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# Vision

To bring quality of life to all people with arthritis and eliminate their suffering.

## Mission

To provide dignity, support and education for Australians suffering from arthritis and their carers.

To radically restrict the rate of growth of arthritis in Australia.

To be a leader in funding and advocating world-class research.

Arthritis Australia to be identified as the only independent, arthritis focused and patient driven national body.

## Working together

## A new website for people with joint pain or osteoarthritis

On 18 March 2013, Arthritis Australia launched <u>MyJointPain.org.au</u> during Arthritis Awareness Week.



Olympic basketball star and Australian Opals captain, Lauren Jackson was the website ambassador and spoke about her own journey with joint pain. She highlighted the need for people to take action to manage joint injuries which can lead to osteoarthritis and also the importance of establishing a health-care team for support.

Prof David Hunter, rheumatology clinician and researcher and the website's clinical leader spoke about how osteoarthritis is one of the most challenging health conditions in Australia. It is the leading cause of mobility disability for seniors, a major cause of individual pain, and it costs the economy more than \$20 billion a year.

Through the MyJointPain website, people living with osteoarthritis have access to a credible resource, which can inform and empower them to be active in managing their condition and improve their mobility and quality of life. The website provides:

- a screening tool to assess the risk of osteoarthritis in a user's hip or knee
- comprehensive, evidence-based information on managing the disease and associated joint pain
- software to help people track their condition and learn what treatments work
- links to a wide range of appropriate healthcare practitioners and services that can facilitate optimal management.

In the first six months of use the site has attracted over 24,000 visitors leading to nearly 140,000 pageviews.

Further enhancements are being planned. These include a moderated online community, new video content, and a mobile version of the website.

We are grateful to the Bupa Health Foundation for being our website development partner, and to AstraZeneca and Pfizer for additional unencumbered financial support.



## Funding to help reduce the pain of arthritis

New federal government funding for Arthritis Australia was allocated from the Chronic Disease Prevention and Service Improvement Fund. The investment of \$3.2 million over a three year period will fund a new Exercise for Arthritis initiative, enhance the online support tools on our osteoarthritis-specific website, <u>MyJointPain.org.au</u>, and allow us to continue to develop quality consumer resources, including in-language information sheets. In 2014 Spanish, Korean, Persian, Croatian and Macedonian will be added to our list of translated materials. This funding marks the first time that Arthritis Australia has secured federal government funding beyond a 12 month period.

### Global collaborations foster joint effort



L to R: Franca Marine – Arthritis Australia's National Policy & Government Relations Manager, The Hon Tanya Plibersek MP – Former Minister for Health, Anne Ashford – OA consumer and Prof David Hunter

In June 2013 CEO, Ainslie Cahill, travelled to Europe to represent Arthritis Australia at meetings in Madrid and London which yielded future opportunities for strengthening the international, as well as local push, for better arthritis management and health outcomes.

At the European League Against Rheumatism (EULAR) the results of a new international survey conducted among more than 10,000 adults with rheumatoid arthritis (RA) in 42 countries, including Australia, were launched. The results revealed

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that Australian women living with RA are significantly overwhelmed and severely restricted in the many aspects of their lives and, when compared to their global counterparts, have reduced workforce participation due to their RA was higher. On the upside, the survey found that Australians who have a disease management plan are more likely to say that their condition is well-managed. Arthritis Australia will be working with its State/Territory Arthritis Affiliates to address some of the issues highlighted in the survey and, in particular, exploring best methods for promoting and increasing the use of RA management plans.

Participation in an inaugural National Arthritis Charity Research Funders Round Table (made up of representatives from the UK, US, Canada, The Netherlands and Australia) resulted in the formation of an alliance which will promote group interaction and international collaboration regarding research investment and research priorities. In the long-term, the group will encourage research collaborations and shared understanding of the nature of musculoskeletal care and its needs and successes in each participating country.

The EULAR sector was funded by AbbVie and the London sector by Arthritis Australia.

#### **Rural outreach education**

Arthritis Australia joined forces with the Australian Rural Rheumatology Service, led by

Dr Louis McGuigan, to develop and implement a new and combined model of clinical care and education services in rural Australia. A pilot program is being undertaken in the New England Medicare Local region (NSW) with the educational services for consumers and health professionals being coordinated by Arthritis New South Wales. This pilot is being evaluated by NEWSTAT, the statistical arm of the University of Newcastle. It is anticipated that the Rural Outreach Education Project will improve access & equity issues in rural areas by building local health service capacity, increasing arthritis education and awareness among health professionals and consumers, and, ultimately, leading to better health outcomes. The project is being funded by Janssen.

### **Congratulations!**

We were delighted to see the following people recognised for their exceptional service to the arthritis cause:



Ita Buttrose AO OBE – Australian of the Year 2013 (former president and currently Emeritus Director)



**David Motteram** OAM (right) – for services to the community, Australia Day Honours (currently Deputy Chairperson)



Judith Nguyen OAM (left) – for services to community health, particularly in the field of arthritis, Queen's Birthday Honours (former Consumer Representative/Board Member)

State and Territory champions who were also honoured – Assoc Prof **Ben Marosszeky** AM (Arthritis NSW), **Enid Monaghan** – OAM (Arthritis NSW) and **Bill Wood** AM (Arthritis ACT)

## Advocacy

## Improving care for people with arthritis

Arthritis Australia has embarked on a major project to establish national models of care to improve the prevention, diagnosis and treatment of osteoarthritis, rheumatoid arthritis and juvenile idiopathic arthritis.

While models of care for these diseases already exist in a number of states and territories, evidence suggests that their implementation remains localised. Such a fragmented approach means that the care being received by consumers varies depending on where they live and where they seek care. This project aims to develop nationally applicable models of care for RA, OA and JIA that are focused on placing consumers and their needs at the centre of the healthcare system.

A multidisciplinary steering committee of experts from rheumatology, general practice, pharmacy, patient advocacy, allied health and key services has been convened to oversee the project which will develop a White Paper recommending the key elements of care to optimally support people with these conditions.

The recommendations of the White Paper will provide a strong evidence and consensus based platform for the development of a comprehensive advocacy campaign to improve care for people with arthritis.

#### **Disability issues**

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#### National Disability Insurance Scheme

Arthritis is the second most common cause of disability in Australia, with one in six people with a disability having arthritis as their main disabling condition. However, there is limited awareness of the extent of the disability burden of arthritis. Anecdotal evidence also suggests that people with arthritis-related disability have difficulty accessing support services because they fall through the gaps between the health, aged care and disability systems.

To ensure that the support needs of people with arthritis are addressed, Arthritis Australia made a number of submissions in relation to the development and roll out of the National Disability Insurance Scheme, now known as DisabilityCare. These submissions highlighted the disability burden of arthritis and the often hidden and episodic nature of arthritis-related disability, which often features disability associated with chronic pain and fatigue.

Indications to date are that people with severe arthritis-related disability will be covered by the scheme, but ongoing monitoring of the launch sites for DisabilityCare is planned to ensure that the needs of people with arthritis-related disability are being appropriately recognised as the scheme rolls out.

## Research into arthritis and disability

To better understand arthritis-related disability and the problems people face, Arthritis Australia has commissioned research into the impact of living with arthritis-related disability. This research will cover the personal, social and economic impact as well as investigating the support and service needs of people with arthritis-related disability. The research is expected to be finalised by the end of 2013. The findings of this research will help inform our advocacy in relation to the roll out of DisabilityCare.

## More funding needed for arthritis research

Arthritis Australia is seeking bipartisan support for increased federal government funding for arthritis research in Australia.

Research into arthritis and musculoskeletal conditions in Australia is chronically underfunded relative to the personal, social and economic burden of these conditions and relative to other National Health Priority Areas (NHPAs). Total research funding for the arthritis and osteoporosis NHPA in 2012 was only \$25m, lower than all the NHPAs except asthma, and is falling.

Yet the burden of arthritis and musculoskeletal conditions is growing and now accounts for 15.3% of the total disease burden in Australia, second only to cancer. These conditions are also very costly, costing over \$9 billion annually in direct costs to the health, welfare and aged care systems.

Underinvestment in arthritis and musculoskeletal research is impeding improvements in care for people with these conditions, undermining research capacity in the field and costing the government millions of dollars due to the preventable burden of these conditions.

Consequently we are seeking a strategic investment in research funding in this area of an additional \$125m over the next five years including

• Targeted calls for research proposals in the field





- Dedicated research and practitioner fellowships to build research capacity
- Funding for Centres of Research Excellence and Partnership Centres.

Increased funding for arthritis research was included as one of our three top priorities in the pre-budget submission we made to the government in early 2013 and in our priorities for the 2013 election.

A Parliamentary Friends of Arthritis meeting was also held in conjunction with the National Health and Medical Research Council (NHMRC) to discuss issues relating to health and medical research with a view to shoring up continuing support for government investment in this area. Constructive discussions were held with Professor Anderson. the CEO of the NHMRC and some parliamentarians regarding how to address the disconnect between the burden of musculoskeletal conditions, as highlighted in the most recent global burden of disease study, and the low level of research funding available for this area in Australia.

A more comprehensive campaign in support of increased funding for arthritis research is being developed for 2014.

### Joint injections campaign highlights issue of rising out of pocket costs for health care

A consumer advocacy campaign in support of restoring Medicare rebates for joint injections by consultant physicians was conducted in late 2012, targeting Ministers and parliamentarians with an interest in health and disability issues.

Although the campaign did not achieve the reinstatement of Medicare rebates for these procedures, the consumer survey conducted as part of the campaign, which was completed by around 500 people, generated valuable information regarding the physical and economic impact of arthritis on people living with the condition. In addition to highlighting the disability and pain associated with arthritis, the survey identified three key issues in relation to equity and costs of care.

Firstly the survey highlighted the enormous variation in costs to individuals to receive joint injections, with some individuals facing hundreds of dollars in out-of-pocket costs to receive these procedures and others facing no out-of-pocket costs. Secondly the survey highlighted that the additional costs now being borne by some individuals for joint injections was part of a broader issue of high and increasing out-of-pocket costs for their care overall. Thirdly, the high costs of care meant that many respondents had to delay or go without recommended procedures or medications, or had to go without essentials in other areas of their lives to meet the costs of their care.

The issue of rising out-of-pocket costs is an issue that affects all health consumers and is increasingly being recognised by a range of health consumer organisations. Consequently, Arthritis Australia will now join with other organisations to seek broader system-wide action to address the issue of rising out-of-pocket costs for health consumers.

## User-friendly packaging

## Having a cup of coffee just got easier

Arthritis Australia worked in collaboration with Nestlé to redesign the Nescafé Gold coffee jar shape so that it is easier to hold and, by introducing a 'click and lock' screw cap, easier to open. This local innovation has now been adopted globally by Nestlé.



Locally-designed Nescafé Gold coffee jar adopted globally

"In partnering with Arthritis Australia, this pack delivered a more intuitive cap opening for our consumers of Nescafé Gold"

Jacky Nordsvan, Packaging Technologist, Nestlé Oceania

# Working with retailers to make all food packaging easier to open

Everyone deserves easy open packaging, not just those living with arthritis, which is why we approached Woolworths and began working with them in 2012 to try and fix packaging at the retail level. Woolworths has several thousand home brand foods products with hundreds of suppliers, and is conscious of the need to effect change.

"Woolworths recognise that their customers need to have packaging that they can easily open.... Woolworths is working with Arthritis Australia to find practical solutions at a retail level, but this will not happen overnight due to the complex nature of the problem."

Kane Hardingham, Sustainability Manager, Woolworths

In 2013, Arthritis Australia began work with other retailers, with the same objective in mind.

### What may be easy for you is a struggle for many – design awards for industry and young designers

The Packaging Council of Australia in collaboration with Arthritis Australia introduced the first, and now annual, industry and university design awards for packaging accessibility in 2011.

Mark Fiscario studies at the Australian Academy of Design, Victoria and his winning entry is of an easy open juice package. One of Mark's motivations for entering the design awards was seeing his mother and aunt, both of whom have arthritis, struggle to open packaging. Mark, who now works for Kraft Foods, wanted to design juice packaging that all consumers can open easily.



Mark Fisicaro, winner of the 2012 Southern Cross design award for Packaging Accessibility with Wendy Favorito, Arthritis Australia's Consumer Director



Winning 2012 Southern Cross design award for Packaging Accessibility Design

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### Designing food packaging that hospital patients of all ages can easily open

Working with Arthritis Australia and Georgia Tech Research Institute (GTRI), the applied research arm of the Georgia Institute of Technology (USA); NSW Health tested a large number of food products served in hospitals against a new measurement system developed specifically for NSW public hospital patients. Those results were shared with manufacturers and, in a formal survey, 61 per cent now say they have either redesigned their packaging to increase ease of opening, or plan to do so in the near future. The packaging has been redesigned based on design recommendations made by Arthritis Australia and Georgia Tech.

#### Australian food company becomes the first to certify, that their packaging is easy to open and use

Eatwell Foods make Gumnut biscuits and supply a range of assorted biscuits to hospitals, aged care facilities and hotels across the country. Eatwell Foods became the first Australian food company to qualify for the Ease of Use program. The Ease of Use program is a way for companies to promote their packaging to consumers, industry and government. The program is unique because it involves independent testing of the packaging with people who have moderate to severe arthritis.

"You can have the best product, but if you can't open it, it is no good. Pack unopenability is a big problem and it's starting to be addressed, which is great."

Matthew McAlpin, Director of Eatwell Foods

This is a great outcome for Eatwell Foods whose sales have grown and for consumers who can now easily open their biscuit whether it is in hospital or in a hotel.

### Food Packaging Design Accessibility Guidelines adopted by health system and globally

Arthritis Australia developed design guidelines for NSW Health food suppliers in collaboration with Georgia Tech from the USA. The guidelines focus on single serve food items like cheese portions, milk and cereal which are served in hospitals but also appear in aged care, hotels and airlines etc. Their purpose is to provide specifications and practical examples to food companies so they can design easy open packaging and get the design right the first time!

The guidelines have been adopted by Australian and global food and packaging companies. They were heavily promoted by industry groups and appear on multiple websites, including the Consumers Goods Forum which is a global industry group with over 400 retailers from 70 countries as members. This means that in Australia and around the world small fiddly packaging with which many people struggle has got a little easier to open.



now part of the Ease of Use program

## User-friendly packaging continued

### Arthritis Australia's work recognised in the media in Australia and internationally

Every day people experience frustration and many are injured trying to open packaging. Most of the packaging we buy is badly designed. This is unacceptable but it is also fixable. One of the challenges that Arthritis Australia faced is providing independent research to industry and government to prove the level of frustration and injury experienced by consumers. In 2012 and 2103 Arthritis Australia worked with Reader's Digest to bring about independent research, performed by Catalyst research. Media coverage of our campaign to bring about easy open packaging plus proof that it is fixable resulted in multiple media coverage including cover stories in Reader's Digest, The Sydney Morning Herald and Choice Magazine. Our efforts were also recognised in the international media in the UK, Europe, Africa and Asia.



Arthritis Australia's packaging work recognised in the media



canberratimes.com.au The Canberra Times



The Sydney Morning Herald National

## Research

#### **Research retrospective**

A comprehensive survey of more than 100 grant recipients of Arthritis Australia research funding over a period of six years was launched at the end of 2012. Informed by the research evaluation initiatives undertaken by large UK-based medical research funders in recent years, the Arthritis Australia Retrospective Research Survey sought information on a wide range of research impacts occurring not only during the life of the grant, but developing in the years that followed. The survey results will be launched at the end of 2013 and assist Arthritis Australia in having a greater understanding of the ongoing value of its research investments and prioritising future research funding.

#### Arthritis Australia National Research Program

In the 2012 calendar year Arthritis Australia allocated almost \$800,000 to musculoskeletal research including support for the Florance and Cope Chair of Rheumatology at the University of Sydney.

Over the years, we have awarded funding to researchers engaged in basic and clinical research that aims to increase knowledge about arthritis and develop treatments and cures. In the main, grant recipients are early or mid-career scientists and clinicians, and one year fellowships, project grants and scholarships are offered.

Despite the economic burden and social impacts caused by arthritis, we have yet to win the case for higher government and community recognition and support of arthritis research. However, our Research Retrospective Study further demonstrates advances being made over the past years and we hope that its publication in late 2013 will encourage increased funding in the future which may ultimately lead to further clinical and scientific breakthroughs.

For outcomes of the 2012 Arthritis Australia National Research Program and projects currently being undertaken in 2013, see pages 21 to 30

### Orthopaedic Fellowship Program

The Arthritis Australia/Zimmer Orthopaedic Fellowship Program continues to grow in popularity since its initiation in late 2009. It has provided unique educational opportunities for post graduates to improve their clinical and operating skills in arthroplasty surgery, including general orthopaedics.

To date, the program has funded more than \$1 million dollars for fellowships.

Arthritis Australia values Zimmer's support and ongoing commitment to this worthy and successful program.

For full details of recipients of the Arthritis Australia/ Zimmer Orthopaedic Fellowship Program for 2012-2013 see page 31

## Chairperson's report

This past year has been a landmark for Arthritis Australia and its state and territory affiliates that saw the membership unanimously vote to adopt a new constitution at a Special General Meeting held on April 22. The new Constitution for Arthritis Australia establishes an independent Board of between 6 to 8 Directors elected by the members of Arthritis Australia, and a Council of Advice consisting of nominees of organisations that are affiliated with Arthritis Australia, which will provide advice and recommendations to the Board. A formal Memorandum of Understanding between Arthritis Australia and affiliated organisations will establish guidelines for collaboration and outline clear roles, responsibilities and obligations of each partner.

The process of constitutional reform has been careful. consultative and future-looking. External drivers for change included the Federal Government's initiatives to establish the Australian Charities and Not-for-profits Commission. This national regulator will ensure that registered charities such as Arthritis Australia comply with appropriate governance standards, and our advice has been to adopt structures similar to corporations with independent Boards. Furthermore, in pursuing advocacy for arthritis consumers and interactions with the Federal Government and large corporations, we have found a strong desire from these organisations to interact with single national bodies for implementation of programs or funding proposals. Internally, we identified wide consensus amongst Board members and Affiliates that too much effort had been dispensed in the past on managing internal relationships within the existing federated structure, often at the distraction of pursuing our mission to improve the lives of Australians living with arthritis.

The new Board and Council of Advice will commence after the upcoming Annual General Meeting in November. I believe these new structures will enable our collective Arthritis Foundations to set our sights to increased levels of advocacy, consumer support, and research funding, bringing the voice of people with arthritis to prominence within government, media and corporate Australia. To members of the current Board who will not continue in the new structure, I offer my deep appreciation for the immense contributions you have made to our activities and support for change.

Another important event in 2013 was the appointment of Prof David Hunter as our new Florance and Cope Chair of Rheumatology at Sydney University. David graduated with his medical degree from the University of New South Wales, trained in rheumatology in Sydney and after completing a PhD, he spent many years in Boston developing an international reputation for his arthritis research, particularly focused into osteoarthritis. I am confident that David will continue the tremendous standard of arthritis research achieved by his Florance and Cope Chair predecessors.

Particularly pleasing was the news that our former President, Ita Buttrose AO OBE was named as 2013 Australian of the Year, our current Deputy Chairperson, David Motteram received an OAM in the Australia Day Honours and our former Consumer Representative, Judith Nguyen received an OAM in the Queen's Birthday Honours. Ita, David and Judith have been tremendous supporters of our work for many years and I'm sure all members will join me in formally offering our congratulations.

In closing, let me again thank all the many supporters and members of Arthritis Australia who have contributed to our work over the past year in achieving our mission of improving the quality of lives of Australians living with arthritis.

Patrick McNeil MBBS (Hons) PhD FRACP GradDipHEd



## CEO's report

This year saw further consolidation of our work, greater awareness of our activities and a strengthening of our national political profile. While we experienced mixed fortunes this financial year, I'm pleased to report that it closed on an optimistic note with Arthritis Australia securing Australian Government funding until 2015.

With input from key stakeholders, we are developing two position papers on acceptable models of care and exercise; taking a closer look at arthritis and disability for osteoarthritis, rheumatoid arthritis and juvenile idiopathic arthritis; expanding our education services through the launch of an osteoarthritis specific website, MyJointPain.org.au; influencing the introduction of user-friendly packaging in Australia and, with the completion of a retrospective study, have a greater understanding of the discoveries that are evolving from the Arthritis Australia National Research Program. Further details of all these activities can be found within the pages of this report.

In our last annual report I wrote of our disappointment with the lack of action from the Department of Health and Ageing (DoHA) following a review of the scoping studies that were funded by DoHA to investigate and identify options for future activities that would benefit Australians living with arthritis. We had been led to believe that priority projects would be funded so that Arthritis Australia could begin their implementation during this financial year.

Regrettably – and despite the support of the former Minister for Health, Tanya Plibersek - a combination of DoHA staffing changes and government fiscal restraint resulted in delayed funding. This ultimately impaired our ability to develop and deliver priority projects and had a negative effect on the 2012-13 bottom line. We will be working with the incoming federal government for an assurance this does not happen again.

We now have the financial security to plan and implement a range of activities with confidence and to focus our resources on supporting Australians living with arthritis. These include an exercise project that will combine guidance for the best forms of exercise for arthritis, an accreditation system for appropriate exercise programs and the creation of nationally accessible delivery points; the introduction of additional features on MyJointPain which will make the site even easier to use for people wanting to manage their condition and improve their quality of life; and the review and development of evidence-based consumer information sheets, including the creation of a new set of titles translated in Korean, Croatian, Macedonian, Persian and Spanish.

As Arthritis Australia moves towards a different governance model with a new and independent board being formed this November, I would like to give special thanks to our outgoing board members - led by Prof Patrick McNeil - for their voluntary work, commitment and guidance; to my fellow state and territory CEOs who contributed to the rigorous development of our memorandum of understanding; and to the Arthritis Australia team, all of whom work passionately and effectively for Australians living with arthritis.

Finally, I'd like to acknowledge the many Arthritis Champions who

give so willingly of their time and personal experiences to ensure all of us at Arthritis Australia keep at the top of our minds the purpose and benefits of the work we undertake.

Amelebarel

**Ainslie Cahill** 



## Directors reports

#### **Medical Director**

Internationally in 2012 there continued to be exciting advances in arthritis research and the place of existing therapies is becoming much clearer e.g. studies have demonstrated that both methotrexate and some of the biologic DMARDs decrease mortality in rheumatoid arthritis showing that controlling the disease is good for overall health. Osteoarthritis and some of the rarer arthritides still remain strong priorities for further research but there has been a focus on these in recent years.

Nationally, despite the National Health and Medical Research Council specifically creating two committees for arthritis and musculoskeletal conditions, our proportion of national funding continues to decrease despite strong efforts to prevent this decline. The role of Arthritis Australia's Grants Assessment Committee becomes increasingly important given this especially in terms of funding new investigators and developing good ideas into fundable large projects. Our recent Research Retrospective Study of research grant outcomes shows that we have been very successful taking this approach.

The Grants Assessment met in October to determine recipients of Arthritis Australia's 2013 funding round. Overall funding levels improved but budget restrictions meant we could only fund 20% of the applications. Special thanks to Helen Keen, Michelle Leech, Susannah Proudman, Rachelle Buchbinder, Gethin Thomas, Chris Little, Sharon van Doornum and Rana Hinman for their voluntary assistance. After 10 years as medical director it is time to hand over the position to others to guide Arthritis Australia through the exciting but challenging period ahead as the new constitution beds down. It has been a privilege to be part of the last 10 years.

**Graeme Jones** MBBS (Hons) FRACP FAFPHM MMedSc MD



#### **Consumer Director**

It has been an interesting and diverse 12 months for me. I have undertaken a range of different activities including: giving presentations; participating in media activities; undertaking the role of board member for the Arthritis Foundation of Australia: chairing the National Arthritis Consumer Reference Group; contributing to the steering committee for the Arthritis Models of Care Project and the advisory group for the Arthritis and Disability Research Project; and attending some professional development courses to enhance my skills as a consumer representative.

I have continued to work closely with Fergal Barry giving presentations to the packaging industry on the topic of difficult-to-open packaging. Fergal and I were invited to speak at a symposium on portion control foods in healthcare at Southern Health (Victoria) in November 2012 and more recently we presented on the subject of difficult-to-open packaged food and beverages at the Institute of Hospitality in Healthcare (in Adelaide). My role was to raise the awareness of how difficult, and at times impossible, it is to open packaged food and drinks in hospital leading to missed meals, frustration, and disempowerment. The invitation to present to health sectors is exciting as it provides the opportunity to advocate for people with arthritis in hospitals and healthcare facilities when we are perhaps at our most vulnerable.

I participated in several print, radio and television interviews in June providing a personal perspective on living with rheumatoid arthritis following the launch of the findings of an international study addressing the burden of RA. Other media activities throughout the year related to the topic of accessibility of packaged goods.

A highlight for 2013 was chairing the second face-to-face meeting for the National Arthritis Consumer Reference Group in June. This is a great opportunity to collect a broader range of experiences and commentary to contribute to projects such as the Arthritis Models of Care. Garnering a greater number of voices can only strengthen our advocacy work and I look forward to the ongoing contribution of the members.

On a personal level, it's inspiring to meet other people with arthritis who make such valuable contributions to their communities via their families, professional roles, and advocacy work. I'd like to thank Franca Marine for her valuable work in facilitating the group.

I would like to thank the Arthritis Australia board and team members for their ongoing support and encouragement.

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Wendy Favorito BAppSc (Sp. Path.)(Hons)



## Governance

#### **Board of Directors**

The Board is responsible for overseeing planning, resource use, growth and liaison across the community, and enhancing the image of Arthritis Australia.

#### THE BOARD

Patrick McNeil – Chairperson

MBBS (Hons) PhD FRACP GradDipHEd

- Elected as President in November 2010
- Member, Constitution Subcommittee Member, Executive Committee
- Member, Finance Advisory Committee
- Member, Strategy Subcommittee

Prof McNeil holds the University of New South Wales' Chair of Rheumatology at Liverpool Hospital. He also heads a research group in the Inflammation and Infection Research Centre at UNSW's Kensington campus. He is recognised as a national leader in academic rheumatology in Australia and has been a member of the Scientific Advisory Committee for Arthritis Australia and the ARA Research Trust, and discipline panels for the National Health & Medical Research Council.

#### David Motteram – Deputy Chairperson

- Elected as Vice-President in November 2009
- Member, Constitution Subcommittee
- Member, Executive Committee
- Member, Finance Advisory Committee
- Board member since December 2002



Arthritis Australia Board of Directors Front row from left: Dr Ian Dover – Arthritis QLD nominee, Wendy Favorito - Consumer Representative and Dr Helen Cooley – Arthritis TAS nominee Back row from left: Wayne Jarman – Treasurer, Hilary Fowler – Arthritis NT nominee, Prof Patrick McNeil – Chairperson, Dr Irene Froyland – Arthritis WA nominee, Roger Mattar and David Motteram - Deputy Chairperson Board members absent from photo: Prof Graeme Jones - Medical Director and David Graham – Arthritis ACT nominee

Mr Motteram is a retired business manager and was President of Arthritis South Australia from October 2002 until October 2012. He is currently a Board member of Arthritis South Australia where he acts as Treasurer.

#### Wayne Jarman – Treasurer

GradDipFin AMP (Harvard) FAICD

- Elected as Treasurer in November 2010
- Member, Executive Committee
- Member, Finance Advisory Committee
- Board member since November 2007

A Fellow of the Australian Institute of Company Directors, Finance and Treasury Association, Wayne consults for the service firm Deloitte, Maddocks Lawyers and Burnvoir, an Advisory firm in the Infrastructure and Resources sectors. Wayne is also Chairman of the Investment Advisory Board of Altius Asset Management. Prior to these engagements Wayne was Executive Director of the NSW Government Asset Management Task Force which had carriage of a number of NSW Government asset sales. Prior to these engagements Wayne was Vice-Chairman and Managing Director of RBC Capital Markets and CEO of TCorp, the New South Wales Government's Central Borrowing Authority, a position he held for a period of ten years.

#### Graeme Jones – Medical Director

MBBS (Hons) FRACP FAFPHM MMedSc MD

- Elected as Medical Director in May 2003
- Chair, Grants Assessment Committee since May 2003
- Member, Scientific Advisory Committee
- Member, Strategy Subcommittee

Prof Jones is Head of the Musculoskeletal Theme at the Menzies Research Institute, University of Tasmania and a rheumatologist in private practice.

#### Ainslie Cahill – Board Secretary & Chief Executive Officer

- Chief Executive Officer of Arthritis Australia since December 2005
- Elected Secretary in November 2010

Ms Cahill was appointed CEO of Arthritis Australia in December 2005, having served as its Marketing and Business Development Manager from August 2003. She has more than 25 years' experience in a variety of industries, including senior management/board positions in vocational education (TAFE NSW), public relations (Write Communications Group), publishing (Capricorn Publishing Pty Ltd) and film, television and theatre production (Melaleuka Productions Pty Ltd). Ms Cahill is also Deputy Chair of the Consumers Health Forum and a member of their Governance and Membership Subcommittees.

#### Helen Cooley

• Board member since November 2010

Dr Cooley is currently working as a rheumatologist in Hobart and is Director of Ambulatory Care at the Royal Hobart Hospital. She has been a director on Arthritis Tasmania's Committee of Management for the past eleven years, and was elected President in September 2010. Dr Cooley is a graduate of the University of Tasmania and undertook most of her rheumatology training in Melbourne. Returning to Tasmania in 1999, she accepted a postdoctorate position at the Menzies Research Institute, focusing on osteoporosis and osteoarthritis.

#### Wendy Favorito – Consumer Director

BAppSc (Sp. Path.)(Hons)

• Elected as Consumer Representative in November 2010

Mrs Favorito holds a part-time position as a senior speech pathologist at St Vincent's Hospital, Sydney, and works part-time in private practice. At the age of six years, Wendy was diagnosed with juvenile arthritis (JIA). In her teens and early twenties she actively assisted Arthritis New South Wales in their JIA activities, including being a member of the Working Committee for their inaugural JIA Camp.

#### Ian Dover

BSc MEng PhD CMP FAICD

- Board member since November 2010
- Alternate Board member from 2006 to October 2010
- Member, Strategy Subcommittee

Dr Dover is currently Director, Business Development and Commercialisation for the CSIRO's Minerals Research Flagship. He began his career as an engineer in the international metals industry and over the years has held the roles of general manager, managing director, non-executive director and business advisor in a number of companies. He has served on various state and federal industry-government bodies, has been a member of the Queensland University of Technology Council and was Arthritis Queensland's President from 2009 to 2012.

#### Irene Froyland

PhD (Crim) MA (Psych) DipEd

- Board member since September 2009
- Member, Constitution Subcommittee

With a PhD in criminology, Dr Froyland has recently retired from her position as Foundation Director of Corruption Prevention, Education and Research (CPER) in the Corruption and Crime Commission. She remains an honorary professor in the School of Justice and Law at Edith Cowan University and is regularly invited to lecture to Australian New Zealand School of Government.

#### Hilary Fowler

Board member since
 November 2010

Hilary Fowler is a retired high school teacher who has lived in the NT for 27 years. She is currently Secretary of Arthritis NT, and also a volunteer in the office and with various other tasks. She has osteoarthritis herself so can talk empathetically with other sufferers.

## Governance continued

#### David Graham

B Pharm FPS PhD FAICD

- Board member since March 2012
- Member, Strategy Subcommittee

Dr Graham worked as a senior manager in the Commonwealth Public Service including as the National Manager of the Therapeutic Goods Administration and the Pharmaceutical Benefits Scheme. Following retirement, he is now a non-executive director for a number of not-for-profit organisations including Arthritis ACT.

#### **Roger Mattar**

BComm/LLB (UNSW) Member AICD

- Board member since
  November 2010
- Member, Constitution Subcommittee

Mr Mattar commenced legal work as a student volunteer at Redfern Legal Centre while completing his commerce/law degree at UNSW. Following his graduation he worked as a paralegal and later as a solicitor in a large national law firm in the property, construction and banking practice groups. Since 1997 he has been a solicitor at Kemp Strang lawyers where he was appointed a partner in the Property Banking and Finance (Commercial) Group in 2004. Mr Mattar practises in the area of property, leasing, banking and finance.

#### ALTERNATE DIRECTORS

#### Simon Burnet

MBBS FRACP

Dr Burnet is Arthritis South Australia's Alternate Director. An Adelaide-based rheumatologist, he is a consultant at the Queen Elizabeth Hospital and also Medical Director of Arthritis SA.

#### Gail Keddie

Mrs Keddie is the Alternate Director for the Northern Territory. As well as volunteering with Arthritis Northern Territory, Gail also volunteers with Pit Stop, a men's health program with the NT Department of Health, and as a pension and welfare officer and a men's health peer educator with the Department of Veterans' Affairs.

#### Andrew Kilby

GAICD

A graduate of the Australian Institute of Company Directors. Andrew is a director of Safe Places Community Services. Andrew provides general consulting services, including turnaround, restructure merger and acquisition advice to various companies through his private consulting business. He has previously held senior positions at United Technologies Inc, James Hardie Industries, Honeywell and Marconi Communications.

#### Helen Tyrrell

BA (Hons), MBA, FACHSM

Ms Tyrrell is the Alternate Director for Arthritis ACT. A Fellow of the Australian College of Health Service Managers Helen has more than 25 years' experience working in teaching hospitals in clinical nursing, management and executive positions. She was appointed CEO of the health promotion charity, Hepatitis Australia in 2005 and in 2007 became a founding board member of the World Hepatitis Alliance. She serves on numerous government, advisory and research committees.

#### EMERITUS DIRECTORS

#### Ita Buttrose AO OBE

Mona Marabani MBBS (Hons) FRACP

#### EXECUTIVE

Ainslie Cahill – Chief Executive Officer & Board Secretary

(Refer to listing on page 17)

#### SCIENTIFIC ADVISORY COMMITTEE

This committee provides the Arthritis Australia Board with medical expertise.

#### Peter Youssef – Chair

MBBS (Hons) FRACP PhD

Assoc Prof Youssef is a staff specialist in rheumatology at the Royal Prince Alfred Hospital in Sydney. His research interests are in the mechanisms of joint damage in inflammatory arthritis, particularly rheumatoid arthritis, and the effects of therapy on the synovium.

#### Peter Brooks AM

MD FRACP FAFRM FAFPHM FRCP (Glas, Edin) MD Hon Causa (Lund)

Prof Brooks is Director, Australian Health Workforce Institute at the University of Melbourne and the University of Queensland. He is the author of more than 300 publications in the areas of rheumatic diseases, drug therapy and psychological aspects of chronic disease. He has been a major driver of health workforce and education reform.

#### Simon Burnet

MBBS FRACP (Refer to listing on page 18)

#### Julien de Jager

MB BCh FRACGP FRACP

Dr de Jager is Senior Visiting Rheumatologist at the Gold Coast Hospital and a visiting consultant rheumatologist at Allamanda and Pindara private hospitals in Queensland. He is an international fellow of the American College of Rheumatology and a past president of the Australian Rheumatology Association. As of early 2011, Dr de Jager is also a Professor of Medicine at Griffith University.

#### John Edmonds

MBBS MA FRACP MMedHum

John Edmonds is a conjoint professor at the University of NSW and the former director of rheumatology at St George Hospital in Sydney. He is currently Chair of the St George and Sutherland Medical Research Foundation and a past president of the Australian Rheumatology Association.

#### John Hart

MBBS FRACS FAOrthA FASMF FACSP (Hon)

Assoc Prof Hart is an orthopaedic surgeon based in Melbourne, an adjunct clinical associate professor in the Department of Surgery at Monash University and Emeritus Orthopaedic Consultant at the Alfred Hospital. He was head of the Orthopaedic Unit at the Alfred Hospital from 1980 until 2003 and is a past president of the Australian Orthopaedic Association and Sports Medicine Australia.

#### Graeme Jones - Medical Director

MBBS (Hons) FRACP FAFPHM MMedSc MD

(Refer to listing on page 17)

#### Mona Marabani

MB BS (Hons) FRACP

A practising rheumatologist, Dr Mona Marabani was president of Arthritis Australia from 2006 to 2010. Dr Marabani has previously served the ARA as vice-president and councillor, the NSW Branch as Honorary Secretary and the NSW Advanced Trainee Selection Committee as Chair. She maintains an active interest in health education, equity and advocacy.

#### Anna Dorai Raj

FRCP, FRACP GradCert in Higher Education

Dr Dorai Raj is a rheumatologist in private practice in Canberra and a visiting medical officer at the Canberra Hospital. She is also a clinical lecturer at the Australian National University Medical School.

#### Andrew Taylor

MBBS FRACP

Dr Taylor is a consultant rheumatologist at Royal Perth Hospital, Clinical Associate Professor with the University of Western Australia, and is engaged in private practice at St John of God Healthcare, Murdoch. He is past head of the Rheumatology Unit and Director of the Goatcher Clinical Research Unit at Royal Perth Hospital.

#### GRANTS ASSESSMENT COMMITTEE

This committee assesses all applications for research funding.

#### Graeme Jones – Chair & Medical Director

MBBS (Hons) FRACP FAFPHM MMedSc MD

(Refer to listing on page 17)

#### Rachelle Buchbinder

MBBS (Hons) MSc PhD FRACP

Prof Buchbinder is a rheumatologist and clinical epidemiologist. She is Director of the Monash Department of Clinical Epidemiology at Cabrini Hospital and Professor in the Department of Epidemiology and Preventive Medicine, School of Public Health and Preventive Medicine, Monash University.

#### Rana Hinman

BPhysio (Hons), PhD, MAPA

Assoc Prof Hinman is a physiotherapist and academic in the Centre for Health Exercise & Sports Medicine, Department of Physiotherapy, University of Melbourne.

#### Helen Keen

MBBS, FRACP, PhD, CCPU

Assoc Prof Helen Keen is a rheumatologist and clinical researcher. She is Head of Department of Rheumatology at RPH, and associate professor at UWA school of Medicine and Pharmacology.

## Governance continued

#### Michelle Leech

MBBS FRACP PhD

Assoc Prof Leech is a research fellow at Monash University, Melbourne, and Director of Bachelor of Medical Science Programs at Monash Southern Clinical School. She is also a consultant rheumatologist at Monash Medical Centre.

#### Chris Little

BSc, BVMS, PhD, DACVS

Prof Little is a veterinarian and basic scientist. He is Director of the Raymond Purves Bone and Joint Research Laboratories in the Kolling Institute University of Sydney at the Royal North Shore Hospital, and SubDean of Research at the Northern Clinical School, Sydney Medical School.

#### Susanna Proudman

MBBS (Hons) FRACP

Assoc Prof Proudman is a senior staff specialist in rheumatology at the Royal Adelaide Hospital and Associate Professor in the Department of Medicine in the University of Adelaide. She is Chair of the Australian Scleroderma Interest Group.

#### **Gethin Thomas**

BSc (Hons) PhD

Dr Thomas is a Deputy Director (Education) and a Group Leader at the University of Queensland Diamantina Institute, based in the Translational Research Institute in Brisbane. He is also an honorary senior research fellow at the Mater Medical Research Institute. He has a keen research interest in all aspects of bone and joint biology with a particular focus in ankylosing spondylitis. He utilises transcriptomics and functional



Grants Assessment Committee Front row from left: Assoc Prof Rana Hinman, Assoc Prof Helen Keen, Prof Rachelle Buchbinder and Prof Chris Little Back row from left: Dr Sharon Van Doornum, Assoc Prof Michelle Leech, Susanna Proudman, Prof Graeme Jones (Chair) and Dr Gethin Thomas

approaches to elucidate the role of genes identified through genetic approaches in skeletal disease.

#### Sharon Van Doornum

MBBS, MD, Grad Dip Clin Epi, FRACP

Dr Van Doornum is a rheumatologist and clinical academic. She is a senior lecturer in the Department of Medicine (RMH) of The University of Melbourne, and a consultant rheumatologist at Royal Melbourne Hospital and Cabrini Hospital.

### PATRON

Her Excellency Ms Quentin Bryce AC, Governor-General of the Commonwealth of Australia.

20 ARTHRITIS AUSTRALIA ANNUAL REPORT 2012–2013

## Funded research

#### 2012 outcomes

#### Grants-in-aid

#### Arthritis Australia and State & Territory Affiliates Grant – \$10,000

(funded by Arthritis South Australia)

#### The burden of musculoskeletal conditions in children and adolescents on primary care in Australia

Little is known about how often young patients with musculoskeletal (MSK) problems visit their GP, or how their conditions are managed. This study has provided the first description of GP management of MSK disorders in Australian children and adolescents.

The study found that an average of 6 in every 100 consultations for children under the age of 18 concerns a MSK disease. This rate rises with increasing age, with boys aged 15-17 years being most likely to visit their GP with a bone or joint complaint. There are also differences in the ways that GPs manage MSK disease in children and adolescents. For example, medication is more often prescribed to older girls. Referral to other health professionals (such as a physiotherapist) is also more common in older children. Interestingly, when compared to arm and leg problems, children and adolescents with spine conditions (such as low back pain) are more likely to be managed with medication but less likely to be referred for imaging, such as x-ray.

These findings show that MSK disorders form a significant work-load for Australian GPs. By highlighting differences across age groups, the study represents an important first step in improving the prevention and treatment of MSK disease in children and adolescents. Improved knowledge of these conditions in young people will lead to better understanding of the possible link between childhood MSK pain and injury and the development of MSK disease in adults. Continuation on this research will determine the best management strategies for the most common MSK disorders in children and adolescents.

Dr Nicholas Henschke Musculoskeletal Division The George Institute for Global Health

### Arthritis Australia and State & Territory Affiliates Grant – \$10,000

(funded by Arthritis South Australia)

# A standardised set of physical performance outcome measures for lower limb osteoarthritis

A number of different patient-reported questionnaires and clinical tests have been used to assess physical function in hip and knee osteoarthritis (OA), but there is no consensus about which measures are best. This makes it difficult to select the most reliable tests for research purposes, and makes clinical monitoring and treatment comparisons challenging. This study aimed to identify a 'gold-standard' core set of performance-based clinical tests that can be used to consistently measure physical function in people diagnosed with hip or knee OA.

An international expert advisory group selected five tests for comparison in this study: the 30-second chair stand test, the 40m fast-paced walk test, the stair climb test, the timed up and go test, and the six-minute walk test. The first three tests were recommended by the advisory group as the minimal core set of performance-based tests for people with hip or knee OA. This set has now been endorsed by the Osteoarthritis Research Society International (OARSI). An instructional manual (with videos to follow) is now available for clinicians and researchers on the OARSI website.

Future research priorities are the development of a recommended set of tests for higher functioning people, as well as expanding our knowledge on the accuracy of the recommended tests. This will involve collecting and examining data from world-wide leading research centres. The information will help develop a more definitive set of tests for clinical and research use, helping researchers and clinicians better understand which treatments work best for people with hip or knee OA.

#### Dr Fiona Dobson

Centre for Health, Exercise and Sports Medicine, Department of Physiotherapy University of Melbourne

#### Arthritis Australia and State & Territory Affiliates Grant – \$15,000

(funded by Arthritis South Australia)

# Investigating the potential use of IAP inhibitors for treatment of rheumatoid arthritis

Most currently available oral medications for rheumatoid arthritis (RA) must be taken over a long period. Often, patients need a combination of two or three different medications. This research study investigated whether use of a single oral medication, Embelin, could reduce the signs and symptoms of RA over a shorter time period.

## Funded research continued

Embelin has already been trialed for other diseases such as skin inflammation and cancers. Its safety profile in humans is well established, reducing the time needed to translate this drug into clinical practice for RA. The use of drugs such as Embelin will reduce the number of hospital visits for injections of anti-rheumatic medications.

Given in low doses, Embelin was found to reduce the physical and microscopic signs of arthritis in experimental models of arthritis. If larger studies confirm this finding, pre-clinical trials of low dose Embelin in humans with RA will be possible.

Further research will help to determine the most effective dose of Embelin. Another aim of this research study is to examine in more detail the changes that occur in the joint tissues as a result of Embelin treatment, and to investigate how Embelin affects the levels and activity of various 'natural killing' molecules that are key to the inflammatory process in RA. The micro computed tomography (CT) analysis performed during these investigations has demonstrated the sensitivity of this tool for the visualisation of the joint tissues and the detection of tissue swelling associated with inflammation. Further funding will enable this study to extend the micro CT analysis for use in humans with RA.

Dr Anak Dharmapatni Anatomy and Pathology, School of Medical Sciences University of Adelaide

### Arthritis Australia and State & Territory Affiliates Grant – \$15,000

(funded by Arthritis Queensland)

#### Hand function in obese subjects before and after weight loss following bariatric surgery

We know from previous research that general physical function and mobility improve following weight loss surgery. This research study set out to understand how weight loss can relieve the symptoms of a common and debilitating musculoskeletal condition, carpal tunnel syndrome, as well as to assess more broadly how weight loss can affect levels of pain and other musculoskeletal symptoms.

In this study, 13 cases were examined from public hospital obesity outpatient services. Each had elected to undergo gastric bypass surgery in order to improve their health, energy levels, mobility, appearance, or - in the words of one participant - to "get her life back". Musculoskeletal symptoms were common in these patients, including carpal tunnel syndrome, or pain elsewhere in the body, particularly the knee or back. Prior to surgery, the majority of the participants found it difficult to engage in regular exercise at a moderate level. Pain was a barrier to exercise, as were concerns about exacerbating the symptoms of urinary stress incontinence or high blood pressure.

This study is still on-going, but early indications are that as weight is lost, musculoskeletal symptoms ease and physical health improves. Dramatic weight loss following gastric bypass surgery is accompanied by improved health, with reduced blood pressure and improved blood sugar control. One participant described the result as "life changing". However, the study has shown that gastric bypass surgery can also result in lethargy and further limitations of activities, highlighting a role for rehabilitation following surgery.

Health care providers, including physiotherapists, often focus on managing the impairments and limitations associated with carpal tunnel syndrome. This research study shows that greater attention should be paid to the context of the individual's overall health, and there is an important role for general health education, with an emphasis on exercise.

Further research is needed to investigate whether exercise in tandem with surgery improves patient outcomes. Continuous patient follow-up in hospital or GP clinics may provide opportunities to personalise treatment, provide feedback on safe and effective exercise, address barriers to engaging in physical activity and progress goals to suit individual needs.

Ms Christine Redmond Discipline of Medicine, Faculty of Health Sciences University of Adelaide

#### Arthritis Australia and State & Territory Affiliates Grant – \$15,000

(funded by Arthritis Queensland)

Linking chronic anterior knee pain to patellofemoral joint osteoarthritis: an exploratory study of clinical, biomechanical and structural relationships

Chronic kneecap pain, a chronic and often disabling condition, may lead to kneecap arthritis, but there is limited evidence to substantiate this. This study set out to investigate the frequency of kneecap arthritis in people with chronic kneecap pain, and to determine whether certain features can be used to differentiate those who have kneecap arthritis from those who don't.

To date, 70% of participants have been recruited into the study, and data has been analysed so far to answer some questions that are important for people with chronic kneecap pain. For example, it was noted that that people with less movement in their ankle tend to have worse control of their hip movement during a one-leg squat task. However, increased rolling in of the foot (over-pronation) was not related to hip movement in this study.

This information is important for health professionals who treat people with chronic kneecap pain, as it suggests that treatments directed at increasing movement at the ankle, rather than controlling movement of the foot, may help to improve hip control during oneleg tasks, reducing loads on the kneecap joint.

The findings of this study have already been incorporated into Dr Collins's clinical practice. Communication of the results to other physiotherapists will help them to make better clinical decisions regarding appropriate treatments for chronic kneecap pain, improving management of patients with this condition. This research team is also investigating whether treatments applied to the ankle and foot (e.g. in-shoe orthotics) can improve abnormal movements throughout the leg that might place additional load on the kneecap, and ultimately reduce chronic kneecap pain.

This important study is part of a larger, long-term investigation into the relationship between pain and symptoms, x-ray findings, clinical

tests and leg joint motion in people with chronic kneecap pain. It is assisting to identify the factors that can predict the onset or worsening of kneecap arthritis in these patients. This research may lead to the development of new and novel interventions to prevent or slow the progression of kneecap arthritis in this group of people.

Dr Natalie Collins Department of Mechanical Engineering University of Melbourne

#### **Project grants**

#### ARA Project Grant - \$30,000

(funded by Australian Rheumatology Association)

#### The Victorian Juvenile Arthritis Cohort Study

Juvenile idiopathic arthritis (JIA) is a painful and disabling childhood immune disorder affecting up to four in every 1000 Australian children. Understanding the causes, development and outcomes of the disease is vital for the development of new, more specifically targeted treatments for JIA. The JIA Cohort Study combines with the existing large and on-going study CLARITY (ChiLdhood Arthritis Risk factor Identification sTudY). It will investigate the activity of JIA, prognostic and predictive factors, other associated illnesses, joint destruction, medications and monitoring, and long term outcomes for patients. The data collected will help to identify the risk factors for the development of JIA as well as how the disease behaves over time and the impact of the disease and treatments on the child physically and psychologically. The ultimate aim is to identify markers in the blood

which will predict the severity and likely treatment response for each child with JIA.

Recruitment has begun for this national and international landmark study which includes patients from the time of their diagnosis to follow ups with repeated research assessments over the course of their disease. Continuation of the recruitment of patients will occur at the Royal Children's Hospital and Monash Children's Hospital, Melbourne. Ultimately, it is hoped that the Juvenile Arthritis Cohort Study will help us understand more about why arthritis behaves in different ways in each child and how we can improve and target our treatment of this disease.

#### Dr Jane Munro

Department of Rheumatology Murdoch Children's Research Institute

#### ARA Project Grant – \$15,000

(funded by Australian Rheumatology Association)

## An examination of shoulder pain using MRI in older people

Shoulder pain is a common problem in the general population. Magnetic resonance imaging (MRI), commonly used to investigate the causes of shoulder pain, is a significant cost to the healthcare system. As MRI findings may not necessarily reflect the symptoms commonly reported by patients, the utility of this technique for investigating shoulder pain has been brought into question. This pilot study aimed to determine to what extent muscle or joint damage seen on MRI scans of the shoulder correlates with shoulder symptoms.

## Funded research continued

Comparing people without shoulder pain, people with past experience of shoulder pain, and those currently suffering from shoulder pain, we found that there was little association between symptoms and the presence of joint or muscle damage in the shoulder across all three groups. All had very similar findings on X-ray, as well as evidence of arthritis. On MRI, evidence of inflammation and degeneration of tissues was common in all three groups, irrespective of symptoms.

This study showed that symptoms of shoulder pain and stiffness are not necessarily consistent with X-ray or MRI findings, bringing into question the value of MRI as a useful diagnostic tool. Unless shoulder surgery is being contemplated, this form of expensive investigation should probably be deferred. Plans have been put in place to expand on the findings of this small pilot study with a larger investigation to validate these findings.

#### Dr Tiffany Gill Benson Radiology University of Adelaide

#### ARA Project Grant - \$7,000

(funded by Australian Rheumatology Association)

### Effect of obesity and metabolic syndrome on osteoarthritis

Obesity is an important risk factor for osteoarthritis (OA). Both the mechanical and metabolic changes that occur as a consequence of obesity are thought to be important in the development of OA. Metabolic syndrome is a collection of disorders and risk factors – one of which is obesity - that occur together to increase the risk of developing diabetes or cardiovascular disease. This study aimed to determine whether the metabolic syndrome also predicts the risk of OA.

The researchers have begun to analyse data from 11,000 individuals to understand the association between weight and body composition, the change in these factors over five years and the risk of total knee or hip replacement for OA will be investigated. Another aim of this study is to uncover the link between metabolic syndrome and birth weight with the risk of future joint replacement surgery. Meanwhile, a smaller study has been carried out in parallel to provide early insights into some of these issues. This study has found that the more metabolic syndrome components that an individual has, the more likely the risk of knee osteoarthritis, but not hip osteoarthritis.

This study was also able to determine that people with diabetes and impaired glucose tolerance are more likely to need total knee replacement (TKR) for OA, those who have undergone TKR have higher blood cholesterol and have higher blood pressure than those who have not, and people whose birth weight was low are more likely to develop hip OA.

Better understanding of the risk factors and pathogenesis of OA will inform effective prevention and treatment strategies to reduce the burden of the disease.

Dr Yuanyuan Wang Department of Epidemiology & Preventative Medicine Monash University

### Arthritis Australia and State & Territory Affiliates Grant - \$30,000

(funded by Arthritis South Australia)

#### Investigating keratan sulphate in juvenile arthritis

Current therapies for arthritis have greatly improved the outlook for children with juvenile idiopathic arthritis (JIA), but irreparable joint damage remains a risk for these children. The development of treatments that limit cartilage erosion and damage in JIA is hampered by the lack of fundamental knowledge about the mechanisms of cartilage breakdown in this disease. This study set out to map fragments of a crucial structural molecule in the cartilage, aggrecan, comparing the patterns of aggrecan fragmentation in JIA with that found in adult arthritis.

Analysing multiple synovial fluid samples in detail, it was exciting to find that the pattern of aggrecan fragments in JIA is different from the pattern in adult arthritis. These findings tell us that cartilage-sparing drugs that are in development for adults might not be useful for preventing cartilage erosion in children. As a result of these findings, complex experiments are currently being undertaken of the hypothesis that aggrecan fragmentation depends on the age-related number of sugar molecules that 'decorate' the protein backbone of this molecule.

With this research, the aim is to inform researchers and the pharmaceutical industry about appropriate targets to manage cartilage erosion in children with JIA. It will take many years to translate such findings into therapies to prevent cartilage degradation in JIA, but critically, this work has already shown that we cannot assume that cartilage erosion in children mirrors the disease in adults.

Assoc Prof Amanda Fosang Cell Biology, Department & Disease Murdoch Children's Research Institute

#### Barbara Cameron Memorial Grant - \$20,000

(funded jointly by Arthritis Australia and the late Jean Hale)

A novel mast cell and mactophagederived mediator in arthritis and chronic inflammatory disease

Many factors are involved in producing and propagating the inflammation that is characteristic of disorders such as rheumatoid arthritis (RA), making the development of new treatments a challenge. In a previous research study, it was indicated that a new molecule, CapG, released from important immune cells called mast cells and macrophages, is likely to play a role in inflammation in RA.

This project sought to better characterise the activity of CapG, and how it influences other cells in the joints that produce the tissue damage seen in RA. It was discovered that CapG is released from mast cells and macrophages when they are activated by inflammatory conditions. These results strengthened the theory that CapG plays a role in human diseases that involve inflammation. It was also ascertained that CapG activates a wide range of different cell types, including muscle cells, the cells that line the tissues that come in contact with our external environment and cells in joints that can lead to destruction of cartilage and bone.

The research continues as a PhD project, generating new insight into the role of CapG and developing ways of blocking its actions. The early stage support of this project has been the key to generating experimental tools and strong supporting data that will be used to seek further support for more comprehensive studies. These studies may provide new treatment possibilities for sufferers of inflammatory diseases such as rheumatoid arthritis.

#### Dr Graham Mackay Department of Pharmacology University of Melbourne

#### Clitheroe Foundation Grant -\$20,000

(funded by the Clitheroe Foundation)

## Effect of modulating prostaglandin signalling in ankylosing spondylitis

Ankylosing spondylitis (AS), a form of inflammatory arthritis that causes uncontrolled bone formation and joint fusion in the spine, can lead to severe disability and a shortened life-expectancy. As this process is poorly understood, no effective targeted therapies are currently available. These study set out to establish the precise role of a molecule suspected to contribute to the development of AS, and help us to understand how targeting this factor might affect the course of the disease.

A range of drugs were tested that are known to both specifically stimulate and inhibit the 'suspect' molecule, PTGER4, as well as other closely related molecules. With the continuation of this study, the aim in the next phase of the research is to take 3D skeletal x-rays of animal models to visualise changes in the joints in response to these drugs. If this research shows that manipulating PTGER4 in some way decreases disease activity in AS, the aim will be to investigate the effects of different doses and treatment regimes, as well as testing the drugs in other animal models of AS. Ultimately, the aim will be to test these drugs in human trials.

#### Dr Gethin Thomas Human Genetics Group University of Queensland, Diamantina Institute

#### SA LSS Support Group Grant -\$20,000

(funded by Arthritis South Australia)

## Inflammatory efforts of immune complexes

Sjögren's syndrome is an autoimmune disease that primarily affects the eyes and salivary glands. Immune system cells and autoantibodies - 'anti-self' antibodies - attack the body's moisture-producing glands, resulting in abnormal dryness of the mouth, eyes or other tissues. The disorder impacts substantially on quality of life, but our lack of understanding of how the disease develops means that the currently available treatments tackle only the symptoms and do not affect the course of the disease.

This study investigated how the faulty 'recycling' of dead cells, a feature of Sjogren's syndrome, lead to the formation of inflammasomes – 'mini-factories' that produce large amounts of inflammatory molecules, leading to the symptoms that are characteristic of this disorder. The aim of this study was to develop special cultures of salivary gland cells in the laboratory so that their activation mechanisms can

## Funded research continued

be examined in detail. Early work with a culture model showed that substances that bind to and trigger TLR7, a molecule that sits on the surface of salivary gland cells, activates the cell's inflammasomes.

Fully establishing this model will enable testing the hypothesis that immune complexes formed in patients with Sjogren's syndrome are powerful activators of the inflammasome. The next experiments will reveal which genes are 'turned on' in these cultures when treated with immune complexes and other substances.

These findings have laid the framework for on-going studies. Inflammasome regulation could be an important mechanism that fuels chronic inflammation in Sjogren's syndrome.

Dr Peter Zalewski Discipline of Medicine 5B The Queen Elizabeth Hospital

#### Zimmer Australia Grant - \$20,000

(funded by Zimmer Australia)

#### Characterisation of pathogenic inflammatory cells in autoimmune disease

The white blood cells that make up our immune system play a vital role in protecting our body from disease. The loss of control of these cells (called autoimmunity) in conditions such as arthritis can lead to these same cells causing damaging inflammation in healthy areas of the body. This research focused on the Th17 cell, an immune cell that produces large amounts of the potent 'pro- inflammatory' molecule interleukin-17 in rheumatoid arthritis (RA). With the collection and analysis of blood and joint fluid from people with RA, we have developed methods to isolate the Th17 cells from these samples, and have now established an archive of genetic material from the cells.

Analysis of 47000 genes across Th17 cells in synovial fluid and blood has shown that there are distinct differences between Th17 cells from active inflamed joints compared to those in healthy blood. In addition, the inflammatory nature of the Th17 cell in the joint is "fixed" and distinct from that of the Th17 cell in the blood. These outcomes tell us that the inflammatory Th17 cells can be distinguished from healthy Th17 cells by their pattern of the genes that they express.

Finding out more about how these cells operate allows us to understand how they function in a healthy individual and the changes they might undergo in an inflammatory setting such as a joint with RA. Identifying Th17 cells in arthritic joints and discovering the unique molecules these cells produce may aid diagnosis and prognosis, by correlating the stages of Th17 cell development with arthritic disease progression. The Th17 cell may also be specifically targeted in the development of treatments for arthritis.

Ms Kerry Ko Centre for Inflammatory Burnet Institute

#### **Fellowships**

#### AFA-ARA Heald Fellowship -\$50,000

(funded jointly by the Australian Rheumatology Association and the Vincent Fairfax Family Foundation)

Role of IL-23R + gamma delta T cells in pathogenisis in AS

Ankylosing spondylitis (AS) and related diseases are as common in the population as rheumatoid arthritis. AS mainly affects the spine and pelvis, and can cause severe pain, stiffness and disability. Because the disease usually affects people in their thirties or forties, it can interrupt working lives, and poses a significant socio-economic burden. A better understanding of this disease is needed to bring about the development of more effective treatments.

AS is triggered by the patient's own immune system attacking healthy cells and tissues. This study focussed on the genetic basis of this faulty immune response, and has already identified some abnormalities in an immune cell communication system, known as the IL-23 signalling pathway.

The aim of this study was to examine these findings in more detail - understanding how IL-23 signalling differs depending on the severity of the disease can offer some clues as to its importance.

Overall, people with more severe AS were found to have higher levels of the IL-23 receptor – the 'lock' on the surface of the cell that transmits a signal from the IL-23 'key' – than people with milder AS. It was also found that a common immune-modifying treatment for AS, anti-TNF, has no effect on levels of IL-23 receptor in AS patients. This suggests that TNF does not target one of the most important immune communication pathways driving AS, warranting new therapeutic approaches for this disease. Further research is being undertaken to bring this a step closer, with future changes to the clinical management of AS a possibility.

#### Dr Tony Kenna

Human Genetics Group, Diamantina Institute University of Queensland

#### The Ken Muirden Overseas Training Fellowship - \$100,000

(funded jointly be an educational research grant by Australian Rheumatology Association and Roche Products Pty Limited)

## Clinical fellowship in paediatric rheumatology

Central nervous system (CNS) vasculitis in children has become increasingly recognised over recent years. The affected child's immune system attacks the blood vessels of the brain, leading to inflammation and irritation of the blood vessel wall and the surrounding brain tissue. Stroke, seizures, severe headaches, loss of consciousness, psychiatric symptoms or even death may result.

Although early recognition and diagnosis of CNS vasculitis now allows prompt medical treatment and reduced mortality, the long term impact on cognitive function has never been investigated. The results of this research suggest that children with CNS vasculitis carry significant disease burden and impaired cognitive function. A specific disease subtype most at risk of poor cognitive outcome was identified, and a pattern of neurocognitive deficit described. Risk factors for poor outcome at presentation were also identified. This is the first time cognitive outcome has been described in children with CNS vasculitis.

The findings of this study have already impacted the way children with CNS vasculitis are managed at the Hospital for Sick Children in Toronto. We are now more aware of the impact of this disease and can more clearly counsel families about the potential cognitive complications of CNS vasculitis. Attempts are now made to establish rehabilitation strategies early in the course of a child's illness in order to optimise function and reduce the impact of this disease. These findings will have significant impact on the way children with CNS vasculitis are managed throughout the world.

Dr Peter Gowdie Division of Rheumatology Hospital for Sick Children Toronto Canada

#### The Victorian ARA Fellowship -\$50,000

(funded by Australian Rheumatology Association -Victoria)

#### Citrullination in Rheumatic Diseases

Our understanding of the way that the immune system 'attacks' the joins of people with rheumatoid arthritis (RA) has been improved by the detection of abnormal anti-citrullinated peptide/protein antibodies (ACPA) in the blood. We can do blood tests to detect these abnormal proteins, which help to confirm if a patient has RA. Testing for ACPA is now considered a more useful test than the traditional test, rheumatoid factor, for the diagnosis of RA. This study aimed to examine the trends of ACPA testing, assessing the use and appropriateness of this test not only for the diagnosis of RA, but for two other autoimmune diseases that often involve the joints, systemic lupus erythematosis (SLE) and scleroderma.

The findings of this study were that the rate of testing for ACPA is increasing dramatically - 24-30% per year, compared to an expected rate of 5% per year. Three quarters of the patients in this study were tested both for ACPA and rheumatoid factor. The results of these tests disagreed for only 3.4% of these cases, indicating that just one of these tests is sufficient in helping to diagnose RA, with the potential to save significant health service resources. It is also know that ACPA levels don't change with treatment or with worsening of RA – nevertheless, multiple tests were ordered for more than 15% of patients, representing further potential for savings.

In a large group of patients that were tested with scleroderma, only 3% had a positive ACPA test, and there was no association between ACPA level and disease severity or damage in this group. The story for those with SLE is slightly different – 9% of the patients tested were ACPA positive, and results suggested that SLE patients with more active disease or with more tissue damage are more likely to be ACPA positive. Generally, however, it appears that ACPA testing would be of little benefit for these patients.

This study has highlighted the need for education for GPs and non-rheumatologists addressing the need for testing for different diseases, and guidance for the interpretation of test results.

#### Dr Andrew Foote

Centre for Inflammatory Diseases Monash University

## Funded research continued

#### **Scholarships**

#### ARA Project Grant - \$25,000

(funded by Australian Rheumatology Association)

Expression of leukocyte immunoglobulin-like receptor (LILR) A3 and its ligand(s) in inflammatory arthritis

When we are ill with an infection, it is important that our immune system initiates an inflammatory response to attack and kill the bacteria responsible, but it is equally important that the inflammation is brought to an end once this task is accomplished. Ongoing inflammation can lead to unnecessary damage to healthy tissue. In rheumatoid arthritis (RA), inflammation is initiated inappropriately and continues in an uncontrolled manner, causing pain, disability and damage to the structure of the joints. Earlier research carried out at the University of New South Wales by a team of researchers suggests that two molecules are very important in the initiation and subsequent termination of normal and appropriate inflammation. By comparing healthy people with patients with RA, this project focussed on how these molecules affect different components of our immune system.

This research has found that one molecules of interest, LAMR1, is found in the joint lining of both healthy subjects and patients suffering from RA. Both groups have large amounts of this protein on the blood vessels in and around the joints as well as on the cells which line the joint surface. RA does not change the amount of the molecule present or affect where it is found. Furthermore, this molecule is found on two specific types of white blood cells, and preliminary data suggests that one of these cell types increases in people with active RA.

This work is at a preliminary stage, but there is evidence to provide a rationale for the use of one protein in particular as a possible anti-inflammatory therapy for RA.

Dr Barry Kane Inflammation and Infection Research Centre Department of Pathology School of Medical Sciences, University of NSW

#### Zimmer Australia Grant - \$30,000

(funded by Zimmer Australia)

The Pathogenesis of muscle inflammation in knee osteoarthritis and its effect on gait and muscle function

People with knee osteoarthritis (OA) often have leg muscle weakness and difficulty moving and walking. It isn't known if loss of muscle mass and strength in knee OA occurs as an indirect result of reduced limb use, or if muscle itself is a direct target of the degenerative processes of OA. In this study, an examination of muscle and joint inflammation at the onset of OA and its effect on muscle function was undertaken, as well as the interaction between inflammatory molecules, muscle function and impaired walking patterns in OA.

Studies in animals allowed evaluation of the loss of muscle function during the development of OA and to link these changes to the structural and biological changes of the tissue and cells within the knee joint. The results demonstrated a progressive decrease in muscle strength over a number of weeks, accompanied by an increase in the levels of certain genes associated with inflammation and decreased muscle mass.

In the human arm of this study, it was established that the inflammatory response in the muscle and blood was similar between people with severe OA and healthy people, with some molecule 'markers' of inflammation at low concentrations. However, analysis of the synovial fluid, the lubricating fluid that fills that space between the joint surfaces, indicated that certain inflammatory markers in the joint correlate with the level of pain, function and joint loading for people with knee OA. The research team is currently focusing on further analysis to examine markers in the muscle that are responsible for muscle breakdown.

Dr Pazit Levinger Musculoskeletal Research Centre La Trobe University

## 2013 projects currently being undertaken

#### Grants-in-aid

### Arthritis Australia and State & Territory Affiliate Grant - \$14,000

(funded by Arthritis Australia)

Hip and knee osteoarthritis in younger people: Wellbeing, work limitations and preferences for self-management education

Dr Ilan Ackerman Melbourne EpiCentre, Department of Medicine, Royal Melbourne Hospital, University of Melbourne

#### Arthritis Australia and State & Territory Affiliate Grant - \$12,500

(funded by Arthritis South Australia)

Association between urinary C-telopeptide fragments of type II collagen levels and knee structure

Dr Andrew Teichtahl Department of Epidemiology and Preventive Medicine, Monash University

#### Arthritis Australia and State & Territory Affiliate Grant - \$15,000

(funded by Arthritis New South Wales)

Investigating the pain mechanisms in osteoarthritis

Dr Sanaa Zaki Kolling Institute of Medical Research, University of Sydney

#### Allan and Beryl Stephens Grant -\$15,000

(funded by the Estate of the late Beryl Stephens)

Prostaglandin D2, Resolvins and Lipoxin A4 in inflammatory arthritis

Dr Mahin Moghaddami Rheumatology Unit, Royal Adelaide Hospital

#### Barbara Cameron Memorial Grant - \$15,000

(funded by the late Jean Hale)

Clinical characteristics of children with generalised joint hypermobility

Assoc Prof Leslie Nicholson Discipline of Biomedical Science, Sydney Medical School, University of Sydney

#### Philip Benjamin Grant - \$15,000

(funded jointly by Mrs Benjamin and Arthritis South Australia)

The effect of statins on joint health

Dr Daniel McCulloch School of Medicine, Deakin University

#### Ray and Pam Robinson Grant -\$10,000

(funded by the late Pam Robinson)

Infection after arthroplasty 2002-2010

Dr Megan Bohensky Department of Medicine, University of Melbourne

#### Zimmer Australia Grant - \$10,000

(funded by Zimmer Australia)

The association between socioeconomic status, and total joint replacement across Australia

Dr Sharon Brennan NorthWest Academic Centre, Department of Medicine, University of Melbourne

#### Zimmer Australia Grant - \$15,000

(funded by Zimmer Australia)

A goit analysis and micro-CT study in end-stage knee osteoarthritis

Dr Egon Perilli Medical Device Research Institute, Faculty of Science and Engineering, Flinders University of South Australia

#### **Project Grants**

#### Arthritis Australia and State & Territory Affiliate Grant - \$25,000

(funded by Arthritis South Australia)

Biomechanical testing of wildtype and mutant mouse cartilage by atomic force microscopy

Assoc Prof Amanda Fosang Cell Biology, Development & Disease, Murdoch Children's Research Institute

#### Arthritis Australia and State & Territory Affiliate Grant - \$30,000

(funded jointly by Arthritis Queensland and Arthritis South Australia)

Therapeutic Targeting of MicroRNA-23 in Osteoarthritis

Assoc Prof Yin Xiao Medical Device domain, Institute of Health and Biomedical Innovation, Queensland University of Technology

#### Allan and Beryl Stephens Grant -\$25,000

(funded by the Estate of the late Beryl Stephens)

OSCAR as a marker of disease activity in rheumatoid arthritis

Dr Tania Crotti Discipline of Anatomy and Pathology, University of Adelaide

#### ARA Project Grant - \$25,000

(funded by Australian Rheumatology Association)

Genetics of Giant Cell Arthritis

Prof Matthew Brown Human Genetics Group, University of Queensland, Diamantina Institute

## Funded research continued

#### ARA Project Grant - \$25,000

(funded by Australian Rheumatology Association)

MicroRNAs in knee osteoarthritis

Assoc Prof Changhai Ding Menzies Research Institute Tasmania, University of Tasmania

#### ARA Project Grant - \$25,000

(funded by Australian Rheumatology Association)

Development of ERAP1 inhibitors as novel therapeutics in treatment of ankylosing spondylitis

Mr Tony Kenna The University of Queensland, Diamantina Institute

#### Ray and Pam Robinson Grant -\$40,000

(funded by the late Pam Robinson)

Dampening the aggressive properties of rheumatoid synovial fibroblasts to treat rheumatoid arthritis

Dr Christopher Jackson Department of Rheumatology, Northern Clinical School, University of Sydney

#### SA LSS Support Group Grant -\$25,000

(funded by Arthritis South Australia)

Role of interleukin-3 in systemic lupus erythematosus

Prof Ian Wicks Division of Inflammation, Walter Eliza Hall Institute and Department of Rheumatology, Royal Melbourne Hospital

#### Zimmer Australia Grant - \$25,000

(funded by Zimmer Australia)

Genetics of rheumatoid arthritis

Dr Philippe Bouillet

Molecular Genetics of Cancer Division, Walter and Eliza Hall Institute

#### Fellowships

#### AFA-ARA Heald Fellowship -\$50,000

(funded jointly by Australian Rheumatology Association and Vincent Fairfax Family Foundation)

Humira for treatment of erosive hand osteoarthritis

Ms Laura Laslett Menzies Research Institute Tasmania, University of Tasmania

#### The Ken Muirden Overseas Training Fellowship - \$100,000

(funded jointly by an educational research grant by Australian Rheumatology Association and Roche Products Pty Limited)

The impact of oral glucocorticoid therapy on the risk of cataracts and glaucoma in patients with rheumatoid arthritis

Dr Rachel Black Arthritis Research UK Epidemiology Unit, University of Manchester

#### The Victorian ARA Fellowship -\$50,000

(funded by Australian Rheumatology Association – Victoria)

Biomarkers of response to biologic therapy in rheumatoid arthritis

Dr Maree Micallef Rheumatology Clinical Research Unit, Addenbrooke's Hospital, Cambridge

#### Scholarships

#### Kevin R James Grant - \$23,000

(funded by the Estate of the late Kevin R James)

Chronic knee pain and work disability

Ms Maria Agaliotis Faculty of Health Sciences, University of Sydney

#### Kevin R James Grant - \$28,000

(funded by the Estate of the late Kevin R James)

Association of Vitamin D and disease outcome in SLE: a prospective study

Dr Kate Franklyn Centre for Inflammatory Diseases (Rheumatology Unit); Monash Medical Centre, Monash University

#### Kevin R James Grant - \$28,000

(funded by the Estate of the late Kevin R James)

Expression of leukocyte immunoglobulin-like receptor (LILR) A3 and its ligand(s) in inflammatory arthritis

Dr Barry Kane Inflammation and Infection Research Centre, Department of Pathology, School of Medical Sciences, University of NSW

#### Kevin R James Grant - \$28,000

(funded by the Estate of the late Kevin R James)

GILZ as an immunomodulation in rheumatoid arthritis

Dr Kim Le Marshall Monash Centre for Inflammatory Diseases, Monash University

### Arthritis Australia/Zimmer Orthopaedic Fellowship Program

## Fellowships awarded in 2012–2013

(funded by Zimmer Australia)

#### Joint Replacement & Reconstruction Fellowship -\$50,000

Ms Homa Arshad Royal Adelaide Hospital North Terrace Adelaide, SA

#### Sydney Orthopaedic Research Institute Fellowship - \$50,000

Dr Ziad Dahabreh Sydney Orthopaedic Research Institute Chatswood, NSW

#### Bendigo Orthopaedic Fellowship -\$50,000

Dr Neil Ferguson DSS James Pty Ltd Bendigo, VIC

#### University Hospitals Coventry & Warwichshire Hip Surgery Fellowship - \$50,000

Dr Ilan Freedman University Hospitals Coventry & Warwickshire/ Warwickshire Medical School Coventry, United Kingdom

#### McGill Orthopaedic Sports Medicine & Arthroplasty Clinical Fellowship - \$50,000

Dr Antony Liddell McGill University - Faculty of Medicine, Division of Orthopaedic Surgery - Montreal General Hospital Montreal, Canada

#### Centre Albert Trillat Fellowship in Knee Surgery - \$25,000

Mr Timothy Lording Centre Albert Trillat - Croix Rousse Hospital - Lyon University Centre Lyon, France

#### Adult Reconstruction, Hip & Knee Fellowship - \$50,000

Dr Peter Misur The University of British Columbia (UBC) Department of Orthopaedics Vancouver, Canada

### Adult Reconstruction &

### Arthroscopy Fellowship - \$25,000 Dr Justin Munt Peninsula Orthopaedic Research

Institute Dee Why, NSW

#### Knee Arthroplasty Fellowship -\$25,000

Dr Jonathan Robin Centre Albert Trillat - Croix Rousse Hospital - Lyon University Centre Lyon, France

#### Canberra Hip & Knee Replacement Fellowship - \$25,000

Dr Joseph Smith Canberra Hip & Knee Replacement Bruce, ACT

#### Nelson Lower Limb Reconstruction Orthopaedic Fellowship - \$50,000

Dr Paul Voorhoeve Nelson Public Hospital - Nelson Marlborough District Health Board Nelson, New Zealand

#### McMaster University Hip & Knee Recon & Trauma Fellowship -\$50,000

Dr John Yun Seo Choi McMaster University Canada Ontario, Canada

## Finance

#### **Statement of Financial Position**

	12/13 \$	11/12 \$
Current Assets		
Cash Assets	2,299,794	1,514,650
Receivables	609,984	1,440,084
Financial Assets	-	-
Total Current Asset	2,909,778	2,954,734
Non-Current Assets		
Receivables	50,000	-
Financial Assets	4,831,382	3,649,129
Property, Plant & Equipment	32,797	30,898
Total Non-Current Assets	4,914,179	3,680,027
Total Assets	7,823,957	6,634,761
Current Liabilities		
Payables	2,038,856	1,446,916
Provisions	430,967	392,081
Total Current Liabilities	2,469,823	1,838,997
Non-Current Liabilities		
Long Term Provisions	27,097	16,130
Total Non-Current Liabilities	27,097	16,130
Total Liabilities	2,496,920	1,855,127
Net Assets	5,327,037	4,779,634
Accumulated Funds		
Contractually restricted funds	4,582,896	3,787,654
General Funds	744,141	991,980
	5.327.037	4.779.634

### Statement of Profit or Loss and Other Comprehensive Income

	12/13	11/12
	\$	\$
Income		
Donations/fundraising		
General	1,637,596	2,081,277
Affiliates	199,750	175,750
Total	1,837,346	2,257,027
Membership Fees	1,676	1,924
Investments		
Interest	54,582	54,842
Profit on Sale	214,843	15,509
Dividends	316,645	286,009
Total	586,070	356,360
Other	49,038	60,851
Total Income	2,474,130	2,676,162
Expenses		
Research	726,192	626,084
Patient & Community Services	-	-
Education & Awareness	1,141,456	1,335,305
Administration	403,055	378,194
Fundraising	142,136	270,806
Depreciation	7,856	6,100
Total Expenses	2,420,695	2,616,489
Net Surplus/(Deficit)	53,435	59,673
Contribution to contractually		
restricted funds	152,602	-
Asset Revaluation / (Devaluation)	341,466	(172,592)
Change in Foundation Funds	547,403	(112,919)

Total Foundation Funds at 30 June 2013 include \$4,582,896 (2012 \$3,787,654) of contractually restricted research funds administered by the Foundation.

The above tables showing the Statement of Financial Position and Statement of Comprehensive Income for the year ended 30 June 2013 have been prepared from audited financial statements passed by the Board of Directors, who are responsible for the presentation of the financial statements and the information they contain. The complete financial report of the Foundation and the audit report by William Buck is available from Arthritis Australia PO Box 550 Broadway NSW 2007.

### Arthritis Australia Summary

Following is the summary of revenue and expenditure of Arthritis Australia. Assets held \$7,823,957 and liabilities held \$2,496,920

### Revenue

TOTAL	\$2,474,130	100%
Membership/Admin/Fees	\$79,926	3.23%
Donations/Bequests	\$246,355	9.96%
Investments	\$635,108	25.67%
Research Grants	\$633,500	25.60%
Projects	\$879,241	35.54%

### Expenditure

TOTAL	\$2,420,695	100%
Depreciation	\$7,856	0.32%
Administration	\$403,055	16.65%
Research	\$726,192	30.00%
Projects	\$1,283,592	53.03%





## Supporters

We are extremely grateful to our supporters who have allowed us to continue our work in raising awareness, delivering education and support services, providing annual research grants and developing advocacy programs. Many have contributed expertise, time, funding, goods and services.

#### Awareness and education

AbbVie Pty Ltd AstraZeneca Pty Ltd Australian Institute of Packaging Australian Rheumatology Association Bupa Health Foundation Commonwealth Department of Health and Ageing Janssen-Cilag Pty Limited Lanham Public Relations Packaging Council of Australia pdq design Pty Ltd Print National Pty Ltd Roche Products Pty Limited Social Policy Research Centre, University of New South Wales

#### **Business services**

Amcor Limited Ardagh Group Cormack Packaging Pty Ltd Handeepax Pty Ltd H.J. Heinz Company Australia Ltd Kellogg (Aust) Pty Ltd Kraft Foods Group, Inc Metalprint Pty Ltd Nestlé Oceania Pty Ltd NSW Health Support Services Sara Lee Pty Ltd SPC Ardmona Operations Limited

#### Donations of \$500+

Best Friends Birthday Appeal John Burville Augusto Contessotto Sharon Easdale Elan Services Pty Limited Allan G Elliott Estate Envato Pty Ltd D & R Field Fire & Emergency Services SA FUCHS Lubricants Australia P/L Luke Goodsell Jo Harris Libby Higgin Clare Hourigan Peter Isaacson Foundation Rebecca Jones (Making A Difference fundraiser) The late Philomena Lam The Luscombe Family Foundation Bronwyn Malouf Mr Peter McGovern Dr Stephen Milazzo AO Thu Ngo Brian Prendergast Carolina Puleston Elisha Rose Sanofi Australia & NZ Dr Paul Scott Manny Stul John Tucker Bruce and Maureen Wallis Georgia White (Blackmores Sydney Running Festival 2012 fundraiser)

#### In-kind support

Anchor Hosting Coverforce Insurance Broking Pty Ltd Georgia Tech Research Institute Google Inc Halltech Services Geoff Hall (Pasco Hall and Associates) Kemp Strang Pty Limited Chris Lowe Medical Media Group Pty Ltd pdq design Pty Ltd Print National Pty Ltd RBS Morgans Ltd

**Licence agreements** Eatwell Foods Ethical Nutrients

### Medicines Australia Community Chest Program

AbbVie Pty Ltd AstraZeneca Pty Ltd Janssen-Cilag Pty Limited Medicines Australia Pfizer Australia Pty Ltd Roche Products Pty Ltd

#### Models of Care Project

Dr Roger Allen Jeff Cheverton Prof Peter Choong Anne Develin Wendy Favorito Dr Stan Goldstein Prof David Hunter Prof Danny Liew Dr Mona Marabani Cameron Milliner Maree Raymer Jennie Roe Dr Norman Swan Dr Rob Walters

#### National Consumer Reference Group

Helen Davies Wendy Favorito - Chair Michelle Graham Annie Grindrod Matthew Leibowitz Suzie Edward May Alison Park Cosi Pupo Colette Smith

#### **Parliamentary Friends**

The Hon Kevin Andrews, Convenor, House of Representatives, Canberra Senator Carol Brown, Convenor, the Senate, Canberra

#### **Research grant funding**

Arthritis NSW – Arthritis Australia State and Territory Affiliate Grant

Arthritis Queensland – Arthritis Australia State and Territory Affiliate Grant

Arthritis South Australia – Arthritis Australia State and Territory Affiliate Grant and SA LSS Support Grant

Arthritis Western Australia -Arthritis Australia State and Territory Affiliate Grant

Australian Rheumatology Association - ARA Grant funding, AFA/ARA Heald Fellowship & Ken Muirden Fellowship

Australian Rheumatology Association - Victoria

Clitheroe Foundation

Estate Beryl Stephens – Allan and Beryl Stephens Grant

Jean Hale – Barbara Cameron Memorial Grant

Pam Robinson – Ray and Pam Robinson Award

Roche Products Pty Limited -Ken Muirden Fellowship

Vincent Fairfax Family Foundation – AFA/ARA Heald Fellowship

Zimmer Australia Pty Ltd













## Resources

### Information booklets











### Information sheets

### Areas of the body

- Back pain •
- Feet and arthritis •
- Hands and arthritis •
- Neck pain ٠
- Shoulder pain •
- Tips for osteoarthritis of the • hip/knee

### Complementary therapies/ supplements

- Complementary therapies
- Fish oils
- Glucosamine and chondroitine •

### **Condition specific**

- Ankylosing spondylitis
- Fibromyalgia

- Gout
- Juvenile arthritis

Arthritis

- Lupus (systemic lupus erythematous)
- Osteoarthritis
- Polymyalgia rheumatica
- Psoriatic arthritis
- Reactive arthritis
- Rheumatoid arthritis
- Ross river virus
- Scleroderma
- Sjogren's syndrome
- Spondyloarthritis
- What is arthritis?

### General management

- Arthritis and emotions
- Dealing with pain
- Exercise and RA





- Exercise and fibromyalgia
- Gout and diet
- Healthy eating and arthritis •
- Juvenile arthritis
- Juvenile arthritis A Teachers Guide
- Massage and arthritis
- Physical activity
- Saving energy •
- Sex and Arthritis •
- Tai Chi •
- Water Exercise •

### Medical management

- Blood tests for arthritis
- Medicines and arthritis
- Surgery for arthritis •
- Working with your healthcare team



### Multicultural information sheets



### Arabic:

- What is arthritis?
- Dealing with pain
- Healthy eating and physical activity
- Medicines and arthritis
- Working with your healthcare team
- Methotrexate
- NSAIDs
- Paracetamol
- Complementary therapies
- Osteoarthritis
- Rheumatoid arthritis
- Fish oil
- Glucosamine and chondroitin

### Chinese:

- What is arthritis?
- Dealing with pain
- Healthy eating and physical activity
- Medicines and arthritis
- Working with your healthcare team
- Methotrexate
- NSAIDs
- Paracetamol

- Complementary therapies
- Osteoarthritis
- Rheumatoid arthritis
- Fish oil
- Glucosamine and chondroitin

### Greek:

- What is arthritis?
- Dealing with pain
- Healthy eating and physical activity
- Medicines and arthritis
- Working with your healthcare team
- Methotrexate
- NSAIDs
- Gout
- Paracetamol
- Complementary therapies
- Osteoarthritis
- Rheumatoid arthritis
- Fish oil
- Glucosamine and chondroitin

### Italian:

- What is arthritis?
- Dealing with pain
- Healthy eating and physical activity

- Medicines and arthritis
- Working with your healthcare team
- NSAIDs
- Paracetamol
- Complementary therapies
- Osteoarthritis
- Rheumatoid arthritis
- Fish oil
- Glucosamine and chondroitin

### Vietnamese:

- What is arthritis?
- Dealing with pain
- Healthy eating and physical activity
- Medicines and arthritis
- Working with your healthcare team
- Methotrexate
- NSAIDs
- Paracetamol
- Complementary therapies
- Osteoarthritis
- Rheumatoid arthritis
- Fish oil
- Glucosamine and chondroitin

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## Contacts

#### Arthritis Australia

Level 2/255 BroadwayCrGlebe NSW 2037FePO Box 550 Broadway NSW 2007Stp: 02 9518 4441Alf: 02 9518 4011Ree: info@arthritisaustralia.com.auChWeb: www.arthritisaustralia.com.auPr

#### Affiliate offices

#### Arthritis ACT

Level 2B Grant Cameron Community Centre 27 Mulley Street Holder ACT 2611 PO Box 4017 Weston Creek ACT 2611 p: 02 6288 4244 f: 02 6288 4277 Helen Krig - Chief Executive Officer

### Arthritis New South Wales

Unit 1.15/32 Delhi Road North Ryde NSW 2113 Locked Bag 2216 North Ryde NSW 1670 p: 02 9857 3300 f: 02 9857 3399 Karen Filocamo - Chief Executive (Resigned) Nettie Burke – Chief Executive (Current) Ainslie Cahill Chief Executive Officer

**Fergal Barry** Strategic Partnerships Manager

**Alexandra Brayshaw** Research Assistant/Administrative Support

**Chris Dickson** Project Manager MyJointPain

#### Arthritis Northern Territory

Shop 18 Rapid Creek Business Village 48 Trower Road Millner NT 0810 PO Box 452 Nightcliff NT 0814 p: 08 8948 5232 f: 08 8948 5234

#### Arthritis Queensland

1 Cartwright Street Windsor QLD 4030 PO Box 2121 Windsor QLD 4030 p: 07 3857 4200 f: 07 3857 4099 Helene Frayne – General Manager

#### Arthritis South Australia

118 Richmond Road Marleston SA 5033 p: 08 8379 5711 f: 08 8379 5707 Julie Black - Chief Executive Officer **Franca Marine** National Policy & Government Relations Manager

**Lindsay Parks** MyJointPain Coordinator

Ron Richardson Financial Administrator

**Dora Stavrakis** Office Administrator /Projects Coordinator

#### Arthritis Tasmania

19A Main Road Moonah TAS 7009 GPO Box 1843 Hobart TAS 7001 p: 03 6228 4824 f: 03 6228 3486 Jackie Slyp - Chief Executive Officer

#### Arthritis Western Australia

17 Lemnos Street Shenton Park WA 6008 PO Box 34 Wembley WA 6913 p: 08 9388 2199 f: 08 9388 4488 Ric Forlano - Executive Director





L to R: Lindsey Parks – MyJointPain Coordinator, Fergal Barry – Strategic Partnerships Manager, Franca Marine – National Policy & Government Relations Manager, Ron Richardson – Financial Administrator, Dora Stavrakis – Office Administrator/Projects Coordinator, Ainslie Cahill – Chief Executive Officer, Alexandra Brayshaw – Research Assistant/Administrative Support and Chris Dickson – Project Manager MyJointPain



#### Leading the charge

From left: Nettie Burke - Arthritis NSW Cheif Executive, Ainslie Cahill - Arthritis Australia CEO, Helene Frayne - Arthritis QLD General Manager, Helen Krig - Arthritis ACT CEO, Ric Forlano -Arthritis WA Executive Director, Julie Black - Arthritis SA CEO and Jackie Slyp - Arthritis TAS CEO.

For all arthritis information: www.arthritisaustralia.com.au

> Arthritis Helpline 1800 011 041

