Researching our research

2006 - 2011

Arthritis AUSTRALIA

Contents

Executive summary

The importance of high quality, well-targeted research to deliver solutions for debilitating diseases such as arthritis can't be overstated. The development and implementation of new and improved therapies, diagnostic techniques and clinical policies can take decades to achieve through dedicated research funding and career support for talented researchers. As a proud funder of arthritis research in this country for 30 years, Arthritis Australia is committed in its contribution to this immense research effort.

We know that Arthritis Australia research is highly valued by the public and the philanthropic community. Strong and growing support from our various benefactors and the foundations that contribute to our research fund is testament to this. What we haven't been able to articulate, until now, is exactly what our research funding has delivered, and promises to deliver, for people with arthritis. This report represents the first in-depth evaluation of the impacts of Arthritis Australia's research funding. We set out to assess, as objectively as possible, the many benefits and achievements that our research investment has produced, and has the potential to deliver into the future.

- Medical research – particularly laboratory based research to understand the causes of disease and establish the foundations needed to develop benefits for patients – is a step-wise process, each piece of research building on the one before and contributing to the next. Our evaluation tells us that **Australian researchers are doing all that they should to drive this process – publishing their research in high quality journals, collaborating nationally and internationally and leveraging further funding**. Particularly encouraging is the level of collaboration developed by our researchers in the years following the completion of their Arthritis Australia grants. Considerable effort is being made to consolidate, progress and expand early research achievements by forming partnerships with national and international colleagues with valuable expertise and resources.
- **Other standout achievements include the rate at which Arthritis Australia researchers go on to win further funding**, with nearly a third awarded highly esteemed NHMRC grants – an indicator of the quality of the foundation Arthritis Australia research that led to these awards. This high funding 'hit-rate' has helped to retain around 85% of Arthritis Australia's 2006-2011 grant-holders within musculoskeletal research in this country.
- With a strong commitment to supporting young researchers and new avenues of research, it is very encouraging to find that **most of the early-career researchers we have supported over this period are still active contributors to the field, with over a quarter achieving promotion**. Many of our survey respondents took the time to comment on the importance of early Arthritis Australia funding to their career development and the valuable opportunity to explore new research questions.
- Also interesting is the 'behind the scenes' insight into some of the important, but little-reported achievements of our researchers revealed by this evaluation. For example, **nearly a quarter of the researchers holding Arthritis Australia grants over this period have received a prize or other measure of professional esteem**, and one in five have communicated their research through the media in some way. These are important indicators of research achievement, but are rarely communicated through traditional end-of-grant reporting methods.

Executive summary continued

The findings of this evaluation have given Arthritis Australia some food for thought regarding future research funding strategy. Maximising the impact of our research investment may mean a new look at ways in which we can build on our excellent seed-funding foundations. Higher value, targeted fellowship schemes to retain the most talented researchers and clinicians, the possibility of program grant funding to enable significant progress in particular research fields, and a commitment to long-term funding for the development of resources for future research, such as DNA 'biobanks', are all potential areas for discussion.

The most valuable outcome of this exercise is the establishment of a research achievement baseline – a reference against which the 'paybacks' of future Arthritis Australia research can be measured. Periodic evaluation of our research portfolio over the coming years will allow us not only to benchmark our research performance over time, but to trace the evolution of the research we fund, helping us to understand how our research contributes to the development of products and policies that benefit people with arthritis. This knowledge will help us to shape funding policy and build a long-term research funding strategy for Arthritis Australia, delivering real results for arthritis sufferers well into the future.

Ainslie Cahill
Chief Executive Officer
Arthritis Australia

Introduction

Arthritis Australia has recognised the need for a fuller understanding of what has been achieved through its research. It is felt that the anticipated expansion of the organisation's research fund and continuing advocacy efforts need the support of a strong evidence base, and this can only be provided by a detailed retrospective evaluation of the research findings.

Such evaluation is an important component of a research funder's activities. Major UK-based funding bodies Arthritis Research UK, the Medical Research Council and the Wellcome Trust have led the way in the development of tools designed to collect and aggregate information on the many different impacts generated by medical research. These tools have been adopted and adapted by medical research funders of all sizes and disease interests throughout the UK.

Evaluating the impacts of research helps funders to:

- Demonstrate accountability to private donors or government funding agencies
- Understand how research advances have led to improved health and well-being
- Identify research gaps and duplications
- Build a foundation on which to plan future research funding strategy
- Provide evidence of research success for fund-raising and advocacy work
- Benchmark research achievements nationally and internationally

It can take many years – sometimes decades – for clinical and other impacts to develop from medical research. For a 'seed' research funder such as Arthritis Australia, few grants will produce benefits for patients as a direct outcome.

The positive effects and outcomes of research however are not restricted to those that can be directly associated with patient benefit. Impacts with a relatively short lag-time, such as peer-reviewed publications and the generation of further funding, can tell a funder much about the value of its research. Arthritis Australia believes that it is important, after 30 years of research investment, to take stock of its achievements in this area, and to establish benchmarks by which future achievements can be measured.

Late 2012 saw the launch of a comprehensive survey of over 100 Arthritis Australia grant recipients, for grants awarded over a six-year period. **The Arthritis Australia Retrospective Research Survey**, which was informed by research evaluation initiatives undertaken by large UK-based medical research funders, in particular Arthritis Research UK and the Medical Research Council, sought information on a wide range of research impacts occurring not only during the life of the respective grants, but developing in the years that followed. This report details the findings.

Acknowledgements

Supported by an unrestricted grant from the Estate of the late Walter Donald Couper

The survey on which this report is based was adapted, by kind permission, from Arthritis Research UK's RAISS research evaluation survey. Mary Robinson, Research Evaluation Manager at Arthritis Research UK, offered further information and guidance as needed, also providing data on Arthritis Research UK's publications for the purposes of the comparative analyses on pages 7 and 8.

We also acknowledge the indirect contribution of the UK's Medical Research Council (MRC) to this project. The MRC's comprehensive and inclusive approach has done much to promote and facilitate biomedical research evaluation in the UK and beyond.

Dr Lisa Croucher - Research Analyst, Arthritis Australia.

The Arthritis Australia Retrospective Research Survey

Methodology

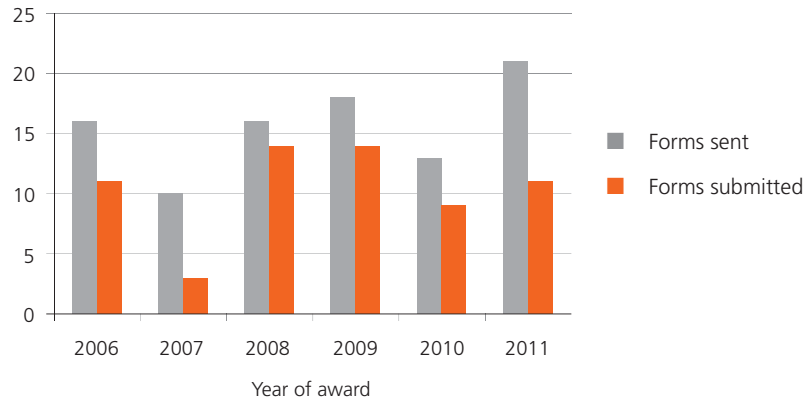
Arthritis Australia's grant records from 2006 to 2011 are relatively complete, and all researchers awarded grants in this period were invited to take part in an on-line survey covering the full range of Arthritis Australia awards: project grants, fellowships, grants-in-aid, special purpose grants and PhD scholarships.

Researchers were asked to provide basic information on a broad range of research impacts. Survey questions were worded to ensure that impacts occurring both during the life of the grant and in the years following its completion were captured. To facilitate form completion by the respondents most questions were presented in a tick-box format with supplementary drop-down lists, and the opportunity to expand on answers was provided throughout the questionnaire. Selected researchers were contacted after receipt of their questionnaires and asked to provide more information.

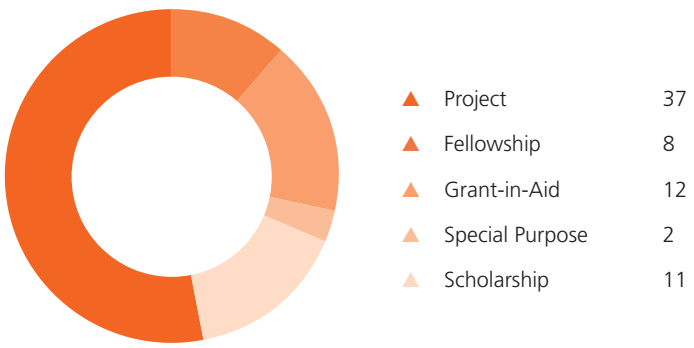
Survey coverage

- 94 on-line forms were sent, covering 108 awards held by 86 award-holders.
- At the close of the survey, 61 forms had been submitted by 56 researchers - a 65% compliance rate. Seven incomplete forms were received.
- The outputs of 70 awards were covered by the 61 forms submitted (a small number of researchers held more than one Arthritis Australia grant during the period covered by the survey). This represents 65% of the awards surveyed.

Survey coverage – response rate



Survey coverage – numbers of each award



Results of the survey

Generating new knowledge – peer-reviewed publications

Bibliometrics – the analysis of the scientific literature – is a powerful, well-established tool for evaluating the impact of medical research. Each paper published makes a new piece of knowledge available to the research community, knowledge that contributes to the understanding of disease and which leads, directly or indirectly, to patient benefit.

A bibliometric analysis of peer-reviewed publications generated by Arthritis Australia researchers was carried out, based on survey responses and supplemented with citations data from PubMed, the free on-line repository for peer-reviewed research articles in the biomedical sciences. Research productivity was determined by counting the number of papers published, and the importance or influence of the published output was assessed by counting the number of times each paper was cited by other papers.

Journal impact factor (JIF), an average measure of how often the articles that a particular journal publishes are cited by other articles, has also been included in this analysis. Acceptance of a paper by a journal with a high JIF is considered to be an indicator of research success, and researchers strive to have their research published in prestigious journals with the highest JIFs. Although still widely used, particularly by research institutions as a surrogate measure of research impact, citation counts are considered by some to be a more direct measure of the importance of a particular piece of research, regardless of the journal in which it happens to be published.

As citation count and JIF are widely used and accepted measures of article quality, both are utilised in this study.

To benchmark Arthritis Australia's published output internationally, an analysis of Arthritis Research UK's published output was also carried out and a comparison of the data was made. Arthritis Research UK is the UK's largest funder of musculoskeletal research, supporting researchers in academic institutions via a wide range of researcher-initiated and strategic funding schemes. Arthritis Research UK's project grant scheme most closely resembles Arthritis Australia funding in terms of grant duration and research scope.

All 27 Arthritis Research UK project grants completed between August 2011 and July 2012 and reporting between January and December 2012 were used for our comparison. Unless stated otherwise, all Arthritis Australia data in this section is current as of March 2013.

Key findings

Arthritis Australia researchers are as productive as their Arthritis Research UK colleagues, generating new knowledge and publishing papers at a similar rate per grant. The most productive awards span the breadth of Arthritis Australia research, from basic laboratory research designed to understand the mechanisms of disease, through to clinical projects undertaken to investigate and improve quality of life for people with musculoskeletal disease. A high proportion of the Arthritis Australia researchers taking part in the survey (81%) published their research in the peer-reviewed literature, or have manuscripts in preparation or under review. This compares favourably to Arthritis Research UK's productivity (75% of awards)[1].

- In total, 106 papers were published from Arthritis Australia awards or follow-up research. This represents a publication rate of approximately 1.96 papers per award, and compares favourably with Arthritis Research UK's publication rate of 2.0 papers per award.
- More Arthritis Australia papers were published in journals with a low to medium impact factor than was the case for Arthritis Research UK. Arthritis Research UK researchers published their research in journals with a higher impact factor more frequently than their Arthritis Australia counterparts.
- 'Nature Genetics' is the journal with the highest impact factor in which both Arthritis Australia and Arthritis Research UK researchers have published. More Arthritis Australia papers were published in this journal (2.8% of total output) than Arthritis Research UK papers (1.8%).
- Arthritis Australia papers are, on average, cited less often (3.84 times), than Arthritis Research UK papers (5.37 times). The most cited Arthritis Australia paper attracted 28 citations, compared to 25 for Arthritis Research UK's most cited paper.

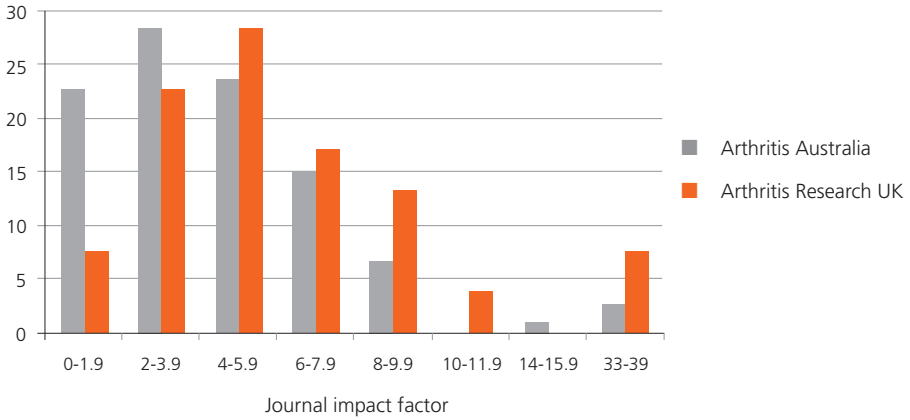
Generation of new knowledge - most productive Arthritis Australia awards

Principal investigator and award	Number of peer-reviewed papers
Professor David Burgner Arthritis Australia and State and Territory Affiliates Grant, 2006 *Host genetics and Kawasaki disease*	8
Professor Richard Day Ray and Pam Robinson Award for Rheumatology Research, 2008 *Better management of gout*	14
Dr Pazit Levinger NSW Branches Award, 2008 *Foot function of patients with knee osteoarthritis*	11

1. The majority of the Arthritis Australia papers included in the analysis have been published in the 1-5 years following the completion of relatively short grants. As such, some of these papers will cover research outcomes that are attributable, to some extent, to new awards made following the completion of the Arthritis Australia grant. In contrast, relatively more Arthritis Research UK papers may owe their content to the original Arthritis Research UK awards, which, on average, are longer in duration and more recently completed.

Journal impact factor - a comparison of Arthritis Australia and Arthritis Research UK papers

Percentage of papers

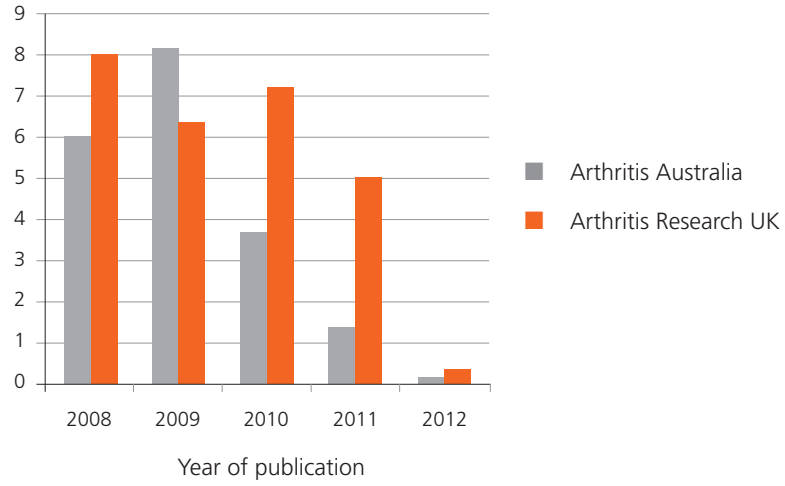


Journals in which Arthritis Australia and Arthritis Research UK researchers most frequently publish their research

Journal	Journal impact factor	% of Arthritis Australia papers	% of Arthritis Research UK papers
Nature Genetics	35.532	2.8	1.8
PNAS	9.681	0	5.3
Annals of the Rheumatic Diseases	8.727	4.7	3.5
Arthritis and Rheumatism	7.866	8.5	10.5
Journal of Immunology	5.788	0.9	8.8
FASEB Journal	5.712	0.9	5.3
Arthritis Research and Therapy	4.450	3.8	3.5
Rheumatology	4.058	6.6	0
Osteoarthritis and Cartilage	3.904	5.7	1.8
Journal of Rheumatology	3.695	3.8	0
Internal Medicine Journal	1.541	4.7	0

Citation impact - a comparison of Arthritis Australia and Arthritis Research UK papers

Average number of citations per paper



Most cited Arthritis Australia publications[2]

Publication	Researcher and Arthritis Australia award	Number of citations
Burgner D, Davila S, Breunis WB, et al. A genome-wide association study identifies novel and functionally related susceptibility Loci for Kawasaki disease. PLoS Genet 2009;5:e1000319	**Professor David Burgner** Arthritis Australia and State and Territory Affiliates Project Grant, 2006 *Host genetics and Kawasaki disease*	58
Shin K, Nigrovic PA, Crish J, Boilard E, **McNeil HP**, et al. Mast cells contribute to autoimmune inflammatory arthritis via their tryptase/ heparin complexes. J Immunol 2009;182:647-656	**Professor Patrick McNeil** Helen Moran Project Grant, 2008 Australian Rheumatology Association Scholarship, 2011 *Mast cell tryptases in rheumatoid and osteoarthritis*	35
Reveille JD, Sims AM, Danoy P, **Thomas GP, Brown, M** et al (The Australo-Anglo-American Spondyloarthritis Consortium (TASC)). Genome-wide association study of ankylosing spondylitis identifies non-MHC susceptibility loci. Nat Genet 2010;42:123-127	**Dr Gethin Thomas** Kilimanjaro Ascent Grant and, Clitheroe Grants, 2009 *Identification of novel genes in ankylosing spondylitis using whole genome expression profiling*	65

2. Data current as of August 2013

Further funding and generation of new research

It is important for Arthritis Australia to know to what extent its initial investment has leveraged further funding. Follow-on funding enables researchers to build incrementally on the knowledge they have gained, leading to a better understanding of disease and bringing the research a step closer to patient benefit.

Arthritis Australia is essentially a 'seed funder', supporting the establishment of new areas of research. The pilot data generated from these grants can attract often substantial support from other funders, facilitating progression and broadening the scope of the research. Success in attracting further funding, particularly if it is from a prestigious funder such as the National Health and Medical Research Council (NHMRC) is indicative not just of the high quality of the research and the track record of the researcher, but of Arthritis Australia's sound judgement in its initial investment.

Key findings

A high proportion (84%) of the researchers taking part in the survey reported that their Arthritis Australia grant helped to leverage further funding to continue their research. The bulk of this funding was awarded by Australian government agencies. NHMRC awarded grants to 32% of Arthritis Australia researchers, with 18% receiving funding from the Australian Research Council. Australian trust funds and foundations were the next most common source of funding, with 25% of researchers receiving funding from 11 different sources within this category. 13% of researchers taking part in the survey received follow-up funding from Arthritis Australia. 20% of Arthritis Australia researchers received further funding from more than one source.

In addition:

- One researcher received funding from a foreign government agency (Singapore).
- Pharmaceutical and healthcare companies (Merck, Abbott Australia and Covidien) funded further research for four award holders.
- After Arthritis Australia, the Heart Foundation was the most common charitable funder supporting further research.
- One researcher reported further funding from a commercial research company (Uniquest).

Sources of further funding - number of researchers

Other	38
Trust fund or foundation	14
Australian Research Council	10
Charity	5
Industry/commercial	4
University	3
Government	2
Bequest	1
Arthritis Australia	7
NHMRC	18

Note: 8 researchers selected more than one option.

Further funding and new research – case studies

As it was impractical to collect detailed information on the monetary value of new funding associated with every Arthritis Australia grant included in the survey, researchers who indicated particular success in attracting funding were contacted for more information about the value of their awards. As such, the case studies below represent a 'best case snapshot' of the Arthritis Australia awards included in the survey.

Dr Jane Munro **Dr Justine Ellis** **Murdoch Childrens Research Institute** Arthritis Australia Kilimanjaro – Ascent for Arthritis Grant-in-Aid, 2008 *Building the JIA biobank at MCRI: Opportunities for risk factor identification* Arthritis South Australia-Juvenile Idiopathic Arthritis Grant, 2009 *Building the Juvenile Idiopathic Arthritis Case-control Biobank* Arthritis Australia Project Grant, 2010 *Establishment of a juvenile idiopathic arthritis case-control biobank* **$80,000**	**Total further funding $1,460,342** NHMRC $567,314 Australian Research Council $687,988 Rebecca L Cooper Foundation $56,700 Equity Trustees Lynne Quayle Charitable Trust $30,640 ANZ Medical Research & Technologies in Victoria $15,000 Australian Academy of Science $7,800 LEW Carty Charitable Fund $40,000 Jack Brockhoff Foundation $54,900	**$18.25** leveraged for every dollar invested by Arthritis Australia	Arthritis Australia funding initiated and provided fundamental early support for this ambitious project. Dr Justine Ellis and colleague Dr Jane Munro have established the CLARITY biobank (ChiLdhood Arthritis Risk Factor Identification StudY), an important collection of data and biological samples from Australian children with Juvenile Idiopathic Arthritis (JIA). This resource has allowed Dr Ellis' team to answer some important research questions on the link between environment and genes in JIA. This early success was crucial in leveraging further funding for CLARITY from several other philanthropic organisations. A substantial research program funded by NHMRC is now supporting the follow-up of several research leads, with a particular focus on further understanding of the potential role of vitamin D in the development of JIA. CLARITY continues to grow, providing a valuable resource to researchers seeking to understand the links between genetic and environmental factors in JIA.
Dr Dawn Aitken **Menzies Research Institute, University of Tasmania** Arthritis Foundation of Australia – Australian Rheumatology Heald Fellowship, 2011 *Structural predictors of knee replacement surgery* **$50,000**	**Total further funding $1,254,160** NHMRC project grant $954,596 NHMRC Early Career Fellowship $299,564	**$25.08** leveraged for every dollar invested by Arthritis Australia	Dr Aitken's research found that bone marrow lesions (BMLs) – abnormal areas of bone tissue that are associated with knee pain – are strongly predictive of the need for future joint replacement surgery in people with osteoarthritis (OA). More than just a useful early warning sign, bone marrow lesions could be a valuable target for treatment to halt the largely untreatable cartilage loss of OA very early in the disease process. A short 'proof of principle' trial carried out during the fellowship found that the commonly used osteoporosis drug, zoledronic acid, decreases the size of BMLs and reduces knee pain in people with OA. These encouraging findings have led to the recent award of a substantial NHMRC project grant to conduct a large, randomised clinical trial of zoledronic acid people with BMLs. The trial is now underway, and is due to report in 2016.

Building capacity – research training and career development

High quality, high impact medical research requires a well-trained research workforce with adequate opportunities for career progression. Attracting talented scientists and clinicians into the field of musculoskeletal research is difficult, and retaining them is even more challenging. Building optimal research expertise and experience helps establish an environment in which new generations of researchers can work productively and at the highest possible level, 'future-proofing' Australian musculoskeletal research for the delivery of valuable research outcomes into the future.

The survey has provided a wealth of information about the role that Arthritis Australia funding has played in the training, development and retention of its researchers, and their subsequent career progression and achievements.

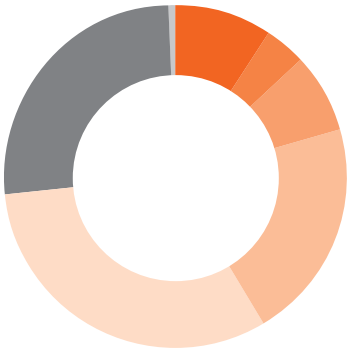
Key findings

A high proportion (85%) of Arthritis Australia grant-holders remain active in the field of musculoskeletal research, the majority working within academic institutions. Five researchers reported that they are now involved in research in another disease area, although four of these individuals also continue to work in musculoskeletal research.

Almost half of the researchers taking part in the survey reported a career development as a result of their Arthritis Australia award:

- 13 researchers (21%) have established their own research group.
- 17 researchers (28%) have gained academic tenure or promotion.
- Arthritis Australia grants supported the award of five higher degrees (all PhDs). A further seven higher degrees are expected as a result of recently awarded scholarships.

Research training and career development – number of researchers



Academic qualification	5
First post-doctoral position	2
Second or subsequent post-doctoral position	4
Fellowship	11
Promotion or academic tenure	17
Established own research group	13
Other career development	1

Note: 15 researchers selected more than one option.

Research training and career development – case studies

Dr Allison Pettit **University of Queensland** Arthritis Australia and State and Territory Affiliates Grant, 2006 *Role of Macrophage Migration Inhibitory Factor (MIF) in Osteoclast genesis and Bone Erosion in Rheumatoid Arthritis*	**Fellowship (NHMRC)** **Academic tenure (senior research officer)** **Independent research group**	Bone erosion is a common feature of severe rheumatoid arthritis (RA) and contributes significantly to the pain and disability of this disease. Dr Pettit's research revealed that a molecule that has a key role in the regulation of inflammation in RA, macrophage inhibitory factor (MIF), paradoxically stimulates the generation of bone-destroying osteoclasts, whilst also acting as a force for good, stimulating immune macrophage cells to promote the repair of bone. This foundation data has supported further research under the leadership of Dr Pettit's co-investigator, Professor Eric Morand, based at the Monash Centre for Inflammatory Diseases, with great potential for the development of new therapies to repair bone in many musculoskeletal diseases. "This grant was a huge boost to my track record at the time and helped me to win both an NHMRC project grant and a Career Development Award. As a consequence I have developed research independence, achieved promotion, and have established my own research group".
Dr Owen Huynh **University of NSW** The Phyllis MacDonnell Grant, 2006 Barbara Cameron Memorial Scholarship, 2007 Arthritis Australia and State and Territory Affiliates Scholarship, 2008 *Regulation and function of activating/ inhibitory Leukocyte Immunoglobulin-like receptors (LIRs) in rheumatoid arthritis*	**PhD**	Dr Huynh's PhD project focused on the role of the Leukocyte Immunoglobulin-like Receptors (LILRs) in RA. LILR molecules help to control the function of inflammatory cells and may contribute to the spontaneous, inappropriate and ultimately destructive activation of immune cells characteristic of RA and other autoimmune diseases. The research revealed one particular receptor, LILR - 7, to be highly prevalent in people with RA, leading to the over- production of TNF-α, a key player in the exacerbation of the destructive immune processes seen in this disease. The outcomes of these complex studies may lead to the development of new therapies or screening tools for RA. Dr Huynh is now applying his skills overseas as a molecular biologist in a different field of biological research, but efforts to further understand the mechanisms of LILR regulation in inflammatory arthritis continue at the University of New South Wales under the direction of his former colleague, Associate Professor Nicodemus Tedla.
Associate Professor Caroline Brand **Monash University** Zimmer Australia Grant, 2010 *Trends in Use of Arthroscopy in Victoria*	**Fellowship** (Melbourne University) for junior researcher, Dr Megan Bohensky	Knee arthroscopy is a minor surgical procedure carried out to examine the interior of the knee joint and sometimes treat minor damage. A common procedure for osteoarthritis of the knee, it is not without complications, and there is inadequate understanding of its effectiveness or safety. By examining routinely collected public and private hospital data, Professor Brand and colleague Dr Megan Bohensky showed that the frequency of knee arthroscopy remained steady in Victoria over a 10-year period. This is despite increasing international evidence for its limited usefulness in older people with osteoarthritis. With the support of healthcare products company Covidien, Professor Brand's team is further exploring data about hip and knee arthroscopy and joint replacement surgery, focusing on complications associated with these procedures and variation in their use. In addition, Dr Bohensky is using her recently awarded Melbourne University fellowship to analyse the relationship between surgical site infections and joint replacement. The team is now planning to develop an intervention for health care providers and consumers to improve shared decision-making about the need for knee arthroscopy. Informed by Professor Brand's and Dr Bohensky's research findings, more appropriate use of arthroscopy in Australia may help to improve outcomes and reduce the complications associated with this procedure.

Research collaborations

Collaborations are important drivers of research progress and development. They are opportunities for the sharing of resources, ideas and expertise, and are a powerful indicator of researcher initiative. Collaborations come in many guises, including partnerships with individuals in academic institutions both in Australia and overseas, national and international consortia formed to collect samples and data for tissue repositories and databases, and collaborations with industry to facilitate translational and clinical research for drug development.

Key findings

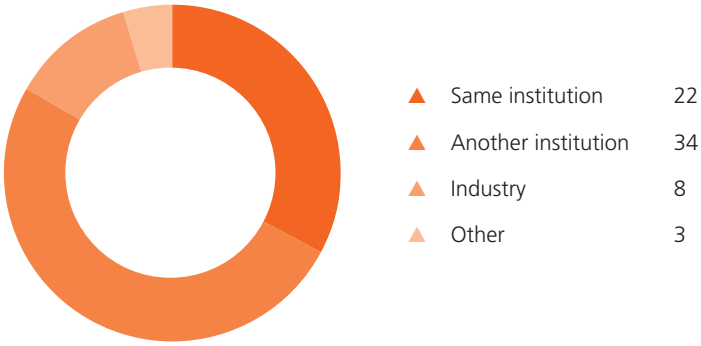
Arthritis Australia researchers are very active in forming collaborations to advance their research. 67% of the awards covered by the survey involved the formation of a collaboration, either during or after the completion of the award. Close to one third (32%) of collaborating awards involved an international collaborating partner.

The survey data also reveals an interesting relationship between collaboration and one of the most significant research outcomes reported by researchers – the development of a clinical product, such as a drug, diagnostic test or other therapy or intervention. 24% of researchers who reported a collaboration also said that their research had led, to a greater or lesser extent, to the development of a product for patients. In contrast, where no collaboration was formed, the development of a product was associated with only 8% of awards.

In addition:

- 12 awards (20%) led to co-funding with collaborators.
- 19 awards (31%) led to peer-reviewed papers co-published with collaborators.

Type of collaboration – number of researchers



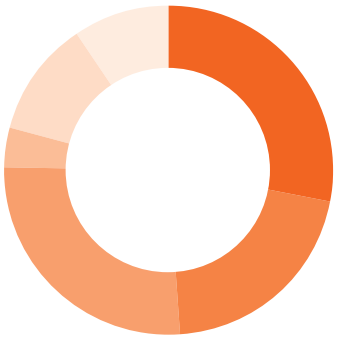
Note: 22 researchers selected more than one option

Associate Professor Kathryn Gibson **Liverpool Hospital, Sydney South West Area Health Service** Australian Rheumatology Association Practitioner Fellowship, 2009 *Using information and communication technology to support improvements in an Ambulatory Rheumatology Practice*	**Ongoing collaboration with Professor Johanna Westbrook, Centre for Health Systems and Safety, Australian Institute of Health Innovation, University of NSW.** **Funded by an Arthritis Research Council linkage grant.** These grants are designed to initiate and/ or develop long-term strategic research alliances between higher education organisations and other organisations, in order to apply advanced knowledge to problems. They also aim to produce a national pool of world-class researchers to meet the needs of the broader Australian innovation system.	The Australian government has invested heavily in 'e-health' computer systems to manage clinical activity in public hospitals, with variable success. Professor Gibson's project evaluated the use of a new electronic Drug Monitoring System (eDMS), setting out to understand the factors central to its successful implementation. Trialled in the rheumatology department at Sydney's Liverpool Hospital, the eDMS improved the efficiency and safety of drug monitoring, freeing up significant nursing staff time to devote to patient care. The department's doctors also generally accepted the new system. Professor Gibson and her health informatics collaborators at the University of NSW are now working towards quantifying the factors, both human and technological, that affect the successful implementation of e-health systems in clinical practice.
Professor David Burgner **Murdoch Childrens Research Institute, Monash Children's and the University of Melbourne** Arthritis Australia and State and Territory Affiliates Grant, 2006 *Host genetics and Kawasaki disease*	**Founding member and co-leader of the International Kawasaki Disease Genetics Consortium, a collaboration comprising researchers from 12 countries.** The consortium collects data and biological material from sufferers of Kawasaki Disease and their families to support international research into its causes.	Professor Burgner's principle research interest is Kawasaki Disease (KD), an important but poorly understood childhood disease. Difficult to diagnose, KD can, if untreated, lead to serious heart complications. Professor Burgner's research is focussed on finding variant genes that may make some children more susceptible to the disease. The outcomes of Professor Burgner's Arthritis Australia grant helped to establish The International Kawasaki Disease Genetics Consortium. The consortium has conducted the largest study so far of the genetics of KD, and has identified a number of genetic variations that are associated with its development. Data and biological material from this collaboration continues to enhance studies into KD worldwide.

Professional recognition

Awards and other indicators of professional recognition are an important research impact. 25 (41%) of Arthritis Australia researchers taking part in the survey reported that they had received a prize or other recognition of professional esteem, such as an invitation to be a keynote speaker, membership of an advisory or funding awards committee, or an invitation to write a review.

Types of professional recognition – number of researchers



Research prize	15
Invited to be a keynote speaker at a conference	11
Invited to write a review	14
Member of an advisory commitee	2
Member of a scientific or medical commitee	6
Other	5

Note: 15 researchers selected more than one option

Professional recognition - case studies

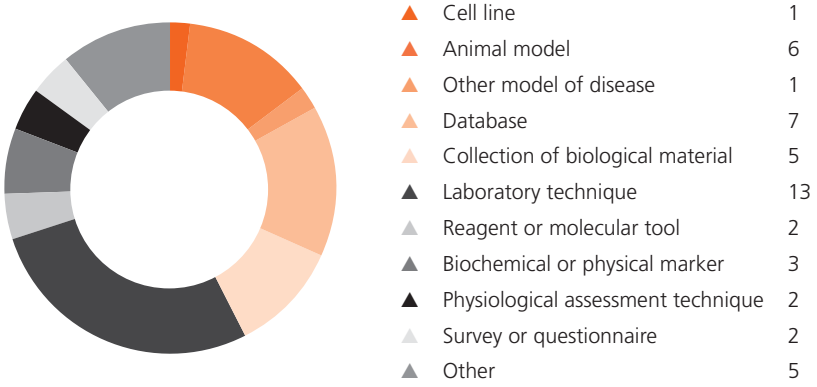
Dr Daniel McCulloch **Murdoch Childrens Research Institute** Arthritis Australia and State and Territory Affiliates Grant, 2006 *Identifying which domain of ADAMTS-5 bind aggrecan keratan sulphate*	**The Matrix Biology Society of Australia and New Zealand (MBSANZ) New Investigator Award**, 2012, for an invited oral presentation given at the annual MBSANZ meeting in 2012	The development of new drugs to inhibit the activity of destructive enzymes in OA and RA is an important goal for arthritis research. Dr McCulloch's research showed that one of these enzymes, ADAMTS5, can be successfully inhibited outside of the highly sensitive intra-cellular environment. This not only avoids the difficulties inherent in designing drugs that need to cross the complex barrier of the cell membrane, but reduces the risks of side-effects and toxicity that can occur with drugs of this type. This has important implications for future drug development work in this area. This program of work formed the foundation of Dr McCulloch's career in ADAMTS research, and he is now recognised as an independent program leader at Deakin University Medical School.
Dr James Melrose **Kolling Institute of Medical Research, Royal North Shore Hospital and University of Sydney** Jack Bloomfield Grant, 2008 *An in-vitro model of meniscal degeneration initiated by inflammatory cytokines*	**Paper selected by F1000 Prime as an exceptional paper in its subject area.** F1000 Prime is a collaboration of the world's leading scientists and clinicians, who rate new peer-reviewed publications and explain their importance. Fuller ES, Smith MM, Little CB, **Melrose J.** *Zonal differences in meniscus matrix turnover and cytokine response. Osteoarthritis Cartilage 2012;20:49-59*	The menisci are small, half-moon shaped cartilages in the knee joint that, when damaged, increase the likelihood of OA developing in some individuals. Dr Melrose's research has shown that inflammatory molecules 'leaking' from damaged menisci lead to the widespread cartilage destruction that is typical of OA. Further research may lead to the development of drugs that specifically target the meniscus, reducing the risk of widespread and irreversible cartilage damage.

Tools and materials for research

The development of new tools and materials for research is an important impact, facilitating research progress and opening up new avenues of investigation. The survey collected information on a wide range of research tools and materials, including cell lines, assays, animal models, physiological assessment methods and information-gathering techniques employed in clinical research.

Nearly half (49%) of the researchers taking part in the survey reported that their research had led to the development of new or improved research tools or materials.

Types of research tools and materials – number of researchers



Note: 12 researchers selected more than one option

Research tools and materials – case studies

Professor Matthew Brown **Diamantina Institute, University of Queensland** Ray and Pam Robinson Scholarship Grant, 2011 *The arthritis genomics recruitment initiative in Australasia*	**AGRIA – the Arthritis Genomics Recruitment Initiative in Australasia** Collection of tissues and DNA from Australasian people with common rheumatic diseases.	AGRIA arose from the recognition that there are knowledge gaps in the causes of three important arthritic diseases affecting Australasians - giant cell arteritis (GCA), ankylosing spondylitis (AS) and gout. Established and led by Professor Brown, AGRIA aims to use the powerful Genome-Wide Association Study approach to detect gene variants associated with increased risk of developing these diseases. Improved knowledge of their genetic basis will enable the development of targeted drugs and more accurate diagnostic tests. AGRIA will enable many future genetic studies, both in Australia and internationally.
Professor Rachelle Buchbinder **Monash University** Trike Around Australia Grant, 2007 *Improving the quality of written doctor-patient information about drug therapy in rheumatoid arthritis*	**The Evaluative Linguistic Framework** Tool for improving the quality of written patient information about medication	Poorly written information for people with arthritis can increase anxiety about their condition and reduce adherence to treatment. Professor Buchbinder and colleagues developed the Evaluative Linguistic Framework (ELF) to assess the quality of written patient information about drug treatment. With funding from Arthritis Australia, the team has been able to further validate and refine the ELF, using it to appraise and update existing written patient information and guide the development of new literature, including medication leaflets produced by the Australian Rheumatology Association. The ELF It is now in use by several other research groups.

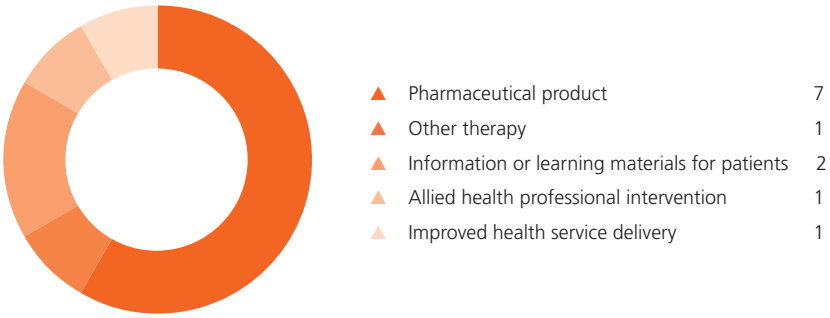
Development of drugs, diagnostic tests and other clinical interventions

The pathway to products for patients is often tangential and may involve research over several years, multiple grants from a range of funding sources, and the contributions of many researchers. Most Arthritis Australia grants will not have resulted directly in a product for people with arthritis, but we are interested in cases where the development, to any stage, of a new or improved drug, diagnostic test or therapy can be attributed to some extent to Arthritis Australia funding.

Key findings

11 researchers (18%) reported that their Arthritis Australia grant has contributed to the development of a product or intervention for patients. Research arising from three of these grants has progressed to the stage of human trials, with NHMRC funding awarded to all three to conduct randomised clinical trials of existing drugs. At the time of writing, one trial has been completed, another is in progress, and the third is due to commence.

Drugs, therapies and other clinical interventions – number of researchers



Note: one researcher selected more than one option

Development of drugs and other clinical interventions – case studies

Associate Professor Kay Crossley **University of Queensland** Arthritis Australia and State and Territory Affiliates Grant, 2006 *Clinical features of individuals with patellofemoral osteoarthritis: a pilot study*	**Physiotherapy regime to treat osteoarthritis of the kneecap**	Osteoarthritis of the knee is not a single disease - different components of this complex joint can be affected, with variable disease and treatment outcomes. With natural population variation in gait, leg alignment and muscle strength, a 'one size fits all' approach to treatment for knee OA is far from optimal. Professor Crossley's research has uncovered differences in leg and knee alignment and function between people affected by OA in the kneecap (patellofemoral joint), those with OA affecting other parts of the knee joint, and people who don't have OA. The research has led to the design of a specific physiotherapy treatment for people with OA of the patellofemoral joint. A recently completed clinical trial, funded by the NHMRC, has proven the effectiveness of this approach. Professor Crossley is now working to ensure that the findings of this research are communicated to and implemented by health professionals.
Associate Professor Changhai Ding **Menzies Research Institute University of Tasmania** Arthritis Australia and State and Territory Affiliates Grant, 2006 *Vitamin D status, knee structural change, fall risk and change in bone density*	**Vitamin D supplementation to slow the progression of osteoarthritis**	Previous evidence for a role for vitamin D in maintaining cartilage health initiated this five-year study, funded in part by Arthritis Australia. The research showed that vitamin D deficiency, which affects a high proportion of Australians, is associated with loss of knee cartilage and a worsening of knee pain. Knee pain is common in middle-aged adults, strongly associated with the development of osteoarthritis. The outcomes of this research led to the award of a substantial NHMRC grant to conduct a trial of vitamin D in people with osteoarthritis. The trial is due for completion in February 2014.

Research communication and dissemination

Communication of research to its users is an important part of the research process. Publication in the scientific literature ensures that the research community has access to the latest research findings, but a much broader reach is achieved when research is disseminated to audiences beyond the research community – patients, health professionals and policy-makers, as well as the wider public.

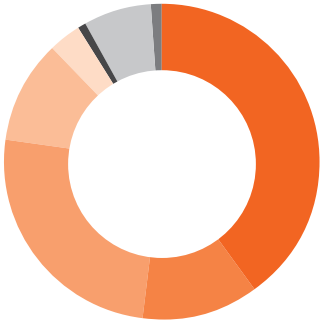
Key findings

Arthritis Australia researchers are active in disseminating their research to a range of different audiences. 75% of the researchers taking part in the survey have communicated their research to fellow researchers at conferences or meetings, with just over half presenting their findings at an international conference. Of the 54 international presentations given, 25 (46%) were oral (podium) presentations. 11 researchers were invited to give a keytone presentation at a conference, and four researchers were given awards for outstanding conference presentations. On average, each Arthritis Australia grant contributed to three conference presentations.

85% of Arthritis Australia researchers have communicated their findings to audiences other than at scientific conferences or meetings. Health professionals form the largest non-scientist audience, indicating that Arthritis Australia researchers go to considerable effort to ensure that their research is communicated to those who may eventually implement their findings for the benefit of patients.

Around 20% of researchers have had contact with the media, with two reporting international exposure.

Research communication and dissemination



▲ Researchers at conference or meeting	46
Talk at a national conference	36
Talk at an international conference	24
Poster at a national conference	24
Poster at an international conference	18
**31 selected more than one option*	
▲ Patients, public	14
Seminar	7
Website	3
Written material	3
Open day	2
Other	3
**4 selected more than one option*	
▲ Social Media	4
▲ Government	1
▲ Other	8
▲ Not yet communicated	2
▲ Health professionals	29
Seminar	16
Conference	16
Written material	3
Website	1
Other	3
**8 selected more than one option*	
▲ Media	12
Press release	2
Regional/national press	5
Regional/national broadcast media	5
International media	2
Other	2
**4 selected more than one option*	

Note: one researcher selected more than one option

Research communication and dissemination – case studies

Professor Patrick McNeil **University of NSW** Helen Moran Grant, 2008 *Mast cell proteases in experimental inflammatory arthritis* Australian Rheumatology Association Scholarship, 2011 *Tryptase-mediated aggrecanolysis in rheumatoid and osteoarthritis*	Professor McNeil's research team discovered a previously unknown role for the enzyme tryptase in the cartilage damage seen in rheumatoid arthritis and osteoarthritis. Although the work is at an early stage, it suggests that drugs that block the actions of tryptase may be useful in the treatment of arthritis. The findings have attracted national media coverage, with a report incorporating an interview with Professor McNeil broadcast by Channel 10 News on 28th March, 2012: http://www.youtube.com/watch?v=ac16fJ1XBD0&feature=plcp&context=C4e91e00VDvjVQa1PpcFPQY8sFMEMwRZArefbDVI41_O5hw00FwwI%3D
Professor David Burgner **Murdoch Childrens Research Institute, Monash Children's and the University of Melbourne** Arthritis Australia and State and Territory Affiliates Grant, 2006 *Host genetics and Kawasaki disease*	Professor Burgner's work on Kawasaki Disease has generated considerable media exposure, including features in local and national newspapers and magazines, and radio and television interviews. He is regularly invited to comment on paediatric infectious disease issues by the media and has provided expert commentary for the Royal College of General Practitioners for ABC broadcasts. His most recent contribution to the ABC was for the science program Catalyst, broadcast on May 17th, 2012. The item set out to raise awareness of the importance of Kawasaki Disease, and included an interview with Professor Burgner: http://www.abc.net.au/catalyst/stories/3505144.htm Professor Burgner is very active in educating and supporting patients and families affected by Kawasaki Disease, conducting seminars and laboratory visits and giving public lectures to community groups. He is also medical advisor to the parent-led support charity, the Kawasaki Disease Foundation.
Professor Thomas Ratajczak **Western Australian Institute for Medical Research** The Heidenreich Paget's Disease Grant, 2006 *Functional characterisation of a novel SQSTM1/p62 mutant Associated with severe Paget's disease of bone*	Paget's disease of bone causes abnormal enlargement and weakening of the skeleton, most commonly the skull, spine, pelvis and femur. The causes of Paget's are unknown, but genetic factors are thought to be important. Professor Ratajczak's research has focused on the sequestosome 1 gene, which plays a crucial role in normal bone turnover. A mutation in this gene, discovered by Professor Ratajczak's colleague Dr Sarah Rea, has been linked to a severe form of Paget's disease. Genetic testing for this and other mutations may help to identify individuals at risk of Paget's and provide opportunities for early treatment. Understanding the genetic basis of diseases such as Paget's also opens up new avenues for drug development. Professor Ratajczak's and Dr Rea's breakthrough was the subject of four articles in Western Australian (Perth and regional) newspapers in 2007, two of which acknowledged Arthritis Australia's funding.

Informing clinical policy and practice

Translation of research findings into best practice policy and applying policy to new diagnostic tests and treatments for the benefit of patients is the long-term aim of medical research.

Two researchers taking part in the survey reported that their Arthritis Australia research has helped to influence clinical policy and/or practice via contributions to government reports, clinical guidelines or expert reviews.

Informing clinical policy and practice – case studies

Associate Professor Lynne Parkinson **University of Newcastle, NSW** **CQUniversity Australia** Arthritis Australia and State and Territory Affiliates Grant, 2006 *Women and arthritis: The burden of suffering for older Australian women*	Byles J, Loxton D, Berecki J, Dolja-Gore X, Gibson R, Hockey R, Robinson I, **Parkinson L**, et al. *Use and costs of medications and other health care resources: Findings from the Australian Longitudinal Study on Women's Health. Report prepared for Australian Government Department of Health & Ageing, June 2008. (Report 144).* **Parkinson L**, Harris M. *Effective population health interventions for the primary prevention of musculoskeletal conditions: An Evidence Check rapid review brokered by the Sax Institute (http://www.saxinstitute.org.au) for the Victorian Department of Health, 2010.*	Professor Parkinson's epidemiological research has examined the impact and management of arthritis in women as they age. Her work for Victoria Health Promotion, detailing effective prevention and health promotion strategies for musculoskeletal conditions, has been adopted as the basis for Victorian health promotion policy and practice.
Professor David Burgner **Murdoch Childrens Research Institute, Monash Children's and the University of Melbourne** Arthritis Australia and State and Territory Affiliates Grant, 2006 *Host genetics and Kawasaki disease*	Tacke CE, **Burgner D**, Kuipers IM, Kuijpers TW. *Management of acute and refractory Kawasaki disease. Expert Review of Anti Infective Therapy 2012; 10:1203-1215* Yim D, Cheung MM, Curtis N, **Burgner D.** *An update on Kawasaki disease II: Diagnosis, treatment and cardiovascular outcomes. Journal of Paediatric Child Health (2013)*	Professor Burgner's internationally recognised research into Kawasaki Disease and a range of other paediatric infectious diseases has enabled him to play a major role in the development of clinical guidelines and policy, both in Australia and overseas. He has contributed to several guideline documents on paediatric infectious disease for the Federal Government, the Royal College of General Practitioners and the Royal Children's Hospital, Melbourne. Professor Burgner is also a peer-elected member to both the Australia and New Zealand Paediatric Infectious Diseases Group and World Society for Paediatric Infectious Diseases, has served as an expert advisor to the Australian Blood Service on Guidelines for the use of intravenous immunoglobulin in Kawasaki Disease and toxic shock and, in 2005, served as an expert panellist for the American Heart Association guidelines for the diagnosis and management of Kawasaki disease.

Arthritis Australia research grants 2006 - 2011

Arthritis Australia and State and Territory Affiliates Grant

Arthritis Foundation of Australia – Australian Rheumatology Association Heald Fellowship

Arthritis South Australia-Juvenile Idiopathic Arthritis Grant

Australian Rheumatology Association Paediatric Grant

Australian Rheumatology Association Practitioner Fellowship

Australian Rheumatology Association Project Grant

Wolf Blass Scholarship

Jack Bloomfield Grant

Barbara Cameron Memorial Grant

Clitheroe Foundation Grant

Win Dunne Research Award

Adam Gilchrist Trading Challenge

Rosalind Griggs Grant

The Heidenreich Paget's Disease Grant

Kilimanjaro Ascent for Arthritis Grant

Phyllis McDonnell Grant

Bruce Miller Grant

Ken Muirden Overseas Training Fellowship

NSW Branches Award

Ray and Pam Robinson Award for Rheumatology Research

Scleroderma Australia Grant

South Australian Lupus Sjögren's Scleroderma Support Group Grant

Allan Stephens Grant

Trike Around Australia Grant

The Eileen Urquhart Scholarship

Victorian Ladies' Bowls Associated Grant

Zimmer Australia Grant

Arthritis AUSTRALIA

P O Box 550

Broadway NSW 2007

www.arthritisaustralia.com.au

ISBN: 978-0-9805024-8-0