

JOINT SUPPORT

ARTHRITIS NEW ZEALAND NEWSLETTER SEPTEMBER 2015



Acknowledging the different faces of arthritis

September is our time to turn New Zealand orange again!

This is our time to remind New Zealanders of the impact that arthritis has on the lives of individuals, families and communities. As the national organisation that advocates for those with arthritis – this is our month in the ORANGE sun.

Yes the donations our wonderful collectors get by standing on streets and in shopping malls are vital to continue our services, but doubly important is the opportunity to raise awareness and respond to all those 'I've got arthritis' comments.

But there are so many stories of "I have arthritis, but it doesn't have me!" where challenges are overcome and we hope that as we share those positive stories during September and throughout the year, they bring fresh hope to others. The ways to manage pain advances in treatments and the search for a cure goes on.

Arthritis is one of the leading causes of disability and chronic pain in New Zealand.

There is a widely held belief that arthritis is simply a consequence of age, the pain of growing old. But arthritis is not just about older people. In fact 51% of people suffering from the disease are of working age.

578,000 New Zealanders have one of the more than 140 different forms of arthritis.



Many call it the invisible condition – you can't see the pain!

With the generous support of our clients, donors and the general public we can help change the lives of as many people as possible – empowering them so that arthritis is a footnote in their story and not the key point.

Our goal is to improve the quality of life for all people affected by arthritis, but we cannot do it without your help.

Our wonderful collectors will be out and about again, some of them in the

major cities will have an eftpos machine. But if you miss passing one of those or collectors with buckets, then we have other options:

Donate \$20 by calling 0900 333 20

If you are a Vodafone user – **TXT PAIN to 7005 to make a \$5 donation**

You can donate via our website www.arthritis.org.nz





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From the President

This is the last time I write as President of Arthritis New Zealand. Our constitution sets the maximum term of a President at four years and my term will end at the AGM in November.

When I came to the role, an organisational restructure had just taken place. I cannot take credit for it but all that has happened since has reinforced for me how timely it was and credit is due to those who had the vision and courage to undertake it. It has made my job that much easier.

That restructure did not address governance. It has been one of my goals to rectify that. With the able assistance of the Committee of the Board led by Peter Larmer, changes have been made to the structure of the Governing Body and its committees, and better training introduced. The comment was made to me recently by a member that he thought that the quality of the Governing Body is higher now than at any time that he has been on it, and there have been times that I have found it daunting to look around the board table. I am confident that I leave the governance of the organisation in good hands.

As I leave the role we are due, in 2016, to undertake our next Strategic Plan review. Preliminary scoping is already underway. It reflects, in a number of subtle ways, my thoughts on the future of the organisation and the direction in which I believe it should be going. It is an important time for the organisation and I hope you will all participate in shaping our future when the opportunity is given to you.

The role of President has at times been time consuming and weighed heavily. The buck truly does stop here. It would be remiss of me not to thank all those who have supported me over the last four years. I include in that the members of the Governing Body on whose expertise and input I have been totally reliant at times. Also the Chief Executive, my working

relationship with whom has been one of the pleasures of my tenure, the National Management Team, and all the staff and volunteers with whom I have had dealings.

I must also acknowledge the support of my wife, family and work colleagues and their tolerance for the time the role has taken from them.

There are many memories I will cherish. They include achievements at board level, particularly gaining buy-in to the direction in which I wanted to take the Governing Body and the organisation, but also the many successes that the organisation has achieved in advocacy, promotion of awareness and improving the lives of those affected by arthritis. I also include the conferences, the instigation of the "Orange Awards", the award to Kathie Smith of her richly deserved OMNZ, and the many happy gatherings with Parliamentary Friends and other supporters. It says much that my major regret (apart from my realisation that there would have been things I could have done better) is that being President did not automatically guarantee success in our annual charity golf tournament.

I will also take away memories of the enthusiasm and goodwill with which I have invariably been greeted wherever I have been. It speaks of an organisation in good heart.

Alan Henwood
President

From the Chief Executive

There has been a great response to the special 50th Jubilee membership cards. With the Jubilee year crossing two calendar years members will receive this brightly coloured card twice before we revert to the more familiar white card.

This is the time of year we reflect on the work done over our past financial year and prepare for the AGM in November. It is now four years since we changed our way of delivering services. It feels so much shorter than that. In these four years we have increased the number of calls we get from around 4,000 to 9,870 this year. Our website visits have increased from under 50,000 to over 200,000 in that time. There have been over 20,000 client services delivered in the form of clinics with Arthritis Educators; seminars; workshops; Living a Healthy Life Course and so much more. More people have accessed our services in each year since the changes and our overhead costs have been much lower. We are reliant on the generosity of the community and they can be confident that the money we raise is being used to deliver services and information that makes a difference.

There have been many highlights to the past year. The drama "Orange"; our gout campaign; the advocacy work that is showing results; our expanded services in Northland; our social media presence. We have trialed new ways of delivering services – such as the waka in Northland; the PEDAL programme in Christchurch and the Facebook sessions with Arthritis Educators that reaches nationally and internationally. The trouble with highlights is that it can't capture everything – we were busy; we have achieved a great deal across all of our programme areas.

The plans for the year ahead already indicate we will have another busy year with highlights waiting. The conference in March 2016 will be a special time. We will also be holding a special Jubilee Awards

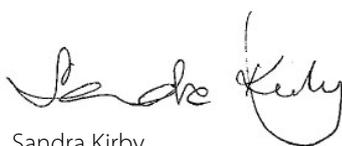
function to be hosted by our Patron the Governor-General, Lt Gen The Rt Hon Sir Jerry Mateparae. Hopefully many of you will join us for some of these events.

I was reading an article in the Herald recently that linked French philosopher Paul Janet's theory in 1897 to an interactive website designed by Austrian Maximilian Kiener. Janet's theory is that our perception of time passing more rapidly as we get older is about our perspective. At age one a year is the whole of your life; by age 35 a year is a mere 2.86% of your life. You can find this website – I warn you a great deal of patience and persistence is required to get through the first year! I think people within Arthritis New Zealand can echo that feeling – the first year we were in existence; the first year after any major change require patience and persistence.

It is interesting to see two articles in this edition that focus on the importance of peer support to getting better outcomes for people with arthritis. Peer support was the original call for people to form the organisation we now know as Arthritis New Zealand. While the form of support has changed over the years – the value of the support remains "beyond rubies".

I think the next year when we celebrate our achievements will pass in a flash.

Nga mihi nui



Sandra Kirby
Chief Executive



Balloons over New Zealand



As part of our Appeal and awareness opportunities in September we will be having some fun with orange balloons.

You will be able to go online and purchase a balloon for \$5 and then track it across the country. There will be a prize for the balloon that completes the greatest distance. Watch out for more information via social media.

To advertise in *Joint Support*, email editor@arthritis.org.nz or phone 0800 663 463.

Products advertised and information provided in editorial in *Joint Support* do not imply endorsement by Arthritis New Zealand.

Arthritis New Zealand Research Grants 2015

In June the Research Grants Committee recommended the Board approve funding for the following grant applications. The following grants were approved.

Professor Nicola Dalbeth; Auckland University

"The Patient experience of musculoskeletal imaging: a mixed models study"

This study will explore the patient experience of medical imaging in the musculoskeletal disorders population. A survey will be taken from a group of people having imaging. This will help to design a questionnaire to find the experience of imaging in a population of people with rheumatic disease. It should inform the decision that clinicians make when ordering imaging.

Dr Hilary Morna Sheppard; Auckland University

"A clinically relevant protocol to rapidly isolate maximum potency Adipose-Derived Stem Cells from adipose tissue"

Stem cells sourced from adipose (fat) tissue will be sorted in four different ways and observed for how they differentiate and grow, Their functional strength will be monitored and they will be observed for how they well they reduce the development of T Cells and reduce inflammation. The committee were highly supportive of this application and thought the grant was an exciting concept in a very competitive field.

Dr Borja del Pozo Cruz; Auckland University

"Exploring new avenues in the clinical management of adults with knee osteoarthritis (OA) aged 55 to 75 years: creation of a model to predict if brief activity insertions in sedentary OA sufferers improve their knee OA, mobility, and quality of life"

The research will look at adults with knee osteoarthritis (OA) aged 55 to 75 years. They will try to find out if brief episodes of activity are helpful to those with knee OA and see if they can predict the impact of altering the activity/sedentary pattern. Then a future study will determine the feasibility of intervention in a large group of people with OA.

Dr Christopher Stuart Walker; Auckland University

"Targeting neuropeptide receptors to treat arthritis"

The researcher is using his expertise in pain and migraine to explore other important chronic diseases such as OA. There were two pain receptors that the peptide studied in the migraine study can act on. This study will try to discover if one of them is present in the dorsal root ganglia (a bundle of nerve fibre in the spine). There is potential to reduce pain and perhaps inflammation.

Dr Nicola Swain; University of Otago

"On-line self-management training using GEM for people with arthritis"

This is a self-management technique used for arthritis pain and improving the ability to cope with pain and disability. A four week programme for 20 minutes each week plus homework. This follows research done with the New Zealand Pain Society. An on-line programme for self-management of pain and chronic illness (GEM) was developed. The testing of the tool was supported by the NZ Artificial Limb Service and this research will test it with the arthritis population.

Three Summer Scholarships for short research projects were approved

Prof Keith Rome; Auckland University

"Cutaneous foot manifestations in systemic lupus erythematosus (SLE)"

This study will seek to determine the characteristics of cutaneous (skin)foot manifestations in patients with SLE and cutaneous lupus.

Professor Peter Larmer; Auckland University of Technology

"An exploration of the sequence and nature of treatment options available to people living with OA of the hip and/or knee in New Zealand"

This study explores early treatment experiences in those with osteoarthritis. The research is worthwhile for Arthritis New Zealand, very interesting and relevant to the early intervention agenda.

Dr Rebecca Grainger; University of Otago

"What can we learn from Arthritis New Zealand social media channels?"

The research will explore the content of Facebook and other social media with a focus on the unmet health needs of people with arthritis and their current requirements for information and support.

Using technology in treatment for arthritis



By Rebecca Grainger, Rheumatologist

Take a moment to watch people waiting and you will notice many of them are face down, closely examining their smartphone.

When you next “go shopping” you may be going online rather than to the shops. Reading a book before bed, many of you will use your kindle. Computers, smartphones and the internet are now an integral part of many peoples day to day lives and activities. The use of information technology solutions in healthcare has held much promise but has been slower to deliver. Although many GP practices in New Zealand have used electronic medical records for many years, the last few years have seen great leaps in the use of information technology to streamline and improve the health care for New Zealanders.

Over the years many people coming to my clinic in at the hospital (District Health Board – DHB) have been surprised that I was not able to access their health record held at their GP clinic. After its establishment in 2009 the National Health IT Board (<http://healthitboard.health.govt.nz>) has provided leadership to DHBs and IT providers so that all DHB’s now use compatible IT systems. This allowed the “shared care record” whereby GPs can directly access DHB health records from their rooms and health providers in the DHBs can view some aspects of GPs records, for example vaccination status, medications or blood results. This allows high quality, timely patient care and improves patient safety.



An even more exciting development is the “patient portal”. Patient portals are secure online tools to “login” to your electronic file. At your GP practice you can book appointments, check laboratory results, email your GP or request a repeat prescription. Over a million New Zealanders could now potentially access a patient portal to view their health records at their GP practice. This can allow you to access services at a time that suits you and enables you be more involved in managing your health. More information about patient portals can be found at <https://patientportals.co.nz>. Many GP practices are offering patient

portals via Manage my Health <http://www.managemyhealth.co.nz>. Next time you are at your GP ask if they are offering a patient portal – you will need to sign up in person.

On the horizon are many other exciting ways that IT may help in delivering health care. At University of Otago and Hutt Valley DHB I am leading a team developing a mobile phone app for people with rheumatoid arthritis to monitor their arthritis activity and communicate with their rheumatology team. We aim to test

the app in formal studies to see if it helps people with their RA management and is a useful addition to the current face to face appointments. Hopefully use of such technology will improve outcomes for people with arthritis.

Make your membership count and attend the AGM

Meet the Governing Body members, regional representatives, the CEO and Management Team – Saturday, 21 November 2015 at the Wellington Airport Conference Centre, Wellington. Are you a financial member? – simply complete the registration form available from Karen.baker@arthritis.org.nz or phone **0800 664 464** to receive one.

Call for Remits & Notice of Motion; Honorary Life Membership

Nominations: Remits and notice of motions will be open from 15 July and close 25 September. Nomination forms for Honorary Life Membership are available on the website or by contacting Karen Baker.



The invisible illness

Finding out at 14 that she had arthritis changed Bridget's life and set her on a path of discovery that has led her to become one of Arthritis New Zealand's advocates.

Bridget recalls initial feelings of frustration and confusion learning to come to terms with her arthritis and how it was going to affect her life but now at 19 she is actively involved with Super Young Arthritics and Arthritis New Zealand. This involvement provides an opportunity for her to support others beginning their journey with arthritis at a young age and also to challenge the myth that arthritis only affects the elderly.

Last year she graduated from high school, and it has always been important for her to be open and up front about her illness to get the help and understanding she needed, to ensure she could achieve everything she wanted to.

Bridget is a keen rider and has competed successfully in Show Jumping, placing 6th in the 15 year old New Zealand Rider of the year. She has always had a huge passion for riding, and being diagnosed was not going to stop her. By keeping riding, she was able to keep a lot more of her strength. She says "Sure some days were very hard, and I couldn't compete to the level I would have liked, but it was important for me to always be involved in the sport I love so much."

Bridget attended a recent training workshop for advocates and is keen to be one of the people voicing the experiences of living with arthritis.

"Working to improve the working lives of people with arthritis and getting easier access to effective treatments are really important issues and I am keen to be

involved as an advocate in these areas" says Bridget. "Most of all I want to show other young people with arthritis that it needn't hold you back."

The quote that she lives by everyday is "I want to live, not just survive!". She says that "Each day I want to do everything I can to make sure my illness doesn't become who I am, But more my illness makes me who I have become."



*"I want to live,
not just survive!"*

Bridget Van Gessel



Advocacy

Recently we have run two training workshops for people interested in becoming active Arthritis Advocates. These workshop included sessions with MPs, lobbyists and media commentators and are part of our laying groundwork to have a national network of advocates.

The key priorities identified were

- **Minimising the barriers to people with arthritis being able to participate in the work force**

Issues such as specialists clinics being available out of office hours, providing workplace education and looking at how to ease the transition from a benefit to paid employment were seen as important issues for Arthritis New Zealand to be promoting

- **Getting effective support for newly diagnosed as soon as possible**

Most participants expressed frustration at the time it took for them to access support such access to medications, counselling and psychological help. One participant compared the support that was provided for someone diagnosed with cancer at the same time she was diagnosed with arthritis and others felt that with more support they may have been able to remain working.

Advocates will also be contacting their local MPs to flag these issues and also follow up on the government commitment to

increase funding for primary care early intervention for people with arthritis.

We are now looking at running a 3rd training workshop, probably in Christchurch later this year- if you are interested or would like to join the advocates team call **Francesca** on **0800 663 4634**



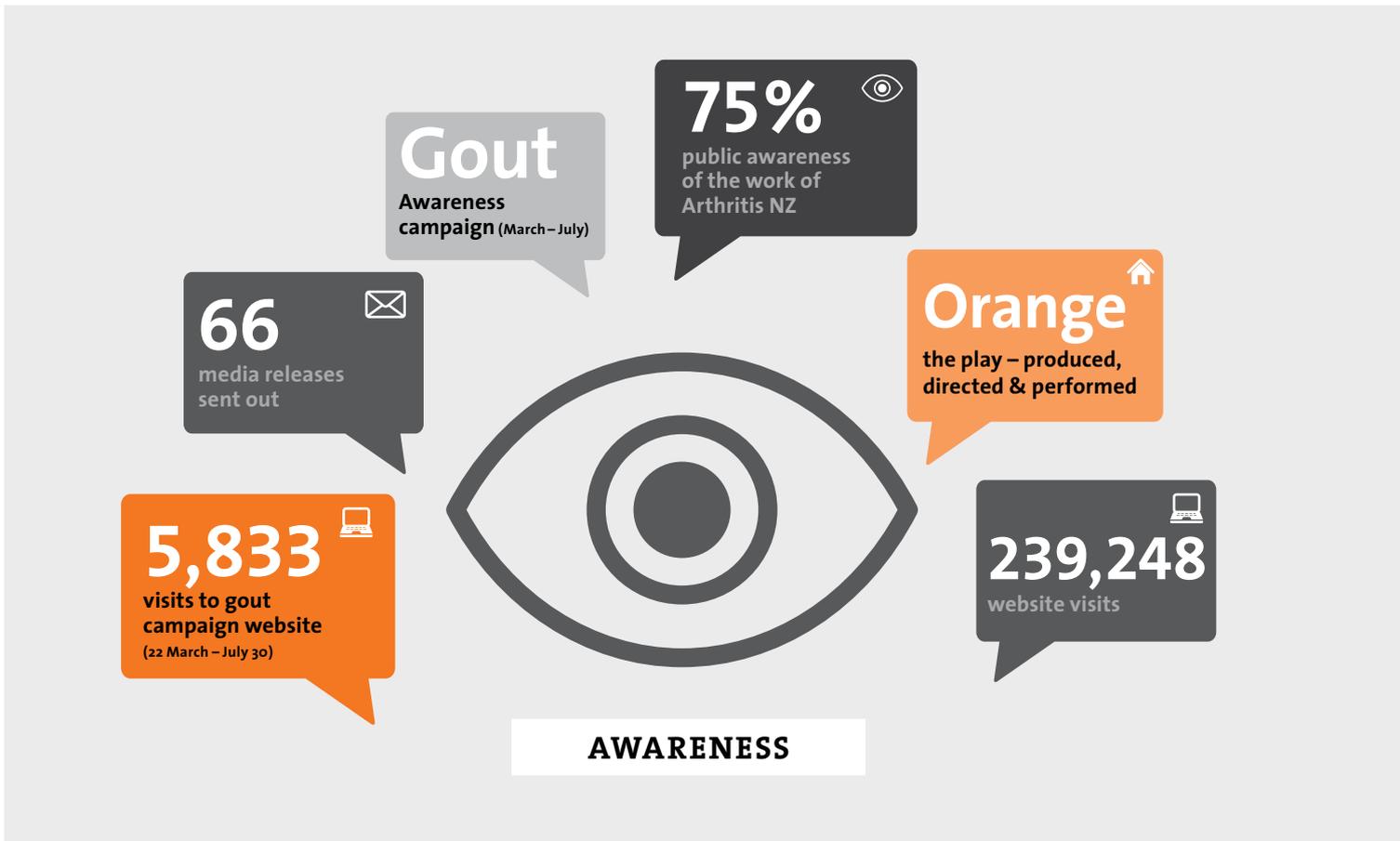
Bridget, Sarah and Alice listen to Roger Sowry on lobbying



Neemia Tialata, advocate for the Arthritis New Zealand Gout campaign
"Don't be trapped by Gout!"

Great to have an opportunity to thank Neemia and family while they were back in New Zealand briefly





2014-2015: It's bee

FUNDRAISING



ADVOCACY



SUPPORT SERVICES



77

attended annual Children's camp



46

clients accessed 'Newly Diagnosed' service



56

Gout champions



Demand for our waterbased exercise classes grows

INFORMATION AND ADVICE



9,870
calls to 0800 help line



59,125
arthritis newsletters and updates



20,089
client contacts:
14% Māori
16% Pacific

n a very good year

MEMBERS, VOLUNTEERS & DONORS

3,131

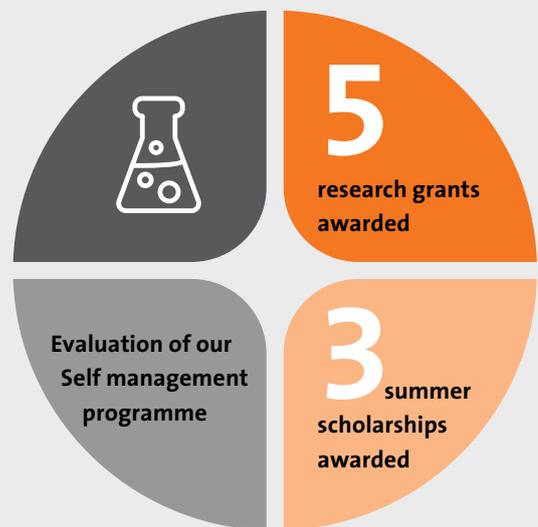
volunteers

9,488

current donors

4,677

members



5

research grants awarded

3

summer scholarships awarded

Evaluation of our Self management programme

RESEARCH

Golden Jubilee

Planning is well underway and excitement building. For reasons outside of our control some of the dates have had to change.

50 Years of Joint Action

The conference dates are now 3–5 March 2016 at Te Papa in Wellington. Saturday 5th will be the Public Day.

We are also planning a Speakers Tour so that as many people as possible outside of Wellington will get the opportunity to hear the conference speakers.

We have seen some sample postage stamps that will celebrate the year and many of you will have renewed your membership and received your 50th Anniversary card.

We are working with the Governor General's staff to confirm dates and planning for our Awards function, at Government House in Auckland.



Other items being planned are a Digital History recording, performance of the Geraldine Brophy play 'Orange' in Auckland, our annual golf and cricket days. Keep those ideas flowing in.

Arthritis New Zealand is grateful to be supported by:



abbvie

Unichem

life
Pharmacy



Bequest

Do you have a Current will? There are many reasons for ensuring that you have a valid and up to date will.

To protect loved ones. And it is only by means of a valid will that you can be certain that your family and friends will be taken care of when you are no longer there.

Once you have taken care of those who are close to you, you might like to remember Arthritis New Zealand. We are always overwhelmed when we receive advice of a bequest. These gifts ensure our work continues for generations and confirms the importance of supporting the 578,000 New Zealanders with arthritis.

If you would like to talk to someone about leaving a gift to Arthritis New Zealand in your will or for more information, please call Dianne on 0800 663 463 or email dianne.armstrong@arthritis.org.nz

September 6-12 is also Include A Charity week. During this week many NZ charities will raise awareness of the importance of considering leaving a gift to a charity in your Will.

Saying goodbye is never easy. Arthritis New Zealand is grateful to those who ask friends and family to donate to us in lieu of flowers. These generous thoughts and donations assist in the funding of our work for the 578,000 New Zealanders with arthritis.



Self Management

Self-management is a term used to describe what we, as individuals and families/whanau do to keep ourselves healthy, to manage long-term or on-going health problems well and to prevent or delay complications. Everybody self-cares for themselves. Over 80% of all medical symptoms are self-diagnosed and self-treated without professional care.

Self-management courses are for people to help manage chronic conditions, they are about enabling participants to make informed choices about their health, adapt skills that can be applied to new problems as they arise, practise new health behaviours, and maintain or regain emotional stability. Being a person who self manages may mean greater knowledge of the condition, being involved in decision making with health professionals, following a care plan and monitoring and managing signs and symptoms of the condition.

Arthritis New Zealand self management courses are offered in 2 different ways:

1. Living a Healthy Life with Chronic Conditions is offered once a week for 6 weeks and is a structured course with an accompanying handbook. In some areas Arthritis New Zealand is contracted to deliver the course, therefore it is free to participants. This course is led by trained volunteers or Arthritis Educators and includes skills that assist people to more confidently self-manage, is for any long term condition, provides role modelling and peer support and teaches action planning to enhance motivation. The course is registered by Stanford University and participants are expected to attend all 6 sessions.
2. The Arthritis New Zealand designed course has three stand-alone workshops that condense the learning of the self management skills. If only one session is attended there will still be learning pertaining to that topic,

e.g. Understanding Pain. The topics are worked through in a group setting and problem solving techniques are used to assist participants to develop their own plans for managing their arthritis.

Recently Arthritis New Zealand funded an evaluation of part of our self management service looking at both the quality of the programmes and their effectiveness. Focus groups and interviews of participants and educators were held. The study's authors said that "participants valued the educators' input" and that they "delivered the information in a meaningful way, promoting discussion". They reported that the goal-setting and planning strategies made the self management "meaningful and gave them a sense of purpose".

Participants gave us some valuable feedback as well that will contribute to how we deliver our service. There were such suggestions as having an individual follow up later to do care planning and to discuss more sensitive issues. These follow up times are available but we need to let people know more about what they can get from us. One thing that came up was how we advertise our programmes. This is always difficult as what works in one place sometimes doesn't work everywhere. What we do know is that we value our participants sharing their experiences with others and with their GP's to spread the word that self management courses really do work!

Orange Tea Party

Do you enjoy having friends, neighbours or your village residents over for a cup of tea? Then you might be interested in hosting an Orange Tea Party to promote our appeal and raise a few funds. We have a comprehensive planning pack that includes some great recipes. Call **0800 663 463** and chat to a Regional Fundraiser to receive a pack.



JD Duathlon

The brilliant JD Duathlon series is running in Christchurch. You may be interested in participating and the link to enter is **www.jdevents.co.nz** but we are also looking for volunteers to help out at the race. If this is something you are interested in please call Emma on **0800 663463**.



Jasmine and Ada, two volunteers at the JD Duathlon

50's Up Concert

Yes the 50's Up Concert is on again in Christchurch on 14 October. If you are interested in tickets for this wonderful annual event please call Emma on **0800 663 463**.

Valuing Peer Support

by Daniel O'Brien, Lecturer Physiotherapy, Auckland University of Technology

I am constantly reminded about the considerable value of peer support when living with a chronic health condition such as arthritis. By peer support I mean support from someone who is going through the same or similar experience as you.

Peer support can provide psychological encouragement and sense of camaraderie that is often not provided by traditional healthcare. Despite the known value of peer support, it seems that it can often be negated in favour of so called 'proper' health care.

In 1977 British psychiatrist George Engel first described his notion of the Biopsychosocial Model of healthcare. Engel argued that the traditional model of healthcare did not allow doctors (and other health professionals for that matter) to account for the psychological, social and cultural factors that influence our health and well being. He argued that if doctors viewed their patients in the social and cultural contexts that they lived in, they would provide care that was better suited to their patients needs. Fast-forward nearly 40 years and despite categorical evidence that Engel's model leads to more effective, more patient-centred healthcare delivery, the model has still not been fully embraced. Potentially this is because it is hard to truly understand the psychological, social and cultural factors that impact the lives of people living with chronic conditions unless you have experienced these things yourself.

It has long been argued that you cannot really understand another person's experience until you have walked a mile in their shoes. Therefore maybe only people who have lived with the condition and can truly appreciate all the ways that the condition can impact life. This is why there is a need for peer support. These are people who have walked a mile in your shoes, or own a pair of shoes that look very similar to yours. These are people who like you have experienced many of the factors associated with living with a chronic health condition such as arthritis.

The benefits of peer support were again highlighted to me in a recent evaluative study that I had the opportunity to work on. The people in the study were involved in an education and self-management programme for their chronic health condition. These people described how hearing other people's experiences



"It has long been argued that you cannot really understand another person's experience until you have walked a mile in their shoes."

made coping easier as it gave them knowledge that they were not alone. Some people described how sharing their stories made it easier for them to accept their condition. These people stated that having peer relationships meant that they felt more socially connected.

Peer support is shown to improve emotional coping and the acceptance of a diagnosis, and has been linked to a greater sense of social integration in people with chronic health conditions. A Canadian based study explored using peer mentors to deliver patient education and peer mentoring to people newly diagnosed with rheumatoid arthritis (Sandu et al., 2013). The mentors were people living with the rheumatoid arthritis who had completed a mentor programme. The study found that peer mentors were instrumental in promoting self-management and facilitating social

support. Furthermore they asserted that peer mentoring could be a useful adjunct to standard rheumatological care.

For me when I think about peer support groups, I imagine people sitting around having a coffee and chatting about issues that are important to them. But I am well aware that I am a little old fashioned by holding this belief. With the expansion of the online world over the last few years, support can come from many places that were until recently impossible. It is now possible to interact with people from all over the world through online forums and chat rooms. Thanks to the Internet, I can now regularly discuss my own research ideas, frustrations and challenges with peers as far away as the UK. These peers often give me great advice and equally I can offer advice and support to them too.

As you are currently reading this article in Joint Support, I am sure you are aware of the vital role that Arthritis New Zealand plays in supporting people with arthritis in New Zealand. However don't forget to value the benefit that peer support can provide you, and don't forget the benefit that you can provide to others by supporting them.

What Arthritis New Zealand means to me

9th July, 2015

Dear Sandra

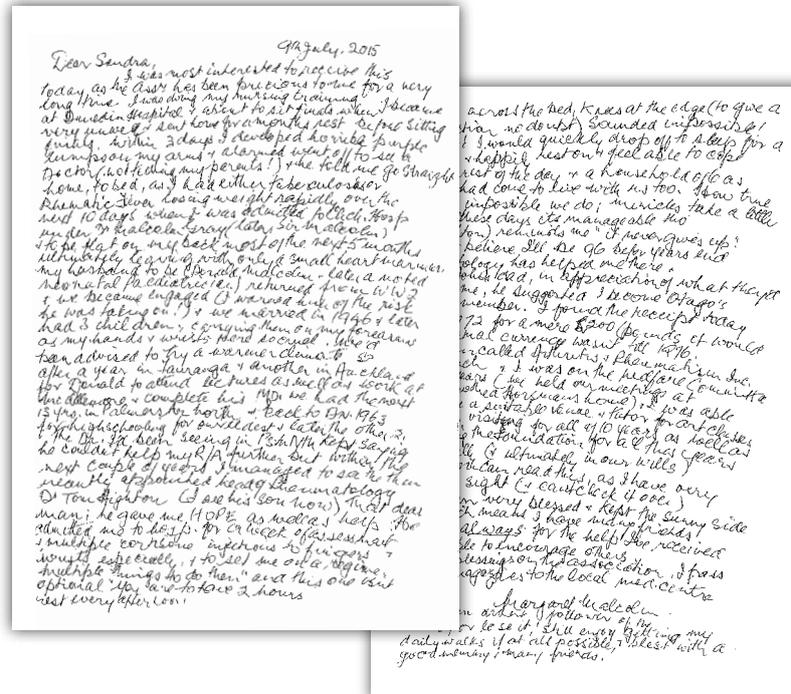
I was most interested to receive this (donor mail letter) today as the Association has been precious to me for a very long time. I was doing my nursing training at Dunedin Hospital and about to sit finals when I became very unwell and sent home for a month's rest before sitting finals. I was admitted to Christchurch Hospital under Dr Malcolm Gray (later, Sir Malcolm) and to be flat on my back most of the next 5 months. Ultimately leaving [hospital] with only a small heart murmur.

My husband to be (Donald Malcolm – later a neonatal paediatrician) returned from WW2 and we became engaged. (I warned him of the risk he was taking on!) and we married in 1946 and later had 3 children. Carrying them on my forearms as my hands and wrists were so cruel. We'd been advised to try a warmer climate so after a year in Tauranga and another in Auckland for Donald to attend lectures as well as work at Middlemore and complete his MD we had the next 13 years in Palmerston North and back to Dunedin in 1963 for high schooling for our eldest and later the other 2.

The Doctor I'd been seeing in Palmerston North kept saying he couldn't help my RA further but within the next couple of years I managed to see the then recently appointed head of Rheumatology Dr Tom Highton (I see his son now). That dear man; he gave me HOPE as well as help; He admitted me to hospital for a week of assessments and multiple cortisone injections to fingers and wrists especially, and to set me on a regime and multiple things to do then "and this one isn't optional", "you are to have 2 hours rest every afternoon".

I can't believe I'll be 96 before years end and Rheumatology has helped me there. I asked John's Dad, in appreciation of what they'd done for me, he suggested I become Otago's first life member. I found the receipt today, for a mere £2. It was then called Arthritis and Rheumatism Inc, Otago Branch. I was on the Welfare Committee for some years and I was able to arrange a suitable venue and tutor for art classes and did hospital visiting for all of 10 years as well as supporting the Foundation for all these years financially (and ultimately in our will).

I've been very blessed and kept the sunny side up which means I have many friends. Thanks always for the help I've received and been able to encourage others.



Many blessings on the Association, I pass on the magazines to the local med centre.

Margaret Malcolm
Margaret Malcolm

P.s: And, as an ardent follower of the "use it, or lose it", still enjoy getting my daily walks if at all possible, and blessed with a good memory and many friends.



Our CEO with three volunteers who helped paint NZ orange during street collection days last year.

European Conference June 2015

Rachel Callear is the physiotherapist with the NZ Paediatric Rheumatology Service based at Hutt Hospital, Wellington. Each year in Europe, EULAR (the European League Against Rheumatism) hold a conference for rheumatologists, allied health professionals and patients. This year it was held in Rome.

Every three years EULAR combine their conference with PRES (the Paediatric Rheumatology European Society).

I had been warned before going that this was going to be a large conference, but with 14,000 attendees it was enormous!

To cater for so many attendees, the conference had 15 presentations occurring simultaneously over four days. The hardest part was deciding which sessions to attend but EULAR have made presentations available online so I can continue to learn from the conference and share information with my colleagues for months to come.

Here are some of the key learning points I took away from conference:

- **Physical activity and healthy lifestyle choices are paramount**

This was an important message, repeated many times over by all health

professionals. There were examples of how many European countries are helping their rheumatology patients be more physically active with lifestyle coaching, education, motivational and exercise programmes. "It is easier to be sick when you are healthy". I felt this quote summed up the message very well.

- **Fatigue associated with chronic conditions is more likely to be due to deconditioning, not disease activity**

Research is now showing that fatigue, which is a key feature of rheumatoid diseases, may not be due to disease but due to the inactivity that often occurs with a flare in disease. The message being given was that we need to continue to encourage our patients to keep active at all times.

- **Research needs to include patient's perspectives**

This presentation highlighted different research methods and emphasised how research which includes patient experiences can help to improve their journey through the health system.

- **Outcomes of children with juvenile idiopathic arthritis (JIA)**

The latest research shows 60% of children with JIA will take active joint disease or joint damage into adulthood so early diagnosis and evidence-based care continues to be vital.

- **European guidelines: transitioning young people from child to adult services**

Helen Foster, a world renowned Paediatric Rheumatologist from Newcastle, UK who visited NZ earlier this year, introduced these guidelines. It was very pleasing to hear that her key messages are at the core of my team's transition process for young people in NZ.

Networking is an important part of any conference and I met up with my Australian colleagues at EULAR to discuss how we can implement new ideas from this conference and make changes within our practise.

Attending conferences is always a hugely valuable experience, not only to hear the latest research and best practice guidelines but to continue to build links with our overseas colleagues. I look forward to sharing my new found knowledge with my colleagues around NZ and feel privileged to have been able to attend EULAR in Rome, the eternal and beautiful city.

Rachel attended EULAR with the aid of a grant from the Lotteries Commission NZ.



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Recognising our volunteers

Whangarei celebrated Community Service awardees and a group of volunteers who have assisted at land and water based exercise classes for many years.



Top left to right:

Bjorke Troost, Thelma Moffitt receiving awards



Bottom:

Left to right: Noreen Moorhouse, Erys Gavin, Ivy Reid and Audrey McKenzie being recognised for their land and water based volunteer work



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Wellington 6143

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Visit our website for the latest news about arthritis, information about different types of arthritis, downloadable brochures, to find out what's on in your area, and more.

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