

# JOINT SUPPORT

ARTHRITIS NEW ZEALAND NEWSLETTER MARCH 2015



*Acknowledging the different faces of arthritis*

## Neemia the face of our gout campaign

Thirty-two year old ex All Black and Hurricanes rugby player Neemia Tialata, now playing for Stade Toulouse, in France, was first diagnosed with gout at 22.

“I was being treated for a foot/toe condition by the Hurricanes medical team and there was no improvement so after a couple of months I was sent for a blood test,” said Tialata.

“Diagnosis was gout! I thought only old people got that and had no idea it was a form of arthritis.”

“I struggle to make people understand how painful it is.”

Other than pain Neemia, knew nothing else about gout. Phrases like ‘uric acid’ and ‘urate levels’ were completely new to him.

“I’m now taking take allopurinol once a day for maintenance and colchicine when I get an acute attack. I still get bouts of gout but am able to get them under control straight away.”

“As a New Zealand born Samoan, I had no idea about the predisposition we have to gout and am fully aware that I’ve got to be very careful of what I eat and drink. Seafood, pork and beer are triggers for me. I’m taking care of my general health and am aware of the diabetes/heart risks that I may face.”

“Go and see your doctor early because leaving it can affect your joints long term. Make sure the doctor educates you on the triggers to avoid further gout attacks,” was Neemia’s clear message.



Neemia Tialata (Photo: Patrick Subotkiewicz / Creative Commons)

- Gout is the second most common form of arthritis in New Zealand.
- New Zealand has one of the highest documented prevalence of gout worldwide.
- About 6% of the adult population in New Zealand has gout.
- 14% of Māori and Pacific males have gout.



**ARTHRITIS  
NEW ZEALAND**

KAIPONAPONA AOTEAROA

*Improving the lives of  
people affected by arthritis  
Te whai kia pai ake te hunga  
kua pāngia e te kaiponapona*



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## From the President

Arthritis limits my participation these days but it is no secret that I am a sports fan.

Describing my golf one day a fellow player suggested I should have stuck to tennis and much the same could be said for my cricket, which has been wholly social apart from a couple of seasons playing business house indoor cricket – and that probably does not count. Unkind references by the captain to my guileful flighted leg spin as “donkey drops” finally convinced me that my sporting future lay elsewhere. It was therefore a surprise to me to be told that I was to captain the Arthritis Allstars in our cricket match with the MPs. The only upside I could see was that that I could insist on a speed camera and zero tolerance policy when the Minister of Police was bowling.

While the afternoon was mostly fun there is always a serious side to such events. This was a chance for us to mingle with our Parliamentary Friends of Arthritis – the group of MPs who have expressed their interest in issues relating to arthritis. Likewise, the annual golf tournament at Paraparaumu which takes place in March this year is an important fundraising event and a chance to talk to some of our sponsors and stakeholders about our work.

Other sports have featured over the summer too. Swimming New Zealand held the second Swimming Legends Charity Relay. The Arthritis New Zealand team was captained by Jaynie Hudgell. I remember her better as Jaynie Parkhouse when she won a medal at the Commonwealth Games in 1974. Then, at the end of last year a number of keen cyclists spent the longest day on their bikes – raising funds in support of Arthritis New Zealand. We have also had supporters fundraising in Round the Bays walks and other events.

There are really good reasons for us to use sporting events as part of our programmes. New Zealanders generally love sport and identify with it. The “Use it or lose it” and other keeping active messages are relevant for all people with arthritis. The sporting image of overcoming challenges has great parallels also.

Our new gout campaign which will go to air late in March continues with the sporting imagery. Neemia Tialata, former All Black and Hurricanes prop, is the face of the new campaign. The rugby field with traps to be avoided is the metaphor for managing gout. Gout as the second most common form of arthritis in New Zealand remains a surprise to many.

Fundraising events have changed markedly over recent years. Added to our more traditional forms of fundraising such as the annual appeal we see more people participating at an individual level with the internet based sponsorship through sites such as Everyday Hero or Givealittle. Research from the Department of Internal Affairs and our own experience tell us that younger people in particular are more likely to use the internet for donations than other forms of giving. As an organisation we continue to work with our tried, trusted and reliable methods of fundraising as well as utilising some of the new ways of doing things. Associating ourselves with sport helps people to identify with us.

I hope that you will be enjoying some of the sporting events this year – either as spectator or participant.

Alan Henwood  
President

## From the Chief Executive

I saw the first ones when I was shopping early in January. A newspaper report said it was the result of customer demand; even so I really struggled with seeing hot cross buns on sale while the Christmas decorations are still up. It was interesting to follow the Consumer New Zealand conversation on their Facebook page asking was it too early.

Our family is one where we value and uphold the traditions around celebrations. Christmas, Easter and birthdays have their own traditions, rituals and special events. It just felt wrong to have Christmas cake and hot cross buns in the same aisle at the supermarket. There is research that indicates families that have strong celebration traditions create a great base that allows the children cope with life changes.

Arthritis New Zealand celebrated its 49th birthday in February. When asked about the beginnings of Arthritis New Zealand Sir John Mowbray said he was asked to attend a meeting of local businessmen called by a well known Wellington physician, Dr Tim Williams. At the meeting Dr Williams outlined the need for a consumer organisation for people with arthritis based on similar organisations in the UK and elsewhere. He then asked for one of those present to head an organising committee. Sir John offered to help on a temporary basis, and thereby started his 14 year term as President.

Next year, 2016, will be our golden jubilee year. This is a great time for Arthritis New Zealand to share stories of our history and build our

community for the future. To start this anniversary year we are planning on holding our next conference in February 2016. It should be a great event with time to reflect on past achievements and to lay the path ahead.

Like all celebrations and traditions it is going to take a bit of planning. This has already begun and we expect to have a number of key events throughout the year and in many parts of the country. We are interested in hearing any ideas you have for the 50th year and keen for local groups to create their own celebrations. I am sure the Regional Managers, Regional Coordinators and Regional Fundraisers will prove a great help to you and your groups as you make your preparations.

And like all celebrations I am sure we will add some new events into the rituals that form part of the Arthritis New Zealand life. Because traditions are not static – they evolve and grow with the generations. We build on the past to create.

With Easter nearly upon us I am now ready for hot cross buns and on Easter Sunday a chocolate egg will be most welcome. I hope you have some celebrations and traditions in your life that link you with past and future generations in your family/whanau.

Nga mihi nui

Sandra Kirby  
Chief Executive



## Live Facebook with Arthritis Educators



Don't forget - we have live Facebook sessions with Arthritis New Zealand staff running on Mondays from 7.00 – 9.00 pm. If you are a Facebook user and have questions on arthritis then please join us.

[www.facebook.com/pages/Arthritis-New-Zealand/141779119206755](http://www.facebook.com/pages/Arthritis-New-Zealand/141779119206755)

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## New MP to lead Parliamentary Friends of Arthritis

Hon Michael Woodhouse has facilitated the Parliamentary Friends of Arthritis since its inception in 2010. With his Cabinet responsibilities the Minister has indicated it is time for a new facilitator – though he will remain an interested member of the group.

Dr Shane Reti (QSM) who was elected as the Member of Parliament for Whangarei in September 2014 has agreed to take on this role. Shane has a professional interest in arthritis as a GP and a personal interest with a close family member having rheumatoid arthritis.

Shane studied medicine at Auckland Medical School, going on to practise family medicine and dermatology in Whangarei for sixteen years. He has a strong record of community involvement culminating in his QSM for public service in the 2006 New Year's Honours List. For the last seven years he was assistant professor at Harvard Medical School in Boston. He says "I am delighted to take on the role for the Parliamentary friends of Arthritis – it fits well with my commitment to work for better health."

The first event for the Parliamentary friends group was the cricket match with the Arthritis Allstars on 9 February.



Dr Shane Reti MP

## Arthritis New Zealand advocates for ACC clients

Many ACC clients have approached Arthritis New Zealand over the last two years, concerned that their claims for elective surgery were being declined. They had been told their injuries were caused by age related age degeneration, in most cases because of osteoarthritis. And this was often a complete surprise, because they had never previously presented any symptoms of osteoarthritis.

Their concerns have added to common perceptions that the ACC's processes are complex and difficult, and that there is no independent oversight of the claims processes.

Arthritis New Zealand has looked into the ACC's claims processes, as part of our role as an advocate on behalf of people with arthritis. And we have found the processes could be considerably improved.

We suggest:

- Improving systems and procedures to help people understand the complexities involved, especially given how legal representation gives claimant challenging decisions much better chances of success.
- Reviewing the fees that successful claimants can be reimbursed. Currently, the cost of legal representation is usually greater than the fees that will be awarded to successful applicants.



- Investigation of independent oversight of ACC processes, perhaps using the Office of the Health and Disability Commissioner, or the Office of the Ombudsman.

We have a register of clients who have had experiences with ACC and have age related concerns.

If you also have an ACC story you would like to tell us, please contact our Northern Regional Manager Francesca Holloway. Email [francesca.holloway@arthritis.org.nz](mailto:francesca.holloway@arthritis.org.nz) or phone 0800 663 463 toll free.

## Arthritis Children's Camp



The warm water hydroslide at Totara Springs Camp

By the time this issue of *Joint Support* reaches you, children and caregivers from across New Zealand will be making their way to the beautiful Totara Springs Camp near Matamata for our annual Children's Camp.

This is one of the highlights of our year. There will be a range of activities for children with arthritis and their caregivers.

It will also give them the opportunity to meet other children who are living with arthritis.

For further information about the camp, phone 0800 663 463, or email [francesca.holloway@arthritis.org.nz](mailto:francesca.holloway@arthritis.org.nz).

Arthritis New Zealand is grateful to Region 4 of The Warehouse for its generous support for our camp.

## Jessika's story

One person who is really looking forward to this year's Arthritis Children's Camp is nine year old Jessika Mann from Christchurch. Jessika has Juvenile Idiopathic Arthritis (JIA). She was first diagnosed when she was about six.

Jessika knows how exciting camp is. Because she went last year, and she had a fantastic time.

Her excitement started long before she got to camp, because her journey included her first ever trip on a plane, before the bus ride to Totara Springs Camp. After receiving a goodie bag and being shown her dormitory, Jessika had dinner.

"After dinner we relaxed in the pool which was fantastic."

Jessika said the food was delicious, and gave a big thank-you to the cooks. The menu included mouth watering delights like ice cream, doughnuts, and pizza. But her favourite was the hash browns.

But there was much more to the camp than food. Jessika got to try archery, karaoke, team games and go on the famous Totara Springs Camp warm water hydroslide which is always the highlight of camp! She met other children with arthritis and made new friends. And she learned that you can still have fun when you have arthritis.

Jessika's Dad Steve said, "The camp is a great place to relax, meet other parents who understand what it means to have a child with JIA and learn from their experiences. The seminars were informative, the food was great, we were well looked after, and the hydroslide is the best I've ever been on! The organisers did an awesome job - thank you."



Jessika Mann

Jessika's Mum Caragh added, "Jessika came back from camp more confident and so happy. She misses out on many activities that she loves, which really negatively impacts her, so to have the camp made her feel very special and helps her see her JIA in a more positive light."

In Jessika's words, "Camp was soooooo cool. I had an awesome time and can't wait for next year! Thank you to everyone that made it possible - I have never had so much fun in my life."

## Charity Golf Classic

There is still time to enter a team into Arthritis New Zealand's Charity Golf Classic, which will be held at Paraparaumu Beach Golf Club on the afternoon of Thursday 5 March 2015.

You and your team will enjoy an afternoon of excellent golf (playing the Ambrose format), exciting competition, exquisite food and beverages on-course and at the 19th Hole to keep up the energy levels, prizes for every golfer, and great company and networking opportunities. Entry is just \$600 for a corporate team of four, and all proceeds go to Arthritis New Zealand.

For further information or to register, email [shireen.maindonald@arthritis.org.nz](mailto:shireen.maindonald@arthritis.org.nz).



Paraparaumu Beach Golf Club

## Fish oil



Arthritis New Zealand is aware of recent media reports of degradation of Omega 3 in various brands of fish oil supplements.

We understand these reports may be of concern to people. However, there is strong evidence that taking Omega 3 has health benefits, and these include reducing the inflammation associated with arthritis. So we advise people who find fish oil supplements beneficial to continue taking them.

If people are concerned about the risk of degradation of their supplements, they should consider buying smaller quantities, and keeping them in a lightproof container in the fridge to help maintain their potency.

## Making care work



Arthritis New Zealand was not surprised by the news that over 420,000 New Zealanders are providing unpaid care for friends or family. This was one of the findings of the recently released Infometrics report that analysed the social cost of caregiving.

The report also found that carers gave an average 30 hours of unpaid care per week to ill, elderly and disabled friends and family members each year, with a grand total of 67

million hours across the country per year, at an annual cost of between \$7.3 billion and \$17.6 billion. This is the equivalent of between 3.4 % and 8.1 % of GDP.

Arthritis New Zealand is aware that many people living with arthritis need additional support. The 2010 Access Economics Report on the Cost of Arthritis in New Zealand suggested that while 1.6% of people with arthritis accessed formal care, over 40% of people relied on informal caregiving provided by family members or friends to assist them with routine daily tasks like housework, dressing, and bathing. In 2010 the cost of carers for people with arthritis was estimated at \$3.2 billion.

Chief Executive Sandra Kirby noted that all have a role to play in making care arrangements work. And suggested that employers in particular can help staff continue to care for friends and family members who need their help. Flexible working arrangements, time off to attend medical appointments for those under their care, and part time work options can all help to make a difference.

## New classification criteria for gout



Classification criteria are very important for clinical research, as they are used to ensure all the participants in the research actually have the same disease.

New classification criteria for gout were presented at the American College of Rheumatology Annual Scientific Meeting in November 2014. These new criteria were the outcome of more than three years of work by a team led by Associate Professor William Taylor (Wellington, NZ), Associate Professor Tuhina Neogi (Boston, USA), and Professor Tim Jansen (Nijmegen, Netherlands).

One of the main studies used to develop these new criteria was the SUGAR (Study for Updated Gout Classification Criteria) initiative, which involved over 20 colleagues in 16 countries. This study collected data from nearly 1000 people with possible gout. The New Zealand arm of this data collection was funded by Arthritis New Zealand, and involved 58 patients in Christchurch (Professor Lisa Stamp), Wellington (Associate Professor William Taylor) and Hamilton (Dr Doug White) respectively.

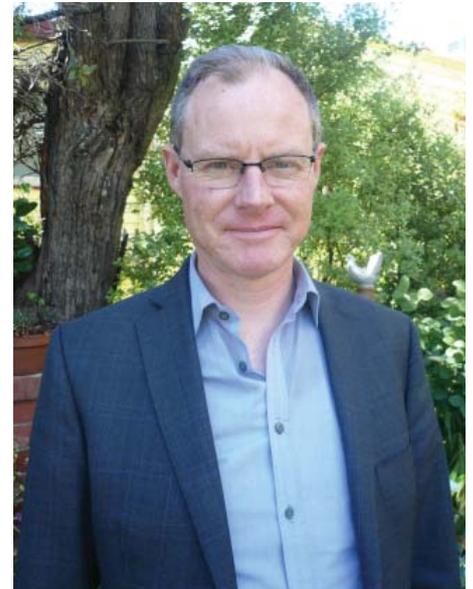
These criteria are more accurate than the previous ones. They enable the identification of gout, with or without the need for obtaining fluid from a joint for analysis. And for the first time, advanced imaging techniques, such as ultrasound and dual energy computed tomography, are included in the definition of gout. Dual energy CT is a powerful method for detecting the uric acid crystals, which are what cause the symptoms of gout. Research about these new imaging techniques

has been led by Associate Professor Nicola Dalbeth (University of Auckland) in collaboration with Dr Alexis Ogdie (Philadelphia, USA).

The presence of serum urate also plays a prominent role in the criteria, as very low levels of serum urate help to rule out gout in patients, and very high levels of serum urate helps confirm a gout diagnosis.

The criteria were developed using expert opinion (using information obtained from SUGAR and other studies), using a structured method of assigning relative importance to the individual components of the criteria. This method was invented by New Zealand economists and was facilitated by a New Zealand physician (Professor Ray Naden), who has done similar work in rheumatoid arthritis and scleroderma, as well as determining access criteria for clinical services.

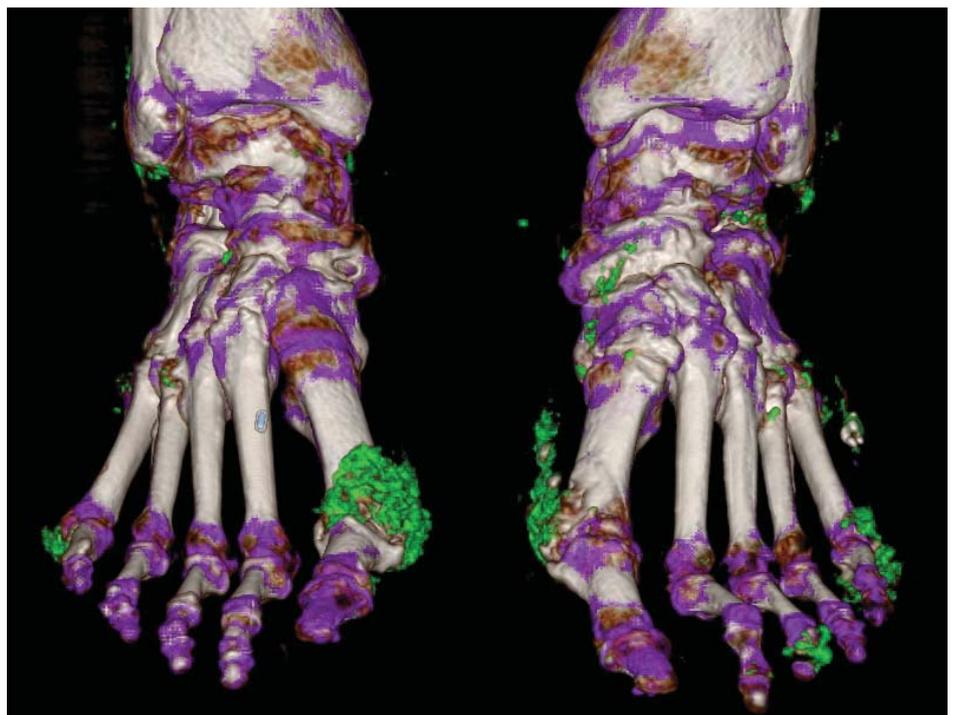
They are not yet published, and they are currently being reviewed by the American College of Rheumatology (ACR) and European League Against Rheumatism (EULAR) before they



Associate Professor Will Taylor

can be officially endorsed by these rheumatology organisations. We expect them to be published some time this year.

Associate Professor Will Taylor  
Department of Medicine  
University of Otago, Wellington



Dual energy CT scan in a patient with gout, showing uric acid crystals colour-coded in green affecting the feet

## What is gout?

If you have been reading this edition of Joint Support carefully, you will have noticed that one form of arthritis has been getting talked about a lot. Gout. This is because Arthritis New Zealand has a major gout campaign coming up. But more about that later.

New Zealand holds the dubious honour of being the gout capital of the world. It is not widely known that gout is a form of arthritis. Yet it is the second most common form of arthritis in the country. It can be both debilitating and incredibly painful. But about two thirds of people with gout are untreated, undertreated or mistreated.

Gout is caused by an excessive build-up of uric acid in the blood. The acid crystallises and results in joint inflammation. Unfortunately, there are a lot of harmful myths circulating about gout, such as that it is a disease of luxury caused by excessive indulgent living, and therefore it is a shameful



Gouty foot

### Key facts about gout

- Gout is the second most common form of arthritis in New Zealand.
- New Zealand has one of the highest documented prevalence of gout worldwide, with very high rates in Māori and Pacific men.
- About 6% of the adult population in New Zealand has gout.
- 14% of Māori and Pacific males have gout.
- Gout is much more common in men than in women – ratio of 3 men with gout for every 1 woman.
- Gout is frequently linked with other conditions – especially diabetes and cardiovascular disease. See: <http://journal.nzma.org.nz/journal/126-1368/5507/>

condition. This myth needs to be dispelled immediately. There is no shame in getting gout.

Gout is three times more common in men than women. And the incidence of gout is also much higher among Māori and Pacific men, who are also usually younger when gout first strikes. This is because of higher levels of uric acid in the blood due to genetic and environmental factors. It is estimated that 14% of Māori and Pacific males have gout.

Gout is also strongly associated with other chronic conditions, such as type

II diabetes, cardiovascular disease, and kidney disease.

But thankfully, gout can generally be well managed with effective medication and lifestyle changes. There are two main types of medicine you can take to prevent gout attacks. Your doctor may prescribe you allopurinol, or probenecid, and occasionally, both. You may also be given pain relief medication to begin with.

If you have gout, you need to see your doctor early to get it under control. Because if left untreated, it can cause permanent joint damage.

### How to prevent gout attacks

- Take gout medicine every day if your doctor has prescribed it.
- Keep to a healthy weight.
- Eat three meals each day.
- Choose small servings of meat and seafood.
- Enjoy low-fat dairy foods each day.
- Drink less alcohol.
- Drink plenty of water.

### How to treat gout attacks

- Go to your doctor for some pain-relieving medicine as soon as you can.
- Keep taking gout medicine every day.
- Protect the part of your body that hurts.
- Rest, put an ice pack on the sore joint, and raise it.
- See your doctor again if you don't get any better after 24 hours.

## Governor-General to preview gout campaign

The Governor General, Lt Gen the Rt Hon Sir Jerry Mateparae, is the patron of many charities, including Arthritis New Zealand. Last year, he invited charities under his patronage to suggest an event or project they would be promoting this year that fitted the theme of nationhood. Some of these events and projects would be chosen to be launched at a function at Government House, Auckland.

Arthritis New Zealand submitted the launch of its upcoming gout campaign. This met the requirements of Māori / Pacific wellbeing category.

We were delighted when we heard that our application had been successful. Arthritis New Zealand will present details of its upcoming



Government House, Auckland

gout awareness campaign (to be formally launched at our Gout Champions Hui on Friday 27 March) at a function at Government House, Auckland, on Friday 6 March.

Three other charities will also be attending: The Fred Hollows Foundation NZ, The Hepatitis Foundation of New Zealand, and the Heart Foundation.

## Gout Champions Hui

Arthritis New Zealand will be hosting a Gout Champions Hui in Auckland on Friday 27 and Saturday 28 March 2015 at Te Manukanuka o Hoturoa Marae (Auckland Airport).

The purpose of the hui is to meet and increase the number of community gout champions there are within Arthritis New Zealand.

Overnight accommodation is available on the marae, and it is likely there will be a request for whanau koha to cover food and accommodation costs.

You are welcome to arrange alternative accommodation if you prefer.

If you are interested in attending the hui, please contact George Ngatai.

Phone 09 523 8912 or email [george.ngatai@arthritis.org.nz](mailto:george.ngatai@arthritis.org.nz).

## Stephen's story

Stephen Herewini of Whangarei had his first gout attack when he was 32, but he says he can remember it like it was yesterday.

"I dug a big hole in my toe, trying to find the pain. Three days later, I was so sore I couldn't walk. I have never felt pain like it!"

He went to the doctor, and was told he had gout.

He had gout attacks off and on, and they became more and more frequent.

Finally, in 2011, he went to a gout clinic with Arthritis Educator Georgina Greville at Manaia PHO.

Georgina explained gout in a way that made sense, and gave him a brochure which explained what gout was, and how to prevent it.

Stephen followed the advice he was given, and in the nearly four years since he went to the clinic, he has not had another gout attack.

## And remember...

## 22 May is Gout Awareness Day!

## Gout and foot care



AUT University in Auckland is the leading provider of foot-related research in New Zealand, and is especially recognised for its gout research. AUT works very closely with academic colleagues at the University of Auckland, and with clinicians at Auckland, Counties Manukau and Waitemata District Health Boards.

AUT's current gout projects include research into the clinical characteristics of the big toe joint, and the function of the Achilles tendon.

Gout is the most common form of inflammatory arthritis in men, and has significant functional, social and financial impacts. The onset of gout is traditionally reported during one's 30s and 40s.

Gout results from an excess uric acid in the body, and the deposit of urate crystals in joints such as the big toe (Figure 1), as well as other sites such as the Achilles tendon, knee and elbow.

Typically, gout initially presents as acute episodic arthritis. Gout also can manifest as chronic arthritis of one or more joints. Gout in men often shows a strong family predisposition, although the genetic basis for this remains unknown.



Figure 1: A person with gout on the left big toe joint

Longer lifespans, increasing prevalence of some other conditions (such as, diabetes, high blood pressure, kidney disease and obesity), the use of certain prescription medications, and changing dietary and lifestyle trends all have been shown to elevate risk for the development of gout.

Gout is a major cause of musculoskeletal disability with foot and ankle pain occurring in most people with gout. Pain during rest and activity as well as pain intensity during and between flares has been reported specifically at the big toe. People with gout walk slower and change their walking style to accommodate for the pain in the big toe. Performing activities like standing, walking, getting up from a chair and walking up and down the stairs are difficult in patients with gout.

To determine what treatment is right for you, talk to your doctor, rheumatologist, nurse, pharmacist or an Arthritis Educator about medicines to treat gout attacks, and about taking medicines every day to bring down your uric acid levels and prevent further attacks.

Arthritis New Zealand produces excellent information about how to manage your gout that includes dietary and lifestyle influences on gout, treatment objectives and the need for comorbidity management.

There is strong evidence that many people with gout often wear inappropriate or poor quality footwear, and that ill-fitting footwear may contribute to further foot problems. There are many conflicting opinions as to what is the 'best' type of shoes to wear. A recent study conducted at AUT University found good walking shoes can help to reduce the foot pain and foot-related disability in people with gout. Our recommendations surrounding footwear for people with gout are those outlined in the Stop Gout Booklet (Workbase Education Trust).

People with gout in their feet need to wear shoes that:

- Are comfortable (not too tight), so there is room if your foot swells up;
- Have a wide toe box to leave room for your sore toe;
- Have laces or Velcro so you can tighten or loosen your shoe;
- Have a cushioned insole that supports your foot;
- Have a deep heel so your foot fits into your shoe properly;
- Have a small heel because high heels can cause problems with your feet, knees and legs;
- Have a firm sole that is not worn (Figure 2).



Figure 2: Features of a good shoe for people with gout

AUT is currently carrying out a large clinical trial examining the effects of a footwear intervention on foot pain and disability. This trial is being funded by the Auckland Medical Research Foundation and it will assess the effect of standard podiatric care and a relevant footwear intervention against standard podiatric care only.

The study findings will be used to make evidence-based recommendations regarding footwear intervention for people with gout.

Professor Keith Rome  
AUT University

## Days to remember

### February was Raynaud's Awareness Month



Raynaud's Phenomenon is a reduction in the blood supply to the fingers and/or toes occurring mainly in response to cold. It has been estimated that 10% of New Zealanders are affected by Raynaud's Phenomenon. And one of the most common causes of Raynaud's Phenomenon is scleroderma, an autoimmune disease that affects connective tissues.

When Raynaud's Phenomenon is a primary condition, and not caused by another condition, it is usually called Raynaud's Disease.

### May is Vasculitis Awareness Month



Vasculitis is a condition that involves inflammation of the blood vessels and can affect any organ in the body. It occurs when your immune system attacks your blood vessels by mistake. This may happen as the result of an infection, a medicine, or another disease or condition.

Because any organ system may be involved, an enormous number of symptoms are possible. Vasculitis can affect persons of both sexes and all ages. And although it is not a form of arthritis, up to 50 per cent of patients with vasculitis will develop arthritis as part of their disease.

Vasculitis can affect people of all ages from childhood to adulthood. There are some types of vasculitis that occur in certain age groups more than others.

For further information about vasculitis see: <http://tinyurl.com/384ddjc>

### 4 May is World Ankylosing Spondylitis Day



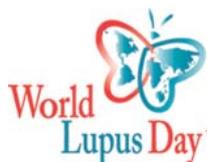
Ankylosing Spondylitis (AS) is a type of arthritis that mainly affects the spine, causing ongoing inflammation of soft tissues around the spinal bones (vertebrae). Over time, the process of spinal inflammation can lead to fusion of part of the spine and sometimes the pelvis. Symptoms usually develop between the ages of 15-35, rarely older than 40 years and men are generally more severely affected than women. The reason for this is unknown.

About half the risk of developing AS is genetic, meaning AS often runs in families. The most common symptom of AS is pain and stiffness in the back and neck, which often result in sleeplessness. And people with AS often experience a form of eye inflammation called uveitis and can develop an eventual loss of spinal flexibility.

Diagnosis is usually made following an assessment of symptoms, physical examination, blood tests, X-Rays or MR scans. Although there is no cure for AS, it can be treated, and the condition can be well managed.

Smoking is known to make AS worse, so this is another good reason to stop smoking, or not start in the first place. For further information about AS see: <http://tinyurl.com/mxzo8zz>

### 10 May is World Lupus Day



Lupus is an auto-immune disease that affects joints, muscles and other organs in the body. As a result, different parts of the body become inflamed and this causes pain and swelling. Lupus can mimic other diseases and can be difficult to diagnose.

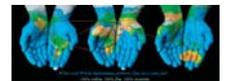
Women are nine times more likely to be diagnosed with lupus, and it is usually diagnosed between ages 15 and 45. Lupus is also more common in Māori, Pacific, and Chinese women. Lupus also affects children or older people. The causes of lupus are not well understood, it is likely that both hereditary and environmental factors are involved. For further information about Lupus see: <http://tinyurl.com/m96ekra>

### 12 May is International Fibromyalgia Day



Fibromyalgia often causes widespread pain leading people to describe the symptoms as if it 'hurts all over'. The word 'fibromyalgia' comes from the Latin term for fibrous tissue (fibro), and the Greek for muscle (myo) and pain (algia). It is a collection of symptoms such as muscular pain, stiffness and fatigue. Around 1 in 50 people will develop fibromyalgia at some time in their life. It most commonly develops between the ages of 25 – 55; and women are more likely to develop this than men. For further information about Fibromyalgia see: <http://tinyurl.com/kkrsnbb>

### 20 May is World Autoimmune Arthritis Day



World Autoimmune Arthritis Day is annually observed by an online, virtual educational & awareness race around the world that unites nonprofits and advocates from around the globe, creating the largest awareness platform & collection of resources anywhere for patients and supporters. It recognises all forms of autoimmune arthritis.

This year's event aims to have double the participation of last year's. For further information about WAAD15 see: <http://tinyurl.com/krykozu>

# JOINT SUPPORT

## ORANGE



The cast of ORANGE takes a break during rehearsal. Rear: Riley Brophy. Front (left to right): Rachael Williams, Lily Simpson, Sharon Waterhouse, Fran Olds, and Kitty Walter.

One of our more exciting recent projects has been ORANGE, a stage work that enabled young people with arthritis to present their unique artistic voices, and celebrated their bodies' responses to life. It told the story of five adventurers who sought to reach the fictional land of ORANGE, but to achieve this goal they had to lay down their burdens, and find a personal strength that allowed them to live a better life.

Arthritis New Zealand is grateful to Geraldine Brophy, who wrote and directed ORANGE, and without whose initial vision and hard work, the show would not have been possible. We are also grateful to the Ministry of Social Development, for its generous support through the 'Think Differently' Campaign's Making a Difference Fund. ORANGE was performed at Wellington's Gryphon Theatre in December.

## Whanganui Garden Amble



Shade garden at 9 Cathro Road, Whanganui

Whanganui members of Arthritis New Zealand organised another enjoyable Anniversary Amble. This has been a regular event on Anniversary Day for a number of years, and involves a stroll around ten gardens that have been opened up to the public, as well as stalls, refreshments, and entertainment.

Attendees paid \$10 each, and all funds raised will be used to support the work of Arthritis New Zealand.

## Swimming Legends Charity Relay



(Left to right) Craig Hudgell, Jaynie Hudgell (captain), Gary Hurring & Corney Swanepoel

Swimming NZ held its first Legends Charity Relay for three years in Auckland on 8 February. The relay was held during the 2015 Zonal Championship.

Arthritis New Zealand entered a strong team consisting of Jaynie Hudgell (captain), Craig Hudgell, Gary Hurring, and Corney Swanepoel.

Our team made a great effort, raising over \$6,000, and increasing the profile of our work.

Well done, team!

## Woodhouse Wonders vs Arthritis Allstars



MPs Kris Faafoi, Hon Michael Woodhouse, and Chris Bishop

On Monday 9 February, Arthritis New Zealand participated in that most gentlemanly of pursuits, the noble game of cricket. A match was held at Kelburn Park, in Wellington, between the 'Woodhouse Wonders', captained by former Parliamentary Friends of Arthritis Coordinator Hon Michael Woodhouse, and the 'Arthritis Allstars', comprising Arthritis Ambassadors and sponsors and other friends of Arthritis New Zealand.

There were sixteen overs per innings, and the 'Woodhouse Wonders' won by a comfortable 50 runs. The umpire was Derek Walker.

Arthritis New Zealand is grateful to the Victoria University of Wellington Cricket Club Inc for the use of its facilities.

## Public trust in charities surveyed

Every second year, Charities Services (previously the Charities Commission) has been conducting a survey about current state of public trust and confidence in the charitable sector. It also looks at the critical factors that drive this public trust and confidence, and New Zealanders' use and experiences of services provided by charities.

Last year, Charities Services commissioned their fourth biennial survey of public trust and confidence in charities. The survey was carried out by Horizon Research, who asked 2,722 respondents, measuring their trust and confidence in charities on a rating scale of 0 (no trust at all), to 10 (complete trust).

The survey showed a 7 per cent increase in trust around charities managing themselves well, an 8 per cent increase with regard to spending money wisely and effectively, and a 12 per cent increase in perceptions that charities' ensure a reasonable proportion of donations get to the end cause.

The survey showed a slight rise in the public's overall trust and confidence in charities. The percentage of respondents now ranking their trust in charities as "I trust charities completely" has grown from 5% in 2012 to 8.9% in 2014.

They survey found that people are more likely to trust charities where they feel that:

"They make a positive difference"

"They protect the environment"

"Their fundraisers are ethical and honest"

"[They] spend their money wisely and effectively"

"They help women"

"I have heard of them"

"They help children"

"I feel a personal connection"

"[They] ensure a reasonable proportion of donations get to the end cause."

### Donation practice

The research also has some useful indicators of how donation methods are changing over time. Generally the use of more mechanical methods of donating (such as posting cheques) in response to a postal or telephone appeal is steadily diminishing. However, as people's relative trust in charities grows, their giving trends upwards, and this is reflected in the use of online giving. The results indicate that people's willingness to give continues to be strong, and that the amount given may actually increase over the next 12 months.

### Next steps

Charities Services is analysing the survey results to support its upcoming work programme with the sector. They will use the survey findings to build charities' awareness of what they can do to build the public's support for their governance and management.

You can read the research summary, and the full report on the research on their website: <http://tinyurl.com/nvx4ksc>

# JOINT SUPPORT



Did you know that you can support Arthritis New Zealand through the Payroll Giving scheme?

Payroll Giving enables employees to make donations to Arthritis New Zealand (as well as other charities, schools and other community groups) through their employer's payroll system. In other words, you can give as you earn.

Donations made via payroll giving receive an immediate PAYE credit of 33% of the donation amount. This means if you donate \$15, it actually only costs you \$10. Since the scheme was introduced in January 2010 almost \$14 million has been donated through payroll giving to community organisations around New Zealand.

Payroll giving works for all involved. For recipient organisations, payroll giving lowers the cost of fundraising and provides a steady revenue stream. And for employees, the donations they make are deducted before they receive their pay. The process is seamless and they receive an immediate tax credit of 33% of the donation value by way of a reduction in PAYE. And for employers, payroll giving supports recruitment and retention strategies, and demonstrates support for the things that matter to employees outside of the workplace.

See: <http://www.arthritis.org.nz/support-us/payroll-giving/> for further information.

## Corporate Gerbera Club



Our Corporate Gerbera Club is a great way for businesses to show their support for Arthritis New Zealand, and help us raise vital funds for the 578,000 New Zealanders who live with arthritis.

By donating \$100, your business will be acknowledged as a community-focused organisation that recognises the serious impact of arthritis in New Zealand.

To find out more, please contact us on 0800 663 463 and speak with a Regional Fundraiser.

## Kiwi Karma



Arthritis New Zealand has been part of Kiwi Karma for almost two years, and is thrilled to be part of this exciting fundraising initiative.

Kiwi Karma is a website where supporters of Arthritis New Zealand can book accommodation.

Kiwi Karma then forwards 3% of the amount you paid to Arthritis New Zealand as a donation.

The rate you pay on Kiwi Karma is fed from the hotels own central reservation system, so almost certainly is the best rate available at time of booking.

So when you next travel use <http://www.kiwikarma.co.nz>, it is a way that you can support arthritis, simply by doing what you would have done anyway.

Kiwi Karma offers over 3,100 places to stay, and there are no booking or credit card fees!

So next time you need to book accommodation, use Kiwi Karma!

## Do you have a current will?

There are several good 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 may 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.

Big or small your bequest will be greatly appreciated. It will help us to continue to provide services now and into the future.

If you would like to talk to someone about leaving a bequest to Arthritis New Zealand or more information, please call 0800 663 463 and ask to speak to Dianne Armstrong, or email: [dianne.armstrong@arthritis.org.nz](mailto:dianne.armstrong@arthritis.org.nz).



## Golden Jubilee



Arthritis New Zealand turns 50 next year!

We will have spent 50 years of supporting, advising, and advocating for people in New Zealand who are living with arthritis. And that will be something to really celebrate!

So please send us your ideas to help us plan our celebrations this incredible milestone!

Email [info@arthritis.org.nz](mailto:info@arthritis.org.nz).

## 16% of New Zealand's population now living with arthritis

578,000 New Zealanders are now living with a diagnosis of arthritis, up from the previous figure of 530,000. This equates to 16% of the total population or about one in six. This data from the NZ Health Survey also breaks down another of the myths that arthritis is a condition of the elderly as 51% are aged 15-64 years of age.

This is backed up by the increasing demand for Arthritis New Zealand's services. In the last year we responded to 9,651 helpline calls, a 13% increase in Arthritis Educator services and there were 195,077 hits to our website. We currently have over 70 land and water based exercise groups across the country, most with waiting lists. People are endeavouring to stay mobile and conscious of the impact extra weight has on their joints.

With this growing impact on New Zealand's work force and health systems the Government's commitment to an investment of \$36 million over the next three years in a plan to help New Zealanders live free from bone, muscle and joint pain is more important than ever.



### 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:

Visa  Mastercard  Amex  Diners

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

#### Card number:

Expiry date:  M  M /  Y  Y

Card holder:

Signature:

Did you know that you can also donate online?

Visit [www.arthritis.org.nz](http://www.arthritis.org.nz).

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

Freepost 157311  
Arthritis New Zealand  
PO Box 10020  
Wellington 6143

Thank you for your generosity!

# JOINT SUPPORT

## 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](http://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

Level 2, 166 Featherston Street, PO Box 10 020, The Terrace, Wellington 6143  
Phone 04 472 1427 Fax 04 472 7066

Facebook



[www.facebook.com/pages/Arthritis-New-Zealand/141779119206755](https://www.facebook.com/pages/Arthritis-New-Zealand/141779119206755)

Twitter



[www.twitter.com/arthritisnz](https://www.twitter.com/arthritisnz)

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