

JOINT SUPPORT

ARTHRITIS NEW ZEALAND NEWSLETTER JUNE 2015



Acknowledging the different faces of arthritis

A face of gout



Su'a William Sio, MP, speaks at the launch of our gout awareness campaign

You have probably seen the ads on television: Don't get trapped by gout. Arthritis New Zealand launched its gout awareness campaign in March. *Joint Support* spoke with **Su'a William Sio, MP**, about his experiences of living with gout.

Su'a William Sio had his first gout attack when he was in his thirties. He didn't realise it was gout, thinking the pain he felt in his wrists and his feet was his childhood rheumatic fever returning. He took Panadol, and only sought medical help after the pain returned unexpectedly during his mother's funeral, and was becoming unbearable. Only then did he learn that he had gout.

Su'a found his diagnosis confusing. He thought gout was something old people got, and like many Pacific men, he thought it was all about food and drink, not genetics, and when he was first diagnosed, his family members all said it was either alcohol, or fish or 'povi masima' (salted beef) or pork, or rich food.

Su'a hid his embarrassment by joking about it, and he remembered his uncle – who also had gout - saying it was a "rich man's disease".

But after his diagnosis, he began taking medication. Elders chanted for his mother to take the pain from his wrists and take it with

her. And he reduced his intake of salt, sugar, alcohol, and red meat, and began to drink more water.

Sua's lifestyle changes and use of medication seem to be working. "Once I had taken those gout pills, and the elders had chanted that my mother take the pain from my wrists and take it with her, that at the end of that week, the pain left, and I've never felt it since."

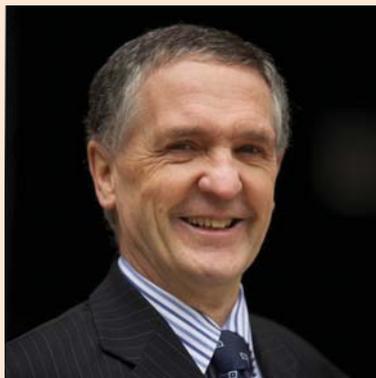
Su'a's message resonates with Neemia's from our advertisements: managing gout is about taking medication, and lifestyle changes.



**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

With this edition of Joint Support you will receive your invitation to renew your membership for the year ahead. In this our 50th year of being the voice of arthritis membership has particular relevance. We are living out the words of anthropologist Margaret Mead "Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has."

It was people like us in 1966 who got together to form what we now know as Arthritis New Zealand. Over the last fifty years the organisation has provided information, advice and support to thousands of people living with arthritis. And in our own way we have changed the world – at least our part of it. Over the years our members and staff have advocated for better access to treatment, including access to the disease modifying drugs that have revolutionised treatment for conditions like rheumatoid arthritis. The organisation has funded research into diagnosis, treatment and management. We have argued for better access to rheumatologists – and also better awareness for people with disabilities. Over the years we have run some very memorable awareness campaigns. "Use it or lose it" from many years ago is now used universally but remember we did it first. The "broken glass in your joints" remains a resonant image to describe the experience of living with arthritis. I hope you have seen the latest awareness campaign – "Don't get trapped by gout" with that powerful image of the trap closing on the joint at the base of the big toe. In

future years we hope people will still hear this message.

You might think with all we have achieved it would be time to step back but the numbers of people with arthritis continues to grow. Latest figures from the Ministry of Health say over 578,000 people have a diagnosis of arthritis. There is no sign that this is going to change in the near future. While treatment has advanced for now there is no cure. We still hear too many times "I thought there was no-one else like me". There is a need for Arthritis New Zealand to keep raising awareness; advocating for better services; funding research and providing advice and support. To do that we need members – because we are a member led organisation.

As well the information about renewing your membership you will also see a call for nominations for the Governing Body and Regional Liaison Groups. It is through these elected representatives that members control the activities of Arthritis New Zealand. It would be great to see our Regional Liaison Groups strengthened and truly representative of the country and the many faces of arthritis.

With over 4,000 members we are not that small and we certainly are committed. There remains room for change to make our world better for the people currently living with arthritis and those who come after us. This can be our legacy.

Alan Henwood
President

From the Chief Executive

What does it mean to be the voice of arthritis?

When I was a child I used to have speech lessons – they helped me in public speaking. I can remember my speech teacher telling me to stand up straight and breathe deeply if I wanted people to hear me. “Speak to the back of the room” she would say. Singers also know that by standing up the voice travels further.

With over 140 different conditions; people aged from babies to centenarians and many issues facing people with arthritis we too need to do the equivalent of standing up and speaking to the back of the room as well as the front.

In this issue of Joint Support you will see a number of ways in which Arthritis New Zealand is standing up to be heard. This is not one person but many people with voices that need to be heard.

Over the next month we are running training for our volunteer advocates. These special volunteers have agreed to use their experiences to help us reach out especially to politicians so they too can see first hand what the impact of arthritis has on New Zealanders. It is our dream that every MP will one day be connected to a person with arthritis in their area so that the voice of arthritis is in their head.

The PORTAL project is an exciting new initiative that aims to incorporate a range of views from people with rheumatoid arthritis – results from this survey group will help shape clinical services. This kind of patient voice is possible with the increased access to technology. I look forward to a time when we have similar

processes for people with other forms of arthritis too but we have to start somewhere.

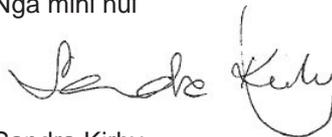
The gout campaign running on television is another way of standing up and speaking out. We can see the response in the number of telephone calls and hits to the website. Campaigns like gout and the two previous ones give us the visibility we struggled to gain consistently in earlier times. The Arthritis New Zealand voice is easier to recognise because people can see we exist.

Research is often a quiet voice. As in life the quiet voice often has a powerful message. When research speaks we should listen. It is a privilege to work in an organisation that supports research and uses research findings to underpin the advice and information we provide.

So yes there is more than one voice of arthritis. Many people contribute to the messages we want heard. Making sure the voices and the messages are in tune continues to be a significant role for Arthritis New Zealand.

Many people think that public speaking is a fate worse than death. Another message from those childhood lessons is that when speaking to a large group focus on individuals. We can all talk to one person and only one person needs to hear our message and act on it for change to happen.

Nga mihi nui



Sandra Kirby
Chief Executive

Arthritis New Zealand is grateful to be supported by:



2015 Arthritis Appeal



September is not very far away, and that means only one thing: Arthritis New Zealand's Annual Appeal!

Planning is well underway, but we need collectors right across the country. This is our major fundraiser for the year, so please help us to held you!

If you would like to volunteer to collect or assist with the appeal, please contact your nearest Arthritis New Zealand Office. Or phone 0800 663 464 toll free or email info@arthritis.org.nz.

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.

JOINT SUPPORT

Volunteers establish Hawkes Bay Arthritis Support Group



Rebecca Houlton & Claire Hatfield

Rebecca Houlton (left) was diagnosed with rheumatoid arthritis when she was 34, and it has been quite a life changer for her and her family. She found it really difficult to find other people out there in a similar situation, and this prompted her to volunteer to help establish a new Hawkes Bay Arthritis Support Group. Rebecca is looking forward to getting the support group up and running, connecting with others,

Claire Hatfield (right) wants to help other people who are living with arthritis. She has been living with osteoarthritis for ten years now. And she has found talking with other people who understand the challenges certainly does help put it in perspective.

This support group is aimed at a wide range of ages and arthritis conditions, particularly those wanting

a relaxed informal type of support. For further information, contact Rebecca at rebecca.houlton@clear.net.nz, or Claire at clairehatfield@vodafone.co.nz, or phone 0800 663 463.

Arthritis New Zealand is grateful for the efforts of Rebecca and Claire, who are but two of our many valued volunteers.

National Volunteer Week

National Volunteer Week (NVW) 2015 is held from 21 and 27 June and is a fantastic chance to celebrate the invaluable knowledge, skill and time contributions given by Aotearoa's past and present volunteers.

This year's theme is "There is a place for you to volunteer" or "he wahi

mohou hei tuao" which highlights the diversity of volunteer opportunities, volunteers themselves, and the impacts of volunteering.

Organisations that rely on volunteers use National Volunteer Week to thank their volunteers and encourage people to join their volunteer



communities. Regardless of how much or how little skills, time and experience one has to offer, there will always be a place to volunteer.

Interested in advocacy?

Advocacy is one of the priorities of Arthritis New Zealand and we are building a network of Arthritis Advocates around the country. These advocates assist in the promotion of our advocacy priorities and are particularly important in providing consumer feedback and perspectives

for us. Later this year we will be running training sessions for advocates with a particular focus on how we can be effective lobbyists.

Our current advocacy priorities are on our website www.arthritis.org.nz. Take a look under the issues section.

To become an advocate, complete this form: <http://tinyurl.com/l7pzu54> and email to: francesca.holloway@arthritis.org.nz.

For further information, phone Francesca Holloway on 0800 663 463.

New Health Navigator website

New Zealanders are going online for health information more than ever. And to meet this growing demand, the Health Navigator website has been redeveloped and merges three existing websites (www.everybody.co.nz, www.liveto100.co.nz, and www.healthnavigator.org.nz) to provide an easy to use front door to comprehensive health information for the public and health sector.

The www.healthnavigator.org.nz site provides a portal to trusted sources of New Zealand information about health subjects including:

- health conditions and symptoms
- treatment, medicines, tests and procedures
- disease prevention, self-help information, lifestyle
- services and support.

Other key features include: a robust quality framework, no drug advertising, a focus on improving health literacy, self-care and behaviour change, and videos and other interactive tools. There is also a health professional



section and a clinician tab with links to clinical pathways. So have a look at www.healthnavigator.org.nz and see what you can learn about your condition.

Adding the patient voice to treatment for RA

There is plenty of evidence that the best outcomes in terms of patient satisfaction, compliance with treatment, and health outcomes occur when the opinions of health consumers are linked to those of the clinical people. Arthritis New Zealand is proud to be part of a project that seeks to incorporate the voice of people living with rheumatoid arthritis (RA) into clinical services and help improve treatment outcomes. People with a diagnosis of RA will be invited to join the project with the aim of creating a representative sample of RA patients and interacting with them in an on-going manner through a series of interactive surveys regarding rheumatology care and experiences – the PORTAL project.

Because there is currently no cure for conditions like RA the goal of treatment is to control joint inflammation and prevent joint damage and disability. Getting the right treatment requires close monitoring and adjustments to treatment over the course of the disease, which normally lasts a lifetime. People with RA have significant interaction with health services.

The PORTAL project will be run from the Arthritis New Zealand website www.arthritis.org.nz

People with RA from Hamilton, Wellington and Dunedin will be invited to join the project when they visit the rheumatology clinics in these areas.

People with RA from outside these centres will be able to join from the website. Then aim is to have at least 400 people linked into the PORTAL project. With a large number of people responding the survey results can be truly representative and weighted to ensure they do represent the full range of ages, ethnicities and other sociodemographic factors for people with RA.

It is often hard to find ways to include the patient voice in a meaningful way. Having one or two people representing a wide group of patients is not ideal and online surveys might be biased through self selection. Although rheumatologists see a wide range of patients in clinics there is an imbalance of power in the relationship that may prevent patients feeling they can express their opinion.

“We see this project as adding to the other work that Arthritis New Zealand does in advocating for better services for people with arthritis” says Sandra Kirby. “While this project is starting with people with a diagnosis of RA once the mechanism is shown to work the potential for wider use is obvious.”

The PORTAL project steering committee is led by Associate Professor Andrew Harrison and includes Associate Professor Simon Stebbings, Dr Douglas White, and Sandra Kirby from Arthritis New Zealand. The project is funded from an unrestricted educational grant from AbbVie.

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!

JOINT SUPPORT

Have you heard of fibromyalgia?

Have you heard of or been diagnosed with fibromyalgia? Then you're not alone. Around one in fifty people will develop this often confusing condition at some time in their lives.

Fibromyalgia can be a confusing condition, for both those with the disease and healthcare professionals, and there are many myths and

misunderstandings about its cause and treatment. It can cause 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. It is not yet known what causes fibromyalgia, but around one in fifty people develop it, most typically between the ages of 25 and 55.

Women are more likely to develop this than men.

For further information about Fibromyalgia see: <http://tinyurl.com/kkrsnbb>

But you don't look sick...



Denise Woodhams

Denise Woodhams was first diagnosed with fibromyalgia about five years ago. Since then, it has had a huge impact on her life.

It is more prevalent in women than men. The symptoms vary from person to person, but commonly include widespread pain, fatigue, loss of sleep, tingling or numbness, irritability forgetfulness and poor concentration, and localised tenderness.

Denise's fibromyalgia had has a "huge impact" on her life. "I can't work full time, plus I'm on my own. How do you support yourself and live?" she asks.

Denise can no longer do many of the things she used to love, such as building and reconditioning furniture. She can still garden,

but on a much more limited scale than she used to. She tries to pace herself, but it can still come up and hit her, which bring home the fact that it will never go away

"I felt like I'd lost my life, the things you take for granted, being healthy and strong, and being able to do anything, are mostly gone. It's made a huge difference to how I live."

One of the main issues Denise faces is that fibromyalgia is not that obvious to others.

"People don't really understand fibromyalgia. They may say, 'But you don't look sick.' Which means that people often don't accept that you really are unwell, and their disbelief can be quite hard to deal with."

Denise found it really helpful to go to QE Health in Rotorua. While she was there, she made friends with two others from the Hawkes Bay. Their mutual support for each other has been a "huge relief", and she encourages others living with debilitating conditions to network with others who are similarly affected. The ongoing continuing support they give each other has worked out really well for them and is a really positive thing.

World Sjögren's Day



Vasculopathy in Sjögren's Syndrome

23 July is World Sjögren's Day. This is the birthday of Dr Henrik Sjögren, the Swedish ophthalmologist who discovered the condition in 1933.

While most people are familiar with the more common forms of arthritis, such as osteoarthritis and gout, other equally challenging forms of arthritis, such as Sjögren's are far less visible.

Sjögren's is a chronic disease where the white blood cells attack moisture producing glands. The hallmark symptoms are dry mouth and dry eyes. Patients may experience many other symptoms as well which include: fatigue and joint pain.

Nine out of ten people who develop Sjögren's are women. Well known people with Sjögren's include former world number one tennis star Venus Williams and singing star Seal.

New Zealand research into spondyloarthritis



Spondyloarthritis is a form of arthritis, which affects the spine, particularly the neck, low back and sacroiliac joints at the base of the spine. It is an unusual form of arthritis because it affects young people, often starting in the teenage years, but always before the age of 45.

Spondyloarthritis (SpA) often runs in families. Several genes have been found which increase the risk of developing SpA, in particular a gene called HLA-B27. Although carrying this gene does not mean a person will get SpA, it increases the risk about 40 times.

SpA is a painful condition, but often comes on slowly, and many people do not realise they have a problem. This is particularly the case when it starts in young people, perhaps because teenagers are experiencing a lot of changes in their life, when symptoms first develop. Sometimes doctors may take a while to make

the diagnosis, some studies showing it may take up to eight years to get a diagnosis.

SpA can cause ongoing pain and stiffness, cause disability, and loss of employment. Many studies show that it adversely affects a person's quality of life if untreated. Fortunately, new treatments have made a big difference to the outlook for people with SpA in the last few years. In particular, biologic drugs.

In New Zealand the Spondyloarthritis Genetics and the Environment Study (SAGE) was set up in 2010 to study SpA. The study has so far enrolled over 300 volunteers with from Auckland to Invercargill. Through this study we hope to learn more about the impact SpA has on people's lives, employment and health. We are looking into the effect of new treatments as well as potential causes of SpA. These include the role of inflammation in the intestinal tract and the role of genes.

SAGE will soon be entering an exciting phase, where data we have collected over a number of years will be analysed. So far we have discovered new information about the HLA-B27 gene. We now know that 9.2% of New Zealanders carry the gene. It is a little less common in Maori (6.5%). This has helped to show how important this form of arthritis is in this country.



Associate Professor Simon Stebbings

Through this research we have been able to develop international research links. We have collaborated with large international studies looking for new genes in SpA (IGAS) and with the Assessment in Spondyloarthritis International Society (ASAS), which is helping to develop better ways of assessing SpA and making an earlier diagnosis. We have worked with Arthritis New Zealand to increase public awareness of SpA. A research project looked at the impact of Arthritis New Zealand's campaign and showed that more people had been referred and more diagnoses made, which was a great result.

We are extremely grateful to those who have volunteered their time to take part in the study. Without your input we could not complete our research. And we hope that in the next few years, we will have more information to share with readers.

Associate Professor Simon Stebbings

Andrew Nicholson: our newest Arthritis Ambassador

Andrew Nicholson has been in the news recently for finishing sixth at the recent Badminton Horse Trials. The New Zealand rider has so far won three medals at the Olympic Games and three World Equestrian Games medals.

Andrew is also our newest Arthritis Ambassador. He has been living with arthritis since breaking his hand

in 2011, but this has not held him back from pursuing an illustrious equestrian career. He is an excellent example of a person who has not let arthritis hold him back

Arthritis New Zealand congratulates him on his recent high standing at Badminton and looks forward to his future successes.



Andrew Nicholson

JOINT SUPPORT

Amelia's story

July is Juvenile Arthritis Awareness Month. There are an estimated 1,000 children with arthritis in New Zealand, including five year old Amelia Ferguson from Lower Hutt.

Amelia was diagnosed with Juvenile Idiopathic Arthritis (JIA) just after she turned four. Her knee became swollen and sore.

Amelia's parents were hopeful that the JIA might be an isolated incident. It was treated with regular ibuprofen and a joint injection just before Christmas and they crossed their fingers and hoped for the best.

However that was not to be. During the past year arthritis has affected both knees, her right elbow twice, and most recently an ankle and the original knee again. Each has been treated with a joint injection, which involves a trip to day surgery where she is given a general anaesthetic and the joint is injected with a steroid. In some cases fluid is also drained from the joint. She takes ibuprofen three times per day when her joints are sore/flare, and most recently has begun taking methotrexate (a chemotherapy drug) in the hope that it will settle her overexcited immune



Amelia Ferguson

system. She will need to be on this medication for at least 12 months with no joint inflammation before her doctor will consider taking her off it. Methotrexate can have side effects so Amelia goes for regular blood tests to ensure that her liver is functioning properly. It can also cause nausea, thinning of the hair and mouth ulcers. So she takes folic acid to counteract this.

Every three months Amelia has her eyes checked as JIA can cause inflammation to the cells in the eyes. So far this has not occurred, but these regular checks will continue for years. There are also physio appointments to keep her joints moving correctly, and exercises for when they are not.

To look at Amelia you wouldn't realise anything was wrong. She is a happy, active child who doesn't let on she is in much pain. She is now five and starting to wiser up to what is going on.

However much her parents worry about how her condition might manifest, they take care not to put that on Amelia. They are sad their little girl has to go through all these invasive procedures and with young twins in the family Mum needs to put on gloves to handle the methotrexate. "It's challenging to learn more and more about a disease we have no experience of. It's our job to worry about it and her job to be a kid," Mum said.

What is scleroderma?

Scleroderma is a rare, chronic, often progressive autoimmune disease in which the body's immune system attacks its own tissue. Scleroderma causes hardening and tightening of the skin and tissue that holds muscles, joints, blood vessels and internal organs together, resulting in restrictions in movement. It is very hard to diagnose Scleroderma because the condition affects each person so differently and even if a person looks well from the outside, they may have serious problems with their lungs, heart, kidneys and gut.

Scleroderma affects the connective tissues of the body (tissues that hold together muscles, joints, blood vessels and internal organs). The connective tissues of people with scleroderma have too much of a protein called

'collagen'. Collagen is important to give connective tissue its strength, but excess collagen causes hardening and tightening of the affected area.

Both sexes are affected by scleroderma, but it affects more women than men. Scleroderma affects around one in a thousand New Zealanders and can occur at any age but usually starts between the ages of 25–55 years. It is not hereditary and rarely occurs in more than one family member. There is no cure for scleroderma, but many treatments are available for specific symptoms.

World Scleroderma Day is observed on 29 June, which remembers the life and work of artist Paul Klee, who died on 29 June 1940, and whose work was strongly influenced by systemic sclerosis, a form of scleroderma.

For further information about scleroderma see: <http://tinyurl.com/m6766r2>



Scleroderma

Gout awareness campaign



Arthritis Educator Lettie Neri-Iseli tests the uric acid level of the Governor-General, Lt Gen The Rt Hon Sir Jerry Mateparae



Dr Shane Reti MP helps launch our gout awareness campaign

Arthritis New Zealand's gout awareness campaign was previewed at a special event at Government House Auckland on Friday 6 March, ahead of its formal launch at our Gout Champions Hui on Friday 27 March.

Charity Golf Classic



The team from Green Cross Health

The weather was perfect for the Arthritis New Zealand Charity Golf Classic, which was held at Paraparaumu Beach Golf Club on Thursday 5 March. A great day was had by all who participated.

Arthritis Children's Camp



The children visit Hobbiton

One of the year's highlights has been our annual Children's Camp at Totara Springs Camp near Matamata. Children from all across the country attended, met other children with arthritis, and had fun. And parents and caregivers also got to share their experience, strength and hope with other parents of children with arthritis.

Stash reHash

Arthritis New Zealand is grateful to everyone who made our recent Stash re Hash in Ashburton a success, including those who bought and sold crafting materials, and the volunteers who made it all possible, especially Rowena and Val who organised it all.

Stash reHash raised \$8,000 to support our work.

Well done!



An exploration of foot problems reported by people with systemic lupus erythematosus



Systemic lupus erythematosus (lupus) affects the body's immune system and attacks various parts of the body. Like many rheumatological problems, several different tissues can be affected by lupus, especially the joints, blood vessels, kidneys and skin. Generally speaking for people with arthritis, foot complaints commonly cause pain and affect mobility. However, very little is known about how feet are affected in people with lupus. What is known largely comes from one-off case reports or studies based on X-ray findings. At AUT we are currently expanding our understanding on what is known about lupus by asking people with this condition about the problems they experience with their feet.

To begin with we wanted to design a new questionnaire to explore what foot complaints people with lupus experienced. To ensure the questionnaire was relevant to people with lupus, we developed it in partnership with both people living with the condition and health professionals. Firstly, we asked people with lupus and doctors to explain what they felt was important about foot complaints. We then compared this with existing methods used to assess the symptoms in lupus. This information was used to design a questionnaire. The questionnaire asked about foot symptoms, how these affect people's lives and the treatment they had received if they had foot pain. The questionnaire was tested with people with lupus for feedback. The finalised questionnaire was posted to 406 people with lupus living across the Auckland region. In total, 131 people completed the questionnaire, with 77% of respondents (particularly women) reporting foot pain during the course of their lupus. This percentage

is more than in many other types of arthritis (such as psoriatic arthritis). As well as pain, people also often reported other symptoms such as cold feet, chilblains, skin rashes, feeling of numbness and swelling of the feet.

All regions of the foot were reported to be involved in lupus, with the heel and ankle being most often affected. This is unusual as the ball of the foot is more often involved in other types of arthritis. Additionally, a third of respondents' said that their foot pain prevented sleeping and had a negative effect on emotions. Life in general was adversely affected by foot pain with almost two-thirds reporting limitations in those daily activities like walking where good foot function is important. Over two-thirds of people who completed our questionnaire reported their foot problems interfered with social activities and over half reported foot complaints interfered with their family activities.

Whilst foot complaints seemed to be common, only one-third of participants had seen a foot specialist (Podiatrist). Often podiatrists provide insoles and sometimes specialist footwear for people with arthritis. Insoles and footwear have been shown to reduce foot pain and improve foot function in other types of arthritis. In our study, less than a quarter of respondents had been provided with insoles and even fewer were continuing to wear them. Being unable to replace insoles was the most common reason for not continuing with insole therapy. No-one reported that they had been provided with specialist footwear. Reasons for this are not clear and need further investigation.

Overall, it seems that foot complaints are common for people with lupus. These complaints are highly varied and appear to have a negative impact on well-being. Foot problems appear to be under-recognised in people with lupus. It is recommended that people with lupus who have foot problems should see a podiatrist for advice as they can help.



Dr Simon Otter

Our next step is to continue with this work in conjunction with others to gain a better understanding of the nature and extent of foot complaints for those with lupus. We have the overall aim of being able to provide better foot care for people with lupus in the future. This may include a recommendation for a comprehensive foot care plan as part of lupus treatment.

Dr Simon Otter, Visiting Research Fellow, AUT University

Contact details and further information
Professor Keith Rome, Professor of Podiatry, School of Rehabilitation & Occupation Studies, AUT University, North Shore Campus, Private Bag 92006, Auckland 1142, New Zealand

Funding
This work was funded by AUT University, Faculty of Clinical Science, Deans' Cafe

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

Volunteers wanted for water based exercise

Exercising with painful joints is often difficult, which is why many people find water based exercise can be a great help with managing their condition. Benefits that have been identified include improved enjoyment of life, emotional wellbeing, mobility (including the ability to carry out day to day activities), fitness and strength; and better pain management.

Arthritis New Zealand runs water based exercise classes at various locations across the country. But it needs volunteer support to continue providing this vital service.

If you have a fitness or exercise background, and would be willing to volunteer your time, you may be just the sort of person we are looking for to lead some of our water based exercise classes, and help people



living with arthritis exercise in an aquatic setting.

A water based exercise class in Nelson

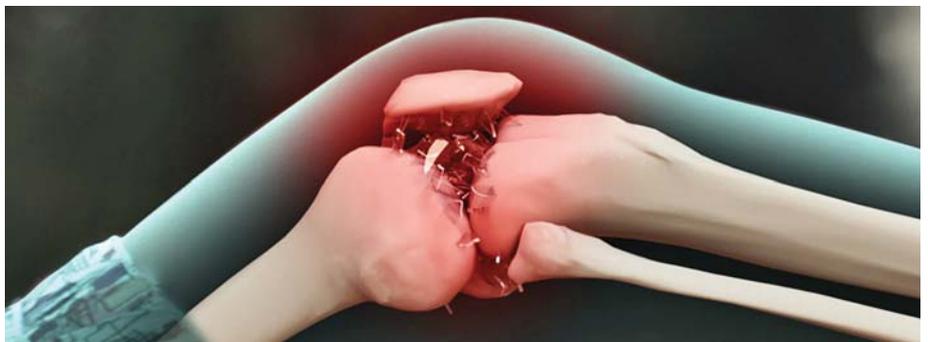
But even if you don't have this background, you may be able to help out as a pool support volunteer in some locations. They help keep an eye on what is happening during classes, and may also assist some

administrative tasks. Either way, we would love to hear from you. Please phone Arthritis New Zealand on 0800 663 463 if you are interested in finding out more about how you can be one of our valued volunteers.

The latest about pain

Arthritis Educators Dave Cox, Georgina Greville, Jane Messer, and Lettie Neri-Iseli recently attended the 40th Annual Scientific Meeting of the New Zealand Pain Society in Auckland, where they heard some of the latest information about pain. Some of the key points they noted included:

- Obesity is a growing problem, and contributes to musculoskeletal pain: joint pain is said to increase by 10% for every 10kg of extra weight.
- Pain experiences are greatly influenced by emotional/psychological factors.
- Interpersonal relationships are a very important factor in pain management. For example relationships with health practitioners.
- Poor breathing techniques can aggravate a person's experience of pain, so pain



- management should explore proper breathing techniques.
- The COMT gene may predispose people to develop fibromyalgia and other musculoskeletal pain. Amongst other things, this gene is associated with enzymes that influence the function of some neurotransmitters in the brain. There are variations in this gene that may relate to how a person copes with pain.
- Dosage of some painkillers may need to be adjusted to take into account a

- person's ethnicity, as this can affect their effectiveness
- Chronic pain can be likened to a disease of the nervous system.
- Anticonvulsants can be effective in neuropathic pain.
- Transplantation/ stem cell techniques are being examined as possible treatment methods for chronic pain.

Our Arthritis Educators are available to talk to about how to manage pain. Phone 0800 663 463 toll free during business hours.

Notification of Arthritis New Zealand AGM and Election

The 2015 AGM is set for Saturday 21 November and will be held at the Wellington Airport Conference Centre. Registrations will be available on our website in June or by phoning Karen Baker on 0800 664 463

The Arthritis New Zealand Election for 2015 will be calling for nominations for:

- 1 x President
- 1 x Northern Representative

And the Regional Liaison Group members for: Northern, Midland/Central, and Southern

Nomination forms and details will be available in June on our website and through Karen Baker, Secretary/PA, on 0800 663 463.

Our newest Governing Body member

Arthritis New Zealand's newest Governing Body member, Steven Renata, was born in the small Northland town of Kawakawa, but grew up in Milton, Otago. He takes pride in both his Maori and Pakeha heritage. Steven now lives in Kumeu, West Auckland, with his wife, Susan, and daughter Grace. In his spare time he enjoys cycling, music, food, viticulture, and travel.

In 1994, Steven became one of the first Maori to graduate from the University of Otago with Masters degree in Marketing. This followed with a short career in Maori tourism

at Auckland University of Technology, and considerable experience in governance and management with various companies in the Les Mills group.

Steven is now the Global Business Development Director, KIWA® is the world's leading production house for experiential digital books, and is a business consultant and executive wellness coach in his spare time.

Arthritis New Zealand is delighted to have Steven on its Governing Body, and welcomes the expertise in education, fitness, and wellness he brings to us. And Steven is very



Steven Renata

keen to be a cultural advocate, and embrace these nuances to strengthen the kaupapa of Arthritis New Zealand.

Being on the Governing Body

Roy Tiffin is a Wellington-based independent Chartered Accountant, who has spent 40 years in various auditing roles in the UK, South Africa, and New Zealand, prior to setting up his own independent practice 11 years ago. He was an Audit Partner at KPMG in Wellington from 1999 to 2004, and formerly an Audit Partner at Deloitte in South Africa. He was a Director of Audit New Zealand from 1994 to 1999. Roy is a Fellow of the New Zealand Institute of Chartered Accountants (NZICA), and served as their President in 1995.

Roy has also been a member of audit committees of a number of public sector bodies, including Auckland Council, Ministry of Education, New Zealand Defence Force, and The Treasury, and undertakes consulting

work for a variety of organisations in New Zealand.

Roy has a personal interest in arthritis, given he has osteoarthritis in his knees, and has lived with gout since he was 35. He was co-opted as an external member of the Audit and Risk Management Committee of Arthritis New Zealand for over eight years, which gave him a great background into the culture, before he stood for and was elected onto our Governing Body, where his accounting and audit knowledge and experience are tremendously useful to the organisation: Roy is currently the Chairperson of our Finance, Audit and Risk Management Committee.

Roy finds his time on the Governing Body extremely rewarding, and encourages any member who



Roy Tiffin

believes they may be able to contribute to the governance of Arthritis New Zealand, to consider putting themselves forward for nomination.

Why take fish oil?



Always read the label and use as directed. If symptoms persist see your healthcare professional. TAPS PP6477

If you're one of the many Arthritis New Zealand members who have experienced some benefit from taking fish oil, you may be wondering why you came to need fish oil (omega-3) supplements in the first place?

The bottom line is, the majority of New Zealanders still don't eat enough fish.

Although, for many years, health professionals have advised 2-3 fish meals a week (every week), most people don't manage that for various reasons – cost, taste and boredom included! That means they miss out on the Ministry of Health's recommended daily intake of omega-3 fatty acids and eventually, can develop a deficiency.

Omega-3 fats are essential to overall wellbeing. In the case of joints, they support lubrication, comfort and mobility. They are also important for heart health, supporting healthy blood fats, and the brain's mental clarity and focus.

Blackmores has a range of high quality fish oils designed to support healthy

omega-3 levels and meet a variety of needs -

Blackmores Omega Daily is a convenient high strength, concentrated fish oil that provides a recommended daily intake of omega-3 fats in just one capsule. Blackmores Omega Daily bottles bear Arthritis New Zealand's gerbera, as Blackmores contributes 5% of sales of this product to Arthritis New Zealand.

Blackmores Omega Triple is triple strength so those who require large doses of fish oil can achieve it with fewer capsules. One Omega Triple capsule is equivalent to three standard fish oil capsules. Taking a large dose of fish oil becomes a breeze and super convenient.

Blackmores' latest release is Odourless Fish Oil Mini Caps. They're half the size of standard fish oil capsules but the same strength. They are perfect for those who don't like swallowing large capsules or for

children who can manage a smaller capsule more easily.

Blackmores fish oil is quality assured. It is sustainably harvested using whale and dolphin friendly techniques. Extensive testing ensures purity and freshness. They are made naturally odourless using vanilla and lemon. No artificial preservatives, flavours or colours are added.

Keep an eye out for Blackmores new easy-to-open amber tubs which help protect large quantities of fish oils from moisture and oxygen. They're easy to open because the smaller cap fits more snugly under the palm of your hand, and have an in-built grip at the bottom of the pack. The innovative new packaging has won several awards, including a prestigious World Star global packaging award and gold, silver and bronze awards in the Australian Packaging Design Awards, for the categories of Health and Beauty, Accessibility, and Consumer Experience & Emerging Technology, respectively.

Golden Jubilee

Don't forget 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!

Planning for celebrations is well underway, but activities currently being planned include: our 50th Jubilee Conference, which will be held in Wellington from Thursday 18 to Saturday 20 February 2015 (with the public day on Saturday 20 February), an Arthritis Awards function, a special commemorative stamp, a special 50th Jubilee membership card, and much more! See the next issue of *Joint Support* for further information.

Obituary: Gordon Michie

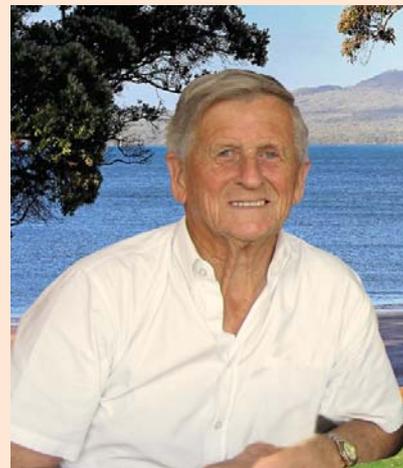
Gordon Michie was a significant supporter of the work and activities of Arthritis New Zealand and an interest in our work in Auckland for over 30 years and his death last month is a great loss to the organisation.

Gordon first became involved with us when Ruth his late wife was diagnosed with rheumatoid arthritis in 1982. At a time when treatment options for RA were relatively limited Gordon provided outstanding support to Ruth and became involved in helping others with arthritis. Gordon was a steadfast help-mate for Ruth-when travelling overseas he took on the task of pushing her wheelchair wherever they visited and stood with her during the times of pain and discomfort.

He and Ruth were very involved in the North Shore Support group and became well known to us

as a couple who would always go the extra mile to provide support and assistance to people with arthritis. They helped with the annual appeal on the North Shore, and became involved in all facets of the organisations work. Their generosity caused them to be called the guardian angels of the Auckland Division and when Arthritis New Zealand became a unified national body Ruth and Gordon were awarded the National President's Award in 2005 in recognition of their service and dedication.

Gordon remained a stalwart supporter after Ruth's death and had indicated to the organisation that he had left a bequest in his will. When he became ill earlier this year it was his wish that he make that gift while he was alive. A 'living gift'. We were unable to thank Gordon personally for his



The late Gordon Michie

generosity as he was too ill for us to visit, but we valued his thinking of us at this time and wanting to fund the work he was so keen to see continue.

We extend our heartfelt condolences to his family- he was a wonderful person who will be dearly missed.

Hon Michael Woodhouse made Honorary Life Member

In December, Joint Support reported how Arthritis New Zealand was thrilled that Hon Michael Woodhouse was elected an Honorary Life Member at its AGM.

Honorary Life Memberships are only awarded to persons who have rendered outstanding service to Arthritis New Zealand, so this was a considerable honour. But also one that was well deserved. Michael was the founding facilitator of the Parliamentary Friends of Arthritis Group, which was established in 2010. This cross-party group gives us a much needed voice in Parliament.

Michael was presented with his Honorary Life Membership by Arthritis New Zealand CEO Sandra Kirby at a special function in Dunedin in March.



Hon Michael Woodhouse receives his Honorary Life Membership from Arthritis New Zealand Chief Executive Sandra Kirby

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. And you need to make this decision yourself. Not leave it to others.

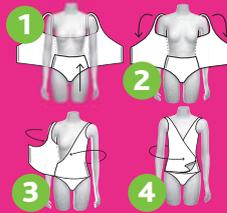
Once you have taken care of those who are close to you, you may like to remember Arthritis New Zealand. We are always overwhelmed when we receive advice of a bequest. These gifts ensure our work continues for generations and confirms the importance of supporting the 578,000 New Zealanders with arthritis.

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.

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3 torso lengths per size
- Choice: modest cut or box leg
Navy, black and two new prints

Enjoy the many benefits of water exercise - easing pain, keeping joints mobile, reducing weight, staying active - without the struggle to get in and out of your swimsuit, with a SlipOn swimsuit.

This world-wide patented design features an attractive double-wrap around bodice with adjustable pleating for figure flattering style and comfort. The quality, four way stretch fabric retains its shape for many seasons of swimming. Best of all it really does take just minutes to slip on and off.

SlipOn[®]

The revolutionary swimsuit that simply slips on and off!

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www.sliponswimsuits.com or 0800 754 766

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

My details:

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Last name:

Mailing address:

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

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Arthritis New Zealand
PO Box 10020
Wellington 6143

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.

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

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

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