

JOINT SUPPORT

ARTHRITIS NEW ZEALAND NEWSLETTER JUNE 2016



Acknowledging the different faces of arthritis

I'm not alone!

The annual Arthritis New Zealand children's camp was held again at Totara Springs in Matamata for children who had been diagnosed with arthritis within the past 2 years.

Some of the children were not willing participants, until they arrived and then there was non-stop chatter and smiles as they realised *there were other kids the same as me*.

Twenty-six families attended and there were five teenage youth leaders and four young adult volunteers, who all grew up having arthritis, there to support the attendees and also share their stories. 92 people in total.

The weekend programme included parents' education with the Paediatric Rheumatology team, lots of fun activities

for the children, including the top favourite – hydroslide, an art workshop and lots of time to meet new friends and learn they are not alone on their journey with arthritis.

The parents found it really useful to talk with the youth leaders and young adults and enjoyed the opportunity to meet with and talk to other parents.

The evaluations from the weekend were overwhelmingly positive. With one participant sharing this lovely quote: "Could we please have a water fight next year!"

Parents and children went away knowing they are not alone, with new friends and lots of ideas to manage their arthritis.

**The 2016 camp
was supported by
Pub Charity Ltd**





From the President

Thank you to all who attended our “50 Years of Joint Action” conference in Wellington. What a terrific day we had – the company was great; we re-enacted the 1999 “Move it; move it” exercise video; the presentations were excellent as was the information from our sponsors and trade displays. To those of you who were unable to come you missed a great experience.

Yes we celebrated how far we have come in the last 50 years. The initial idea to begin some support groups has developed into a leading nationwide organization. While we have grown we have also started to think and challenge ourselves about where we might be going next. There is great synergy in reviewing our strategic plan during this Jubilee year. The Governing Body will be seeking your feedback on what is the most important role Arthritis New Zealand can play into the future to ensure we can help in “Improving the lives of people affected by arthritis”. You will see many opportunities to be included in this discussion; online, in regional meetings and of course you are welcome to write or speak to any member of the Governing Body or National Management Team. While Arthritis New Zealand is not the only solution in assisting people with arthritis we must ensure we are part of the solution.

At the conference we were challenged by Dr Irwin Lim to consider the use of social media to extend our reach. Andrew Briggs, from Curtin University, presented some powerful data that showed that musculoskeletal conditions made up almost a quarter of this country’s disabilities. He wrapped things up saying “big problems need big solutions”.

The numbers of people with arthritis in New Zealand are growing and this is likely to continue to grow. We can see the current healthcare budgets are

not coping with this demand. The way arthritis is managed will need to improve to ensure more people can get access to assistance to improve their health and wellbeing. We too will have to change – we will need to show we are helping people manage their condition better. We must provide more people with the skills and information they need to make changes. How we do this will evolve just as it has over the past 50 years.

As yet musculoskeletal health, which includes arthritis, is not a recognised health priority. I remain hopeful this will change in the near future. Whether it is a priority or not for the government it is a significant cost to the economy. This cost is both at an individual level, as most of us can testify, and also one that affects the country as a whole with respect to rising health expenditure and loss of productivity.

With this edition of Joint Support you will receive your invitation to renew your membership for the year ahead, and a call for nominations for the Governing Body. With over 4,000 members we are a large Incorporated Society. I hope you, like me, consider this a great investment – for you and the people with arthritis who will come after us.


Peter Larmer
President

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From the Chief Executive

Becoming a rugby fan came much later in my life than it did for many New Zealanders. Now I avidly follow the fortunes of my local Super Rugby team, the Hurricanes, and that of the Chiefs because I want to see how their wing, James Lowe, is playing. After Super Rugby I follow the Makos and the Lions for the same reason. And yes I do have opinions on the All Black form.

We first met James Lowe as a member of the Nelson College First XV when he was desperately hoping to make rugby a career despite his arthritis diagnosis. The painfully shy and quiet boy we met back then is barely recognisable in the young man who we believe is a future All Black. I wonder how long it will be before we see James Lowe featuring in a video game with the fantasy First XV. If that happens I might have to become a video game player as well as a rugby spectator.

James has been a generous Ambassador for us speaking at events such as Awards functions; Parliamentary dinner and other events where his schedule allows. I think the Arthritis New Zealand team are nearly as proud of James' achievements as his family – and that is saying something. I hope you enjoy James' story as you read this *Joint Support*.

In April I was privileged to spend a weekend with 26 families of children who are following the same journey as James and his family. It's not all about becoming a rugby player but it is all about making the best of your life whilst managing the challenges of arthritis. The families who attended this year's camp mostly came knowing no-one else like them and left with a group of friends sharing the same journey. Our camp was a highlight for these families who know their journey

need not be an isolated one – there is help and support available from the medical team and others.

Our *Support for Newly Diagnosed* service links volunteers with people who have recently made contact with us also helps break the isolation of arthritis. For over 100 people this service has provided a human link at an especially important stage in the journey. We are fortunate to have willing and able volunteers to share their experiences and support others.

In this day and age our contact is increasingly virtual. Most people talk to us – we had over 10,000 callers to our 0800 number last year. Our Facebook page, social media messages and our website are important ways we reach out to people who might never actually see us. Our challenge is to make even the disembodied contact one that feels human and relevant.

And for each person with arthritis the challenge remains to manage the condition and your life so that like James Lowe you too can achieve your goals.

Kia kaha



Sandra Kirby
Chief Executive



Sandra Kirby, CEO. The T-shirt was a gift from the staff – perhaps our next campaign...

Election 2017

It might seem a long way away but right now we are preparing for the general election next year.

Encouraging people to make appointments to visit their local MP and follow them on social media. To make an impact we need to have as many people as possible making their voice and concerns heard in the political process.

We are preparing questions and background information and would love to hear from you if you are keen to support this advocacy work. Email **Francesca.holloway@arthritis.org.nz**

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

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The role of physiotherapy in the management of arthritis

Over the past 15 years I have worked as a physiotherapist in a variety of different settings, many of these have included jobs working with people with arthritis.

More recently, in conjunction with Arthritis New Zealand, I have been involved in the running of education seminars for people living with arthritis. I am often reminded that many people, including other health professionals, don't have a clear idea of what physiotherapy or physiotherapists have to offer. This generates a problem, how can you ask someone (e.g. a physiotherapist) for assistance if you don't know what he or she has to offer? Physiotherapy and physiotherapists' have abilities and knowledge that can be applied to a broad population of people, not just people with a sore back or sporting injury, as is often assumed. It should be noted that there are many overlapping roles and skill sets in the provision of healthcare. Therefore I am mindful that there are other health professionals such as osteopaths, chiropractors or massage therapists who can also assist people similarly. Additionally, it is important to remember that a physiotherapist (or any health professional) should be part of an integrated team working with you to help you manage your condition.

To understand the role that physiotherapists can have in the management of arthritis, I feel it is important to be aware of two things: the philosophy underpinning physiotherapy, and the abilities and expertise that physiotherapists have to offer. Physiotherapy has its origins in Western massage therapy and orthopaedic medicine. The profession was arguably formalised during the First World War. The war caused a huge number of people to suffer musculoskeletal injuries. A health professional was needed to help

these people rehabilitate and optimise physical function. This became the role of the physiotherapist. Since then, the profession has expanded to not only include the rehabilitation of people with musculoskeletal conditions but also neurological, cardiopulmonary and cardiovascular. Despite this diversity, the ethos of the profession continues to be about getting people moving. This has and continues to be underpinned by a philosophy that exercise, physical activity and movement are medicine.

Physiotherapists' have a good understanding of anatomy, pathology, joint movement and exercise. This means they can advise on the best ways for people to exercise safely and keep active. As with all professions, different physiotherapists have different specialities and interests. Some therapists have specific skills and expertise in the management of arthritis, chronic pain, exercise therapy or joint mobilisation. All of these services can be helpful for someone living with arthritis.

How do you find a good physiotherapist in your area? Ask your GP, specialist, family and friends about health professionals they recommend – word of mouth is still often the best way to find someone. Once you have found a physiotherapist you are happy with, it is important to build a solid partnership with them. Get them working for you and with you. Be an active patient, ask questions and provide feedback on the treatment you are receiving.

In summary, what is the role of physiotherapy in the management of arthritis? Physiotherapists are there to



help you get moving safely and to stay moving. However, it is important to be an active part of the partnership. When consulting with a physiotherapist, or any healthcare professional for that matter, remember to ask them what they think they can offer you.

Daniel O'Brien

Lecturer, Physiotherapy Department
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One of a crowd

Statistics show that the numbers of adults living with arthritis is growing. The Ministry of Health update their New Zealand Health Survey annually. In this survey people aged over 15 years of age are asked the question "Has a doctor ever told you you have arthritis?"

The response to this question gives us the number of adults who have diagnosed arthritis. The most recent survey update shows there are 620,000 people over 15 living with arthritis. The year before the number of people diagnosed with arthritis was 578,000. Over the past year an additional 42,000 New Zealanders were diagnosed with arthritis.

The New Zealand population is increasing and accounts for some of the growth

but there are other factors. Not only is the total number of people with arthritis increasing but the prevalence, measured by the percentage of the population diagnosed with arthritis has also increased from 16% to 17%. The Ministry of Health notes that the rate of arthritis is increasing.

Many people might think this increase is all due to the ageing population – but nearly half of the people are aged under 65 years.



Additional New Zealanders with diagnosed arthritis over the past year.

=620,000

People over 15 living with arthritis.

This survey gives us a very good overall picture of the number of people with a diagnosis of arthritis but we have a number of gaps. The New Zealand Health Survey of children does not include arthritis. We also don't have reliable data for individual conditions like rheumatoid arthritis, ankylosing spondylitis and others.

What we can see from these numbers is that arthritis is going to continue to be a health challenge for the foreseeable future.

This information is available at:
<http://tinyurl.com/NZhealthsurvey>

Notification of Arthritis New Zealand AGM and Election

The 2016 AGM is set for Saturday 26 November and will be held in Auckland – venue yet to be confirmed.

The Arthritis New Zealand Election for 2016 will be calling for nominations for:

- 1 x Midland Central Regional Representative; and
- 1 x Southern Regional Representative

Registration forms, nomination forms, and details will be available in June on our website or by contacting Karen Baker or Dayleen Troke on 0800 663 463



Complementary medicine and arthritis

The Arthritis New Zealand Speaker Series

Proudly sponsored by Blackmores and in association with Green Cross Health

Early in June events were held in Auckland, Wellington and Christchurch featuring a range of speakers that included Associate Professor Lesley Braun, Orthopaedic Surgeons, Arthritis Educators and guest presenters who were the ‘faces of arthritis’. The series was developed as part of the Arthritis New Zealand 50th Jubilee celebrations.

Associate Professor Lesley Braun, from the National Institute of Complementary Medicine based in Western Sydney University and Director Blackmores Institute Australasia was the keynote speaker at all three events.

Lesley’s topic was the use of complementary medicine and arthritis – covering who is using complementary medicines and what has been proven to be effective in the area. This is a topic that is of great interest to people with arthritis and to the health professionals such as Arthritis Educators and pharmacists who are responding to many questions about what works. Lesley noted that the number of scientific papers about complementary medicine has significantly increased over the last 2 decades.

‘Complementary Medicines’ (CM) is the commonly used term for over-the-

counter traditional, herbal and traditional medicines including vitamins, minerals, nutritional supplements, probiotics used as medicine and therapeutic oils.

Research led by Lesley in 2010 in 60 Australian pharmacies asked pharmacy customers about their use of prescription and complementary medicines. They found that more customers had used a complementary product (72%) than used prescription medications (61%). The customers, mainly women, covered a wide range of ages and other demographics. People of all ages reported using a complementary medicine in the previous 12 months although age made a difference to what was used. People over 50 years used significantly more glucosamine (33% vs. 10%) and fish oil supplements (41% vs. 28%) compared to people under 50.

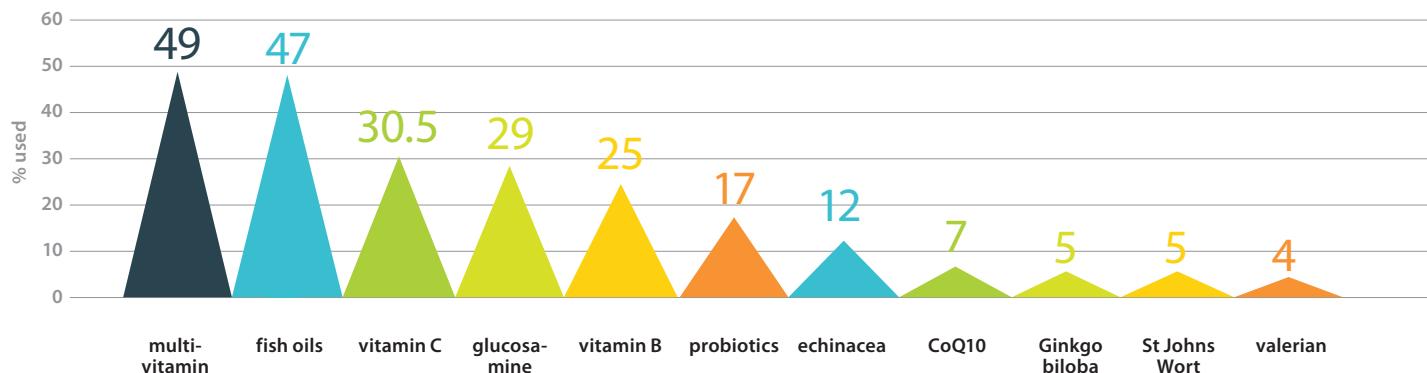
There was a wide variety of products that had been used as this chart shows:

The main focus of the presentation was on the evidence for complementary medicines that work for osteoarthritis and rheumatoid arthritis. It was emphasised that these complementary medicines are used alongside other therapies, not as a replacement.

The final messages from Lesley were that diet, lifestyle and stress management are important for optimal health. Complementary medicines can play a role in managing osteoarthritis and rheumatoid arthritis. It is important to seek professional advice when starting a complementary medicine to ensure correct dose and any possible interactions with other treatments.

[continued next page]

Complementary Medicines used by pharmacy customers/by key ingredient



Osteoarthritis

Complementary Medicines with good evidence for effectiveness	Complementary Medicines where evidence is unclear	Complementary Medicines shown not be effective
Glucosamine and chondroitin	Willowbark	Selenium supplements
Topical comfrey		Vitamin A supplements
Fish oil as anti-inflammatory		Vitamin C supplements
Curcumin (turmeric) as anti-inflammatory		Antioxidant supplements

Rheumatoid Arthritis

Complementary Medicines with good evidence for effectiveness	Complementary Medicines shown not be effective
Omega 3 fish oil supplements	Willowbark
Gamma linoleic acid	



Associate Professor Lesley Braun

PhD, MPS Director Blackmores Institute Australasia
 (hon) A/Prof. National Institute of Complementary Medicine, Western Sydney University
 Snr Research Fellow, Monash/Alfred Psychiatric Research Centre,
 Member Australian TGA Advisory Council, Canberra

Using Education as a Pain Management Tool

Arthritis educators are tasked with providing people with information and advice about how to better manage their arthritic conditions.

Their role is to reinforce and enhance the clinical advice that clients might already have been given by their health professional, to correct any misinformation they have and to enhance feelings of self-efficacy and control over managing what is for most, a long-term health condition. The focus is on self-management strategies, and ensuring that people are aware of the full range of options available to them. Up-to-date information about what pain is and how it works, is one of many useful tools that can be used in this process.

Undoubtedly there are things happening in the body when we have arthritis, however if we only take the view that arthritis pain equates to tissue damage, it limits our ability to explain to people why their pain has gotten worse, is spreading, or is fluctuating, when there haven't been any detectable changes in the body.

Much of what arthritis educators do is to discuss different approaches to manage arthritis. It helps if we are all speaking the same language about how pain works.

There are many sources of pain in an arthritic joint, inflammation of the synovial membrane, pressure or microfractures of the bone, nerve compression, inflammation of tendons or ligaments, muscular tension, instability of the joint capsule and so on.

Pain is essentially designed to protect us, and to keep us safe, telling you that something needs to be done to change the situation, and get you out of danger, thus increasing your chances of survival. This system is so powerful that it is possible for the brain to produce pain, even in the absence of nociceptive information from the periphery. E.g. phantom limb pain.

Chronic pain such as with a long-term condition like arthritis is much less useful. It's like that protective system gets turned on, and it stays on!

This kind of pain has a huge impact on the quality of life of an individual, and can also be more challenging to treat, and we can feel like we are going round in circles. We can take some pain relief, or rest for a while, but when we wake up the next day, the brain still concludes that we are in danger, and continues to produce pain. We therefore need to take a broader approach to managing it.

This is where educating people to understand the nature of pain and their responses to it becomes an effective tool for its management.

Arthritis New Zealand Conference 2016

The Arthritis New Zealand conference was a chance for specialists, health workers and people with the arthritis to come together at Te Papa, in Wellington and share their knowledge and stories.

This year was particularly special, as it was Arthritis New Zealand's 50th birthday.

MC, Frankie Stevens, put everyone at ease by starting the day exercising to the 1999 rendition of *Move it move it*.

There were a range of speakers both International and national that included; Peter Larmer, President of Arthritis New Zealand, Chief Executive, Sandra Kirby, Dr Irwin Lim, Rheumatologist from Sydney, Ainslie Cahill, CEO of Arthritis Australia, Cate Grace winner of the Arthritis New Zealand Premier Award, Dr Dan Bates, Dr Andrew Briggs, Dr Andrew Harrison and Dr Lisa Stamp. A wide range of topics of considerable interest.



Exercising to the 1999 rendition of *Move it move it* – all in a days work at the Arthritis New Zealand Conference.

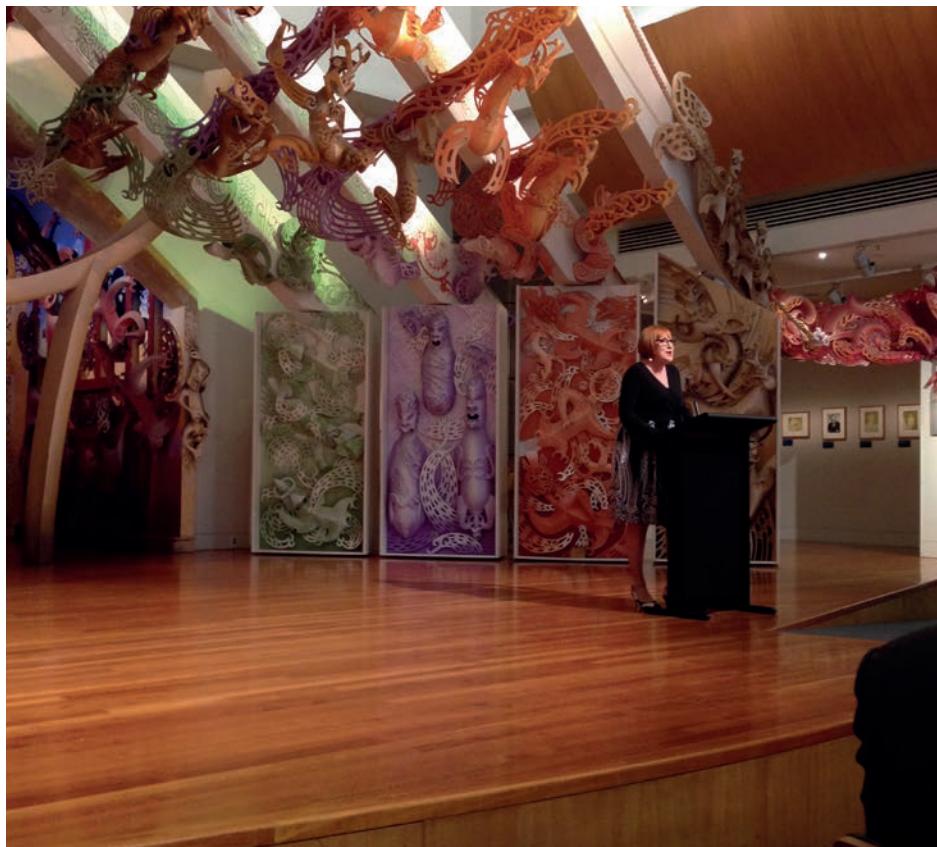


Above: The panel of Irwin Lim, Ainslie Cahill, Andrew Briggs, Sandra Kirby and Peter Larmer being introduced by Frankie Stevens.

Above right: Our delicious 50th Anniversary cake.

Right: Attendees in Dr Andrew Harrison's session.





Ainslie Cahill, CEO Arthritis Australia, was the Key note speaker at our traditional Conference Dinner, held at Te Papa Wellington.

Te Papa proved to be an excellent venue for the 50th Jubilee conference. 170 people gathered to hear a range of speakers. The topics were far reaching – from whether social media is helpful or a distraction to the role of genetics, ancestry and DNA in arthritis. People who attended were excited by the information presented and the skill of the presenters. Arthritis New Zealand would like to thank our sponsors for supporting the conference and ensuring we could offer this opportunity at low cost to people with arthritis.



Dr Irwin Lim, Rheumatologist from Sydney.



Above: Dr Andrew Briggs chatting to attendees during a morning tea break.

Left: Steve Renata, a member of our Governing Body, welcoming attendees on the first day of conference.



The big move

In 2004 Arthritis New Zealand moved into the head office on Featherston Street, Wellington, where staff remained very comfortably until May 2016.

The move wasn't a planned 50th Anniversary event, but on Friday 27 May boxes, desks, kitchen utensils etc., started their move two blocks North on Featherston Street.

The weeks preceding were a lot of fun deciding what could be disposed of and what needed to be kept. It sure posed some challenges.

On Monday 30 May we all arrived at our new space on Level 2, 120 Featherston Street to start the task of unpacking.



But it's all fresh and new – with lots of windows and central heating.



A new digital fundraising platform

We are one of the 20 charities already linked to it.

Easy Giving is a downloadable App that allows you to donate from your smart phone and collects a year's worth of digital receipts so you can claim them.



The better way to give

www.easygiving.nz

A large screenshot of the Easy Giving app interface. At the top, there's a purple header bar with the 'easy giving' logo and navigation links for 'How it works', 'Donation tax credit', 'About us', 'FAQs', and 'For charities'. Below the header, a central box contains the text 'The better way to give' and a description of the app's purpose: 'EasyGiving is a simple way to support awesome NZ-based charities and easily claim your donation tax credit — without pesky receipts.' There are download buttons for 'Google Play' and 'App Store'. To the right, a hand holds a smartphone displaying the app's home screen, which shows a news feed with charity posts and a search bar. At the bottom of the main screen, there are logos for several charities: Asthma + Respiratory Foundation NZ, Arthritis New Zealand, Plunket, For Kiwis For Kiwi, and Child Cancer Foundation.

Chief's Number 11 – a star for Arthritis New Zealand

We learned of James' story in 2010 and invited him to meet us in Wellington for the weekend. At that time, one of our Ambassadors, Neemia Tialata (All Black and Hurricane) who also had arthritis, agreed to chat to James and host him to a Hurricanes training run and to their game on Saturday evening. We got a great story and photo of the pair in the Dominion Post.

James, from Nelson, came home from school with a rash about October 2007. He was also lethargic. He had been at cricket so the family thought it might be some spray on the fields. He slightly improved but in May 2008 everything came back with a vengeance and from Christmas Day till May 2009, James could hardly walk.

*This was a scary time for this sports mad lad and his family, as they sought a diagnosis.
Juvenile Rheumatoid Arthritis!
No, kids don't get arthritis!*

Since that time with the correct medication his condition has been managed and currently James is playing rugby at the highest levels as number 11 for the Chiefs and also the Makos.

But more importantly he is sharing his story with other kids and parents who are confronted by this diagnosis. James clearly recalls the quiet words Neemia shared with him and is now passing that onto others to let them know you can still have dreams.

In 2015 James spoke to parents and kids at the Arthritis New Zealand children's camp. Having someone share their journey is very powerful and removes some of the doubts of the impact of arthritis.

More and more young lads have read his story and James has made himself available, whenever possible, to work with



James Lowe of the Chiefs is an Arthritis New Zealand ambassador.

Arthritis New Zealand and raise awareness of arthritis for young people and talk to others about his journey and how he hasn't given up on his dreams.

This fit rugby player charging around the field is not the face of arthritis you'd expect...



ORANGE Production

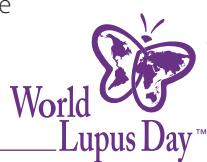
This was planned for Auckland this June but had to be postponed. We will keep you posted on progress.

So many days!

May, June and July have many days that we need to have recognised and remind our readers about. There are over 140 different forms of arthritis and many of these are acknowledged throughout May, June and July.

In May we had:

- Vasculitis Awareness Month
- Ankylosing Spondylitis Day (see the stories in the magazine)
- Youth Week (when we are reminded of the attendees at our camp)
- World Lupus Day
- Fibromyalgia Awareness Day (He's not lazy; he's just been tired his whole life – <http://tinyurl.com/FAarticle>)
- World Autoimmune Arthritis Day (<http://tinyurl.com/zmke3ou>)
- Gout Awareness Day



- World No Tobacco Day – we know the risks of smoking and the diagnosis of rheumatoid arthritis

June brings:

- Men's health week
- World Scleroderma Day



July is:

- Juvenile Arthritis Awareness Month
- World Sjogrens Day

These are all conditions that are challenging for many in New Zealand and the focus for our Arthritis Educator seminars and clinics and often the support provided via our weekly Facebook sessions.

Arthritis New Zealand is interested in starting an online support group to serve the needs of those who work and live with arthritis.

This group will look at the workplace challenges facing people with arthritis and also provide valuable feedback to Arthritis New Zealand about the concerns and issues facing participants as well as helping us develop resources and information that will offer ongoing support.

Minimising the barriers to people in the workforce is one of our Advocacy priorities and we are keen to develop a group to help guide of this work. If you are interested contact **Francesca.holloway@arthritis.org.nz**



Members of the Waikanae Lions present the donation from their Garden Trail to Sandra Kirby and Shireen MainDonald

Arthritis New Zealand is grateful to be supported by:



Andrew Harrison

Rheumatologist, Associate Professor of Medicine, University of Otago Wellington

Andrew was a guest speaker at this years Arthritis New Zealand conference, delivering an engaging talk on recent trends in inflammatory arthritis research. He was generous enough to take some time out to answer a few questions.



Q: Your talk at this years Arthritis New Zealand Conference, was on recent trends in inflammatory arthritis research. Could you outline what some of these trends are?

A: In the 25 years that I have been treating patients with arthritis there have been major improvements in the ability to control inflammation, and this has been associated with a vast improvement in the outcome of several diseases, especially rheumatoid arthritis.

One key reason for this has been the ability to target specific key aspects of the inflammatory process, which can shut down inflammation and joint damage "downstream" from that point. So instead of discovering treatments by accident, scientists have used their understanding of the biology of inflammation to design drugs that target single molecules.

Major improvements in management have also come from trials that investigate the best way to use existing drugs. This often involves a "treat-to-target" approach, where the investigators set a goal and then apply different treatment regimens (combinations of drugs) to see which one provides the best results.

Q: In your talk you spoke of research into switching off the immune response in people with rheumatoid arthritis and other inflammatory diseases. What stage is this research at?

A: There has been a lot of interest in early" and even "very early inflammatory arthritis. As we begin to understand the interaction between genetic and environmental triggers of rheumatoid

arthritis, we are beginning to talk about ways of switching off the immune phase of rheumatoid arthritis, which appears to predate the onset of symptoms by several years in many cases. Trials are being set up to identify at risk individuals, screen them for rheumatoid antibodies such as anti-CCP, and give a course of immunosuppressive treatment to try and "switch off" the process before chronic inflammation develops.

Q: In your opinion does diet play a role in helping to treat types of arthritis like ankylosing spondylitis or rheumatoid arthritis?

A: Diet does not appear to have much influence on rheumatoid arthritis. Supplementation with oils rich in omega-3 might have a modest benefit for relief of symptoms.

Ankylosing spondylitis might potentially be more amenable to control with dietary factors, or - more likely - interventions that change the profile of gut bacteria. This research is still at a very early stage and there is insufficient evidence at this stage to change the recommendations of management.

Q: You spoke of flipping the treatment pyramid upside down. Can you talk briefly about this?

A: When I first started in the early nineties we treated rheumatoid arthritis and similar conditions with safe and conservative measures such as aspirin, bed rest, splinting, orthotics and wax baths, only graduating to drugs like gold injections and methotrexate if there were

indications of severity such as erosions on xray or deformity. Methotrexate was reserved for advanced cases, by which time it was too late.

Now the pyramid has been tipped on its head. Effective medications are now given as early as possible, and physical therapies are mainly applied to the unlucky few whose arthritis progresses in spite of the treat-to-target approach.

There has never been a better time to get rheumatoid arthritis. Increasingly I hear patients say "I feel like a fraud. There is nothing wrong with me. Are you sure I have rheumatoid arthritis?" In some cases it has even been possible to withdraw medication and maintain drug-free remission. The outlook for patients with inflammatory arthritis is much better now than when I first started in rheumatology. These days the patients who do badly tend to be those who drift off their treatments and miss their appointments.

Arthritis doesn't have to hold you back

We all know that keeping active is an integral part of combating the symptoms of arthritis. But Wellington resident James Parker, has taken this to a whole new level. Despite having ankylosing spondylitis (AS), he has competed in three marathons and recently finished the Wanaka Challenge triathlon after a gruelling 15 hours. At the end of the race James' received the Ann Scanlon memorial trophy, awarded each year to an inspirational athlete.

I was diagnosed with AS in 2010. Part of the reason they didn't pick up on my diagnosis earlier is I always kept relatively active, so it masked a lot of the symptoms. They thought it was muscular injuries. In 2010 I did a half marathon in Sydney pre diagnosis, and I was meant to go back the next year to do the full marathon and that's when the body packed in.

Q: Did you notice a decline in your performance before the diagnosis?

A: I did, just like not really being able to run a long distance. I went through physio, and they thought I had stuffed up something in my hamstrings and my hips. But it was the AS so I could only run two or three kilometres and I'd have to stop, and my speed was way down as well.

More stuff started breaking down and I went and got blood tests, and that's when I got the referral to rheumatology.

Q: Did the rheumatologists recommend that you stop running?

A: No but he recommended that I didn't just focus on running. I had always wanted to do Challenge Wanaka so I set my sights on that. The specialist knew that I was really into being active and keeping fit. If I did triathlon I could focus on non weight bearing exercise like cycling and swimming.

Q: Have you found that having a chronic illness has changed your perspective on life?

A: Yes it has, in regards to the fitness side of things I'm up to my third marathon,



I think initially when you're diagnosed, it's all happening quite quickly and you're not sure about stuff, like when you have to go to the hospital and get steroids and they are telling you it's quite bad. You start to doubt what it is that you can do. But when you hear from specialists that there are people out there that do keep active, as long as it's done the right way, it gives you some motivation to keep going. Like

Continued next page...

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 620,000 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

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 620,000 New Zealanders with arthritis.





came off so you're not carrying it on your joints. I cut out a lot of stuff like processed breads, I used to always have sandwiches at lunch but instead I'd switch to having a salad, lots of salmon and tuna, things that have a lot of good protein and omega 3's, lots of green leafy stuff that's probably good for over all health in general.

Q: What kind of support have you had?

A: Arthritis New Zealand has been awesome. They're always sending me nice emails and encouraging me. My partner has been amazing. One of the best things I did when I decided I was going to do challenge Wanaka, was joining a training squad and getting a coach.

Q: What would you say to someone who might be reading this who's recently diagnosed?

A: I've found, that you don't want to put all your goals into the 'not-going-to-happen' pile. It's still achievable, you just have to accept that it's going to take quite a lot longer to do what you want to do. It's

about surrounding yourself with the right kind of positive people. You've just got to not listen to people who aren't in the know. I looked up online and there's only handful of people who have AS who have done something this crazy. I remember way back when it took me 20 minutes to go down and pick up my medicine when it should have taken me 5 or 6 minutes.



Thank you to those of you who visited Z Stations that were supporting Arthritis New Zealand and placed your 'orange' token in our container.

This is an amazing programme run by Z and we value their support of community organisations such as ours.



Yes, I want to support New Zealanders affected by arthritis!

My details:

First name:

Last name:

Mailing address:

Enclosed is my donation of:

\$120

\$80

\$50

\$25 other:

I am paying by:

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Cheque enclosed (please make out to 'Arthritis New Zealand')

Card number:

Expiry date: M M/Y Y

Card holder:

Signature:

Please fill in this donation slip and post back to us:

Freepost 157311
Arthritis New Zealand
PO Box 10020
Wellington 6143

Did you know that you can also donate online?
Visit www.arthritis.org.nz.

Thank you for your generosity!

For further information...

Call free 0800 663 463

When you phone our free 0800 number you will be put in contact with one of our trained Arthritis Educators, who can give you advice and support on managing your arthritis. You can also find out about your region's support groups, and when an Arthritis Educator will next be visiting your district.

Make a donation

Did you know that by phoning 0900 333 20, you can make an automatic \$20 donation to support the more than 530,000 New Zealanders who are living with arthritis?

Visit www.arthritis.org.nz

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.

Regional Offices

Northern (Auckland)	09 523 8910
Midland/Central (Wellington)	04 472 1427
Southern (Christchurch)	03 366 8383

National Office (new address)

Level 2, 120 Featherston Street, PO Box 10 020, The Terrace, Wellington 6143
Phone 04 472 1427 Fax 04 472 7066

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