue 2018/19:

\$1.27m

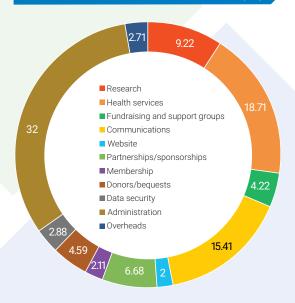
(2017/18: \$1.23m)

Net result 2018/19:

-\$140,010

(2017/18: -\$337,880)

## How resources were used (%)



#### **Resource application descriptions**

**Research:** Review, evaluation and development of programs; Rural Health Initiative

Health Services: Development, delivery and promotion of health services. Includes Infoline, warm water exercise, Strength and Balance, community education, children's camps

Fundraising and support groups: costs to run appeals and liaison with support groups

**Communications:** Publications (Arthritis Matters x 3 and Annual Report), social media, eNewsletter, eDMs, PR / media

**Website:** Development of website and integrated systems

#### Partnerships / sponsorships:

Development and management of partnerships and supporting materials

**Membership:** Promotion of membership, administrative costs of memberships

**Donors and bequests:** Engaging with donors and processing donations, engaging with bequestors and processing bequests

**Data security:** IT support, database management, security upgrades

Administration: Learning and development, administration and finance, accounting fees, stationary, postage, printing, AGM, expos, meetings

Overheads: Utilities, strata levies

# STRATEGIC DIRECTION 2017–2020 FREEDOM FROM ARTHRITIS









# Structuring for Growth



- Development of consumer engagement model
- Development of corporate partnerships
- Realignment of systems for growth

# **Empowering the Individual**



- Full review and evaluation of programs
- Development of new services
- Development of clinical governance and research framework





# Sustainability and Growth

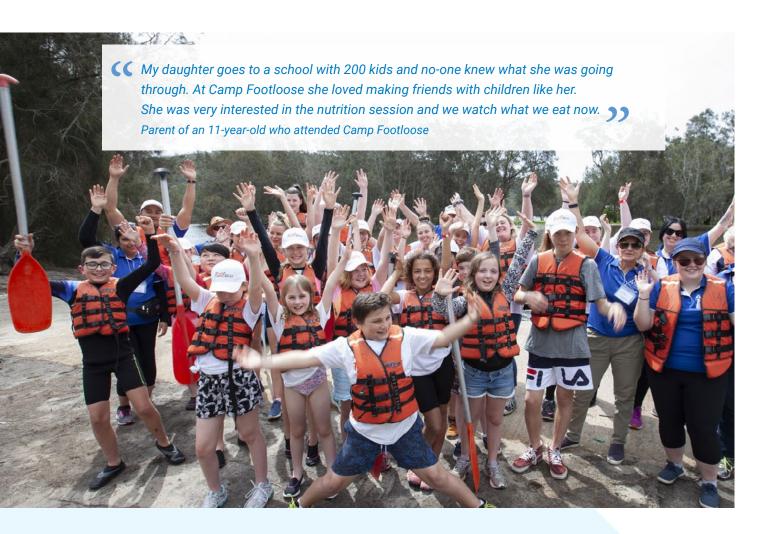


- Development of bequests and major donor program
- Identification and development of new communities across NSW
- Development of internal capabilities to support growth
- Development of brand value









# SUPPORTING COMMUNITY

Arthritis NSW serves the community through our membership program, health services, support group network, publications such as *Arthritis Matters*, eNewsletter, social media, and a toll-free Arthritis Infoline which connects callers with health professionals.

We work towards our vision *Freedom from arthritis* through the following four priorities:

- prevention of disease
- management of conditions
- understanding and support
- research towards improved treatments.



#### **Support groups**

Across NSW we have 18 support groups, a collective of likeminded people who provide support for people who have daily challenges living with arthritis. Our support groups empower and encourage people to self-manage their condition in a supportive environment. The NSW support groups provide:

- Social and friendship support where members have a common understanding of their conditions.
- Sharing of current and new information for their condition within their group and local communities.
- Some groups have guest speakers to their meetings, such as physiotherapists and dieticians.
- Fundraising support for children's camps.

#### **Community education**

The Arthritis NSW Community Education Program gained traction in 2018/2019 with 45 presentations made to more than 1000 people. As well as increasing attendee numbers, we diversified our audiences with presentations not only to support groups, but also to friendship groups, computer groups, Lions and Probus Clubs, 60 Plus, nursing home residents and carers, and retirement villages. The presentation *Living Well with Arthritis*, gives support strategies around nutrition, exercise, and pain management to help people improve their daily lives.

#### Warm water exercise



Our warm water exercise classes are offered over six Sydney locations: Campsie, Castle Hill, Epping, Lane Cove, Potts Point and Ryde and also now in Wollongong. This year we increased the number of classes to 19.

An education component introduced in 2018, consisting of a weekly email message to participants, has been a success with positive feedback from participants and instructors. The messages help to improve the participants' awareness of their condition and the strategies they can use to better manage their condition and health.

Warm water exercises are soothing and help me to stay mobile. It's also helpful to share my concerns with others doing the exercises who have similar conditions.

#### Rural health

Last year, Arthritis NSW trialled a rural health initiative to address the lack of information about arthritis in rural NSW. Funded by a successful Christmas Appeal, our Health Team delivered a series of free seminars on Living Well with Arthritis to audiences in Bathurst, Parkes, Macksville, Henty and Albury. Most of these visits coincided with local agricultural or industry shows which gave us more opportunities to engage with the local residents in need of strategies to manage their musculoskeletal conditions. After speaking to more than 500 people and reaching even more through local media campaigns, it was decided to embed the Rural Health Initiative into our annual calendar. The team returned to Bathurst in May to determine if there had been any uptake of the health strategies presented nine months earlier and found that many people had adopted them at varying levels. The organisation has committed to delivering this program going forward.

#### Telephone support

Arthritis NSW operates a toll-free call back service which connects callers with a member of our Health Services Team who answer questions, give advice and often direct the caller to more resources or refer them onwards to further treatment. Although every caller to Infoline has the right to remain anonymous, each call is logged with information such as the reason for the call and the advice given. The Infoline service is provided in agreement with Arthritis Australia and its network of affiliates.

#### Online support group

Arthritis NSW moderates an online support group on Facebook for children with arthritis and their families. The Juvenile Arthritis Support Group has 232 members who freely ask questions and share experiences.

#### Our social media community

Arthritis NSW has an engaged and growing community on Facebook, Twitter, Instagram and LinkedIn. Facebook is a strong platform for the organisation's awareness campaigns and dissemination of health information and our services. We are also focused on building our Instagram audience, a great platform for connecting with a younger audience and important for building our future community.

#### **Arthritis Matters**

Arthritis Matters is the organisation's member magazine. We produced three editions during 2018–2019.



#### eNewsletter subscribers

Each month Arthritis NSW delivers an electronic newsletter to 1315 members and 1410 subscribers.

#### Strength & Balance



Our Strength & Balance Program was trialled last year as a land-based exercise class that complemented our warm water classes. Developed in line with the latest clinical practice, the Strength & Balance program now runs classes for three groups at the YMCA Epping and North Sydney Community Centre twice a week.

((

'Our instructor does a very good job and has helped with my mobility and given me the confidence to go about my daily tasks. After just a few weeks, I feel strong enough to dance again and I can now bend my knees to pick paper off the ground.'

#### **Camp Twinkletoes**

Camp Twinkletoes is an event designed to help families caring for young children with juvenile arthritis. The program provides education for parents, fun for the children with arthritis and their siblings, and experience sharing between families.

This year, the Heath Services Team delivered Camp Twinkletoes to nine families on May 4–5, at Naamaroo, a group venue in bushland setting next to Lane Cove National Park.

Specialists in paediatric rheumatology and psychology presented education sessions to the parents while their children, a total of 17 including siblings, were entertained by a team of volunteers with games, arts and craft, a native wildlife petting zoo and meditation.

Arthritis NSW has committed to delivering two Camp Twinkletoes events in the coming year: one in Sydney and one in Dubbo, to reach families with children living with juvenile arthritis in rural areas.

#### **Camp Footloose**



Camp Footloose is a week-long sport and recreation camp for kids aged nine to 18 who have arthritis. Apart from having a lot of fun and meeting others like them, the children share experiences in a supportive environment and gain a sense of control over arthritis and their lives.

In October 2018, 28 children attended Camp Footloose at the Sydney Sport and Recreation Centre at Narrabeen. They were supervised by dedicated team leaders and staff through activities such as kayaking, rock climbing and archery. Education sessions gave them the opportunity to ask questions of trained professionals and strategies to help them manage their condition at school and at home.

#### **KidsFlix**

Kidsflix is a program enabling children with juvenile idiopathic arthritis 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, children receive a visit from Santa.

# MACARTHUR SUPPORT GROUP



Arthritis NSW has 18 support groups who help create our community and raise funds for our programs using their considerable baking and craft skills. They also welcome new members and give them space to talk about their condition in a social and supportive environment.

The Macarthur Arthritis Support Group is a collection of enthusiastic people who came together in late 2010 in response to a local newspaper article calling for interest in founding a Macarthur branch of Arthritis NSW. Group coordinator Beth Michie recalled that half a dozen people replied to Camden resident Carol Vleeskens and the inaugural meeting was held at the Campbelltown library. 'Carol was the original convenor, and a great group leader for the past eight years. We are now a much larger group with usually 25 to 30 at our regular meetings, and a membership base of 34 that is quite multicultural, and spans the age range,' Beth said.

'We don't like to be defined solely by a disease or disability so our speakers will sometimes address us on issues related directly to arthritis, but not always. We have also had speakers from the police safety unit, My Health Record, Guide Dogs Australia, and the fire brigade. On one occasion, a horticulturist to show us how to propagate plants,' she said. 'We've visited the Independent Living Centre, and we never miss the opportunity to visit Mt Annan Botanic Garden on our birthday meeting in August and at Christmas.'

#### Special activities

The group has two activities that engage and inspire the members.

#### Trading table

The trading table is very popular. Everyone brings something that they are willing to part with, for example a book, mug, or a plant anything really. Members purchase a \$2 ticket and, at the end of the meeting, the tickets are drawn. When your ticket is drawn, you get to choose an item from the trading table. This is the group's major form of fundraising.

#### Community garden

The group has their own section in the community garden situated adjacent to the Campbelltown Library where they still hold their meetings. They have been provided with a waist high garden bed, and one of their members Carolyn, co-ordinates the plantings and their care. 'This is a very new activity and we are still in the learning stage, but it has great promise, and we fully expect to have more members involved,' said Beth. 'The help provided by the regular members of the community garden makes this possible.'

#### Walks

In the warmer months, the group are active outdoors, usually with a walk that is reasonably easy, but not without some challenge. 'The walks have been very popular, and not just with the younger members. We've been to the river to see native orchids and platypus swimming about,' Beth said.

#### Meetings

Generally, the group plans their program about a year in advance. 'Our meetings are flexible, but generally a welcome, update, finance, a speaker, morning tea, trading table, and information regarding activities planned between meetings,' Beth said. 'During the tea break, everyone has an opportunity to chat and speak in depth with our guest speaker if they wish. There is a gold coin entry fee donation and a small fee for morning tea. The entry donation covers cost of room hire and any funds remaining are donated to Arthritis NSW.

## **Vale Doris Carrall**



This year Arthritis NSW was saddened by the loss of Doris Carrall, former Board Director and convenor of the Ryde Support Group. Doris joined ANSW as a member in 2006 and initially worked as a volunteer in our office. She became active in the Ryde group and eventually led

them with enthusiasm and compassion. She was also an avid participant of our warm water classes and encouraged others to join in and experience the benefits. During her time on the Arthritis NSW Board Doris enriched the Directors' knowledge and understanding of our support groups and their daily challenges living with arthritis. Her friends and colleagues in both groups will miss her very much.



# **FUNDING**

Thank you to all Arthritis NSW donors and supporters who gave so wholeheartedly in 2018/2019 to improve the lives of people of all ages who are living with arthritis and other musculoskeletal conditions.

A total of \$104,271 was raised this year. This consisted of: \$27,045 from the Christmas Appeal for rural health; \$10,422 from the Tax Appeal for children's camps; \$3,150 from our support group network, and our thanks go to them for their hard work and support; \$12,235 to further assist in the running of the camps; and \$51,419 in general contributions and regular giving.

With these funds, Arthritis NSW was able to run a series of health education events in rural NSW, engaging with more than 500 people who are living with arthritis and actively seeking guidance to improve their lives. We also ran Camp Twinkletoes to help educate parents of young children on how to manage juvenile arthritis and Camp Footloose to give teenagers support and encouragement in a fun and shared environment.

#### Other funding



Arthritis NSW also receives income from the delivery of our programs and services such as children's camps, gentle exercise classes and membership fees. Additional income from camp registrations totalled \$7,386. Our Warm Water Exercise classes and Strength & Balance classes generated

\$102,276 in income, and Kidsflix brought in \$79,699. Income from membership fees totalled \$51,494.

#### **Arthritis today**

Here are the latest statistics on arthritis, a reminder to us all why your support is so important to the work we do.

- 3.9 million Australians have arthritis. That's 1 in 6 people
- By 2030, it is projected there will be 5.4 million Australians with arthritis
- Arthritis cost the health system \$5.5 billion in 2015. This will rise to \$7.6 billion by 2030



- 52,000 people (aged 15–64 years) are unable to work due to arthritis
- There are more than 100 different types of arthritis
- Most forms of arthritis are thought to be autoimmune conditions, where the body's immune system attacks its own joint tissues
- Osteoarthritis, rheumatoid arthritis and gout are the most common forms of arthritis
- Arthritis is the single most significant cause of chronic pain and disability in Australia.
- People of any age and background can get arthritis, including children and young people.
- In NSW there are 3000 children currently being treated for juvenile arthritis.
- Two-thirds of adults living with arthritis are of working age.

#### **Bequests**

To those who chose to leave a gift in their Will to Arthritis NSW, we extend our deepest thanks and appreciation. Thank you also to the families of those whose legacies were realised in 2018/2019.

Leaving a gift in your Will is a very personal decision and perhaps the greatest commitment you can make to help people living with arthritis and related musculoskeletal conditions in NSW.

In 2018/2019, ANSW received legacies from 16 donors totalling \$807,867. These bequests made up the majority of our donated income and were critical to the continuation of our services.

## **ADVOCACY**

### Highlighting the JIA funding crisis

This year, Arthritis NSW committed to applying pressure to government through the media to advocate for better services for the families of children living with juvenile arthritis.

Juvenile idiopathic arthritis (JIA) affects more than 3000 children in NSW, and is more prevalent than paediatric conditions such as childhood diabetes, cerebral palsy and cystic fibrosis. It causes pain and swelling in joints, increases fatigue and potentially affects eyesight. Without diagnosis, the condition can cause permanent, irreversible damage.

While some states provide extensive services and training on the condition for medical professionals, NSW is lagging far behind. Through a lack of funding, the NSW Government has allowed a crisis to develop in the diagnosis and care of JIA.

#### Services shortage

Today in NSW there are just two JIA specialists, which is well behind the national standard and states such as Queensland and Victoria which have five and six specialists respectively. The outcome for families in NSW is that the average JIA patient waits 10 months to be diagnosed from the onset of symptoms, and 15 per cent wait 12 months. It's common for these children to present to up to five professionals with their symptoms before JIA is even considered. While Arthritis NSW provides education and support for families through our children's camps, these events help just 45 children annually, or 1.5 per cent of the JIA population of NSW. And it's not enough.

### **ABC TV coverage**

In October 2018, during our annual camp for teenagers with JIA, Camp Footloose, Arthritis NSW invited ABC TV to attend one afternoon to film the children and interview Board member and Paediatric Rheumatologist Dr Davinder Singh-Grewal. The two-minute broadcast highlighted JIA and the social benefits the children experience at the camp. Several teenagers were also interviewed by their local newspapers where they highlighted their 'misunderstood' condition.

In January 2019, we leveraged this interest in JIA and issued a media release on the lack of funding for its diagnosis and treatment. CEO Sandra Vincent called on the State Government to significantly increase funding and education for doctors and nurses treating the condition. This recommendation had been made in the 2013 *Model of Care for the NSW Paediatric Rheumatology Network* commissioned by the Agency for Clinical Innovation, which is part of NSW Health, but had been ignored. Media coverage included ABC TV and radio, 2GB, and multiple regional newspapers online.

#### **Future planning**

This is a complex issue and will require long-term effort for an acceptable resolution. Arthritis NSW will be calling on the Health Minister Brad Hazzard in Parliament for answers in the near future and hopes to engage senior advocates in the medical field to take this issue to a national level if necessary.



ABC TV interviewed Paediatric Rheumatologist Professor Davinder Singh-Grewal on the benefits of Camp Footloose.



Paediatric Rheumatology Nurse Anne Senna spoke to parents at Camp Twinkletoes in May.



# STATEMENT OF PROFIT OR LOSS

and other comprehensive income for the year ended 30 June 2019

|  | 2019\$      | 2018 \$     |
|--|-------------|-------------|
| Revenue  | 1,270,635   | 1,234,240   |
| Other income   | 346,379     | 216,976     |
| Employee benefits expense                                    | (1,048,960) | (1,097,315) |
| Depreciation and amortisation expense                        | (52,081)    | (56,675)    |
| Education expenses   | (78,366)    | (59,989)    |
| Marketing and fundraising expenses                           | (128,334)   | (137,915)   |
| Other expenses   | (449,283)   | (437,202)   |
| (Loss) before income tax                                     | (140,010)   | (337,880)   |
| Income tax expense   | -           | -           |
| (Loss) for the year  | (140,010)   | (337,880)   |
| Other comprehensive income:                                  |             |             |
| Changes in fair value of available-for-sale financial assets | 106,454     | 102,420     |
| Other comprehensive income for the year, net of tax          | 106,454     | 102,420     |
| Total comprehensive income/(loss) for the year               | (33,556)    | (235,460)   |

# STATEMENT OF FINANCIAL POSITION

as at 30 June 2019

|                               | 2019 \$   | 2018 \$   |
|-------------------------------|-----------|-----------|
| ASSETS                        |           |           |
| CURRENT ASSETS                |           |           |
| Cash and cash equivalents     | 1,048,431 | 1,419,754 |
| Trade and other receivables   | 78,815    | 53,438    |
| Other assets                  | 37,657    | 4,211     |
| TOTAL CURRENT ASSETS          | 1,164,903 | 1,477,403 |
| NON-CURRENT ASSETS            |           |           |
| Financial assets              | 5,335,321 | 5,016,464 |
| Property, plant and equipment | 1,040,919 | 1,090,653 |
| TOTAL NON-CURRENT ASSETS      | 6,376,240 | 6,107,117 |
| TOTAL ASSETS                  | 7,541,143 | 7,584,520 |
| LIABILITIES                   |           |           |
| CURRENT LIABILITIES           |           |           |
| Trade and other payables      | 136,286   | 146,125   |
| Employee benefits             | 48,490    | 48,472    |
| TOTAL CURRENT LIABILITIES     | 184,776   | 194,597   |
| TOTAL LIABILITIES             | 184,776   | 194,597   |
| NET ASSETS                    | 7,356,367 | 7,389,923 |



# STATEMENT OF CHANGES IN EQUITY

for the year ended 30 June 2019

|  |                      | 2019 \$               | 2018 \$   |
|--|----------------------|-----------------------|-----------|
| EQUITY                                       |                      |                       |           |
| Reserves                                     |                      | 307,641               | 201,187   |
| Retained earnings                            |                      | 7,048,726             | 7,188,736 |
| TOTAL EQUITY                                 |                      | 7,356,367             | 7,389,923 |
|  |                      |                       |           |
|  | Retained Earnings \$ | Fair Value Reserve \$ | Total \$  |
| 2019   |                      |                       |           |
| Balance at 1 July 2018                       | 7,188,736            | 201,187               | 7,389,923 |
| (Loss) attributable to members of the entity | (140,010)            | -                     | (140,010) |
| Other comprehensive income for the year      | -                    | 106,454               | 106,454   |
| Balance at 30 June 2019                      | 7,048,726            | 307,641               | 7,356,367 |
| 2018   |                      |                       |           |
| Balance at 1 July 2017                       | 7,526,616            | 98,767                | 7,625,383 |
| (Loss) attributable to members of the entity | (337,880)            | -                     | (337,880) |
| Other comprehensive income for the year      | -                    | 102,420               | 102,420   |
| Balance at 30 June 2018                      | 7,188,736            | 201,187               | 7,389,923 |

# STATEMENT OF CASH FLOWS

for the year ended 30 June 2019

|   | 2019 \$     | 2018 \$     |
|---|-------------|-------------|
| CASH FLOWS FROM OPERATING ACTIVITIES:                     |             |             |
| Receipts  | 1,168,587   | 1,193,670   |
| Payments to suppliers and employees                       | (1,748,209) | (1,723,541) |
| Interest received   | 18,893      | 18,542      |
| Dividends received including franking credits             | 404,157     | 236,373     |
| Net cash provided by/(used in) operating activities       | (156,572)   | (274,956)   |
| CASH FLOWS FROM INVESTING ACTIVITIES:                     |             |             |
| Purchase of property, plant and equipment                 | (2,348)     | -           |
| Purchase of financial assets                              | (212,403)   | (114,243)   |
| Net cash provided by/(used in) investing activities       | (214,751)   | (114,243)   |
| Net increase/(decrease) in cash and cash equivalents held | (371,323)   | (389,199)   |
| Cash and cash equivalents at beginning of year            | 1,419,754   | 1,808,953   |
| Cash and cash equivalents at end of financial year        | 1,048,431   | 1,419,754   |





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