

# JOINT SUPPORT

ARTHRITIS NEW ZEALAND NEWSLETTER JUNE 2017



## *Acknowledging the different faces of arthritis*

## Will you be able to work until you're 70?

As we debate the age of entitlement for national superannuation and consider the social and economic impact of an ageing population, Arthritis New Zealand is looking at the impact of such trends and policies for people who have arthritis.

Along with AUT's Centre for Active Ageing, we sponsored a seminar in Auckland featuring Dr Rupendra Shrestha, a Senior Research Fellow at the Faculty of Pharmacy at the University of Sydney.

Dr Shrestha focused on the impact of health issues like arthritis on the work force of the future. While he used Australian research in his presentation, the trends and issues apply equally to New Zealand.

The research showed that:

- The working age population is shrinking. In 2010 there were about five people of working age to one person of pension age but by 2050 this will change to 2.7 workers for every pensioner.
- Long term health conditions are a significant factor in preventing people from staying in the workforce as they age.
- Arthritis is the second most common condition associated with not being able to work; chronic back pain tops the list.
- Health policies that target prevention or treatment of chronic conditions could enable people to stay at work and save significant costs in lost productivity. Factors like employment capacity and patient wellbeing

could be included alongside medical outcomes in clinical trials.

- Employment policies should not be separated from health priorities as they have been in the past.

To address these issues, health care needs to be treated as an investment that brings significant social and economic benefits by encouraging people to stay in the workforce longer.

Early diagnosis and intervention are vital and this will require more resources for management of chronic conditions, especially osteoarthritis. Other issues that were raised at the seminar included the need to consider the effects of heavy



**Rupendra Shrestha**

physical labour on a person's ability to work until the age of 70; the value of volunteering and caring roles that older people may not be able to carry out if they are still working; and the expectations on people as they age. Health initiatives may make it easier for people to work until they are 70 but social and personal expectations also need to be considered.

### **The cost of lost productivity**

Lost productivity accounts for 63 percent of the indirect cost of osteoarthritis. It includes:

- Loss of personal income and the impact on living standards and savings
- Loss of government tax revenue
- Increased government costs in the form of welfare payments.

Effective treatment and management of long term health conditions such as arthritis can have positive economic benefits both for individuals and governments.



**ARTHRITIS  
NEW ZEALAND**

KAIPONAPONA AOTEAROA



## From the President

One of my roles is as a researcher. Every piece of research – be it about exercise programmes, health treatment or climate change – sets out to answer a specific question. You may have noticed that research reports often end with the statement, “More research is needed in these areas.” Is this just because researchers want to drum up more business? Not necessarily. In my experience, when you ask and answer one set of questions, it often leads to more.

That has certainly been our experience at Arthritis New Zealand. When we reviewed our strategic plan last year, we asked you a number of questions. Some of these questions had easy answers and others led to more questions. One area for review by the Governing Body is the issue of membership and the Regional Liaison Groups. This process has raised a number of questions and we are seeking views from interested members over the next month or so. Look out for the item in this newsletter and let us know if you want to be included in the meetings and discussions. This is an important time for our organisation.

At a national level, of course, the parliamentary election is drawing near. We have all agreed that advocating for the needs of people living with arthritis is a key activity for our organisation. Yes, we want Sandra and her team to ask questions of politicians and help shape and change policies. But the strength of a patient group like Arthritis New Zealand is that the people living with arthritis (that means you) also show the politicians that the citizens of New Zealand care about these issues.

Some of you have kindly responded to our online surveys about which issues you think we should pick up on. I hope you see your concerns reflected in this newsletter. You can also do your bit by asking candidates in your electorate questions about their health policies.

When we have answered today's questions there will be more. We are working together to improve the lives of every person affected by arthritis – all 624,000 New Zealanders.

We will continue to ask questions and seek answers until the day when arthritis is well treated, early intervention and treatment are provided, and people can live full lives unfettered by their condition.

I heartily agree with Albert Einstein, who said, “The important thing is not to stop questioning.”

*“The important thing is not to stop questioning.”*

–Albert Einstein

A handwritten signature in black ink that reads "P. J. Larmer". The signature is written in a cursive, flowing style.

**Peter Larmer**  
President

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## From the Chief Executive

Kia ora tatou

“Are we there yet?” If you have ever undertaken a journey with small children you will recognise this question. They often ask it when the journey has barely begun rather than when it’s nearly complete.

We could say the same about our call to have arthritis recognised as the leading cause of disability amongst adult New Zealanders. In the 2014 election campaign, the National Party promised additional funding for musculoskeletal health in a move that caught many people by surprise. The integrated national paediatric rheumatology service was a hard-won gain a few years earlier. In 2016 musculoskeletal conditions were included in a list of long term conditions that require better management to improve the health of New Zealanders. It is worth noting here that the term ‘musculoskeletal conditions’ is quite a mouthful and covers more than just the 140 forms of arthritis. However, arthritis is the major contributor to musculoskeletal health so when you see this term, you can read arthritis into it.

Such recognition at government level that arthritis is a major health concern represents significant progress after more than 10 years of advocacy. But the journey has barely begun. Meetings with Ministry of Health officials and responses from the Minister of Health give no indication of when any additional resourcing will follow the recognition.

Don’t get me wrong – the extra funding since 2014 for more hip and knee replacement surgery and Mobility Action Programmes is welcome. In many ways, the Mobility Action Programme funding, though very small, is the most significant because it targets early identification

and treatment for osteoarthritis. This is where we are likely to make significant improvements in health and reduce long term costs for individuals and the community.

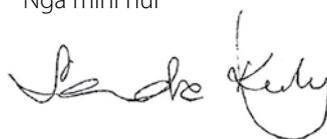
That said, if we really are going to be able to improve the lives of all people affected by arthritis (our goal) and be good at identifying key health problems, preventing them or slowing their deterioration, and keeping people well (the Health Strategy goal) we need to continue to advocate on your behalf.

*“We will keep going — because we aren't there yet.”*

The number of people living with arthritis is growing, according to personal feedback and Ministry of Health data. Early intervention and treatment are not yet being provided. Many of you experience just how stretched our rheumatology services are around the country. We saw how fragile specialist services are after losing two rheumatologists in the Manawatu and waiting almost a year for replacements to arrive.

We will keep going – because we aren’t ‘there’ yet. We can see the signposts that tell us we are on the right track but we need to keep up the momentum and stay focused.

Ngā mihi nui



**Sandra Kirby**  
Chief Executive



### In this issue

- 1 Will you be able to work until you're 70?
- 2 From the President
- 3 From the Chief Executive
- 4 Psoriatic arthritis webinar success
- 5 Growing up with juvenile arthritis/ Children's Camp
- 6 Kapa haka festival
- 7 Hydrotherapy pool/ Madeline turns 110
- 8-9 Election special
- 10 Research: Joint damage in gout
- 11 Reaching out to Asians/ Bequest giving
- 12 Northland gout clinics/ Medications update
- 13 Important issues survey form
- 14 Snippets from around the world
- 15 Members & supporters review/ Yes, I want to donate
- 16 For further information...

## Psoriatic arthritis webinar success

Our first webinar on 4 April was a huge success. A total of 79 people registered to listen to a panel discussion on psoriatic arthritis (PsA) hosted by Errol Pike. Guest speakers were rheumatologist Dr Andrew Harrison and consumer representative Sarah Davey.

About 45 people attended online and most stayed for the whole of the hour-long presentation, including question time. Average attentiveness was 86 percent overall – a ‘top of the class’ result for webinars, so well done to everyone who took part.

Most of the participants completed the survey at the end of the webinar and rated it very highly for interest and information. Again, this result was well above the global average for feedback on webinars. Key results were:

- Almost 94 percent of participants thought the presenters were engaging and effective
- 100 percent thought the content was informative and practical
- 87.5 percent would like to learn more about psoriatic arthritis in future webinars

- Almost 97 percent would recommend Arthritis NZ webinars to a friend or family member.

Here are some of the comments from participants:

*“This was wonderful – thank you and congratulations. As a health professional I would be interested in any future webinars on any topic relating to arthritis.”*

“I enjoyed listening to the speakers. As stated, this is a rare form [of arthritis] and it is not easy talking it through with others. It is nice to know that there isn't something wrong and that we don't make things up for sympathy.”



“My first webinar. Great experience. Loved that I could just log in at home. Great reception, clear pictures. Liked the screen shots/slides and surveys. Good length of time. Can read this material I know, but hearing it from a person is much better. Well done, team.”

## Q and A: what you need to know about webinars

**Q:** What is a webinar?

**A:** A webinar is a live online seminar. You can view the speakers and slides on your laptop, computer or tablet and you can even ask questions!

**Q:** How do I access a webinar?

**A:** We will advertise the next one by email, on Facebook and on our website and you can register that way.

**Q:** Do I need a webcam?

**A:** No.

**Q:** Do I need to download or buy software?

**A:** No, access to the webinar is free.

All you need to do is click on the link on your laptop or use the GoToMeeting App on your tablet or iPad to gain access.

**Q:** How do I ask questions?

**A:** You can type in your questions using the messaging function of the programme. Only the speakers and panel can see your questions – not the other webinar attendees.

**Q:** Can anybody else see me?

**A:** No, the speakers and other participants can't see you.

**Q:** Will I be able to watch again later?

**A:** Yes, a recording of the webinar will be available on our website.

**Q:** Are there going to be more webinars? If so, how often?

**A:** We would like to host a webinar every month or two. Watch this space!

**Q:** Can I suggest ideas for future webinars?

**A:** We'd love your ideas for future topics. To make a suggestion, phone 0800 663 463.

## Growing up with arthritis

Briar's parents, Abby and Scott Matley, felt terribly guilty when she was diagnosed with a form of JIA (Juvenile Idiopathic Arthritis) two years ago when she was 12. They thought her achy joints were just 'growing pains'.

Since then, while they've learnt a lot about the condition, it's been important for them to walk the journey of arthritis together as a family, one day at a time, and surround Briar with as normal a life as possible.

Attending camp this year was part of that process. "Overall it was a brilliant experience, not only for the kids, but for parents as well. Being surrounded by others going through similar experiences brings a sense of normality," says Abby.

At their first camp last year, the Matleys enjoyed being with people who understood what they were going through, as Briar's diagnosis was new and hard to explain to others. Their daughter was able to relate to others and make

friends. "When Briar was first diagnosed we found we didn't talk about it with family or friends unless we were asked as we felt it was a 'downer' on the conversation."

*"It doesn't get easier, but we have learnt to cope better."*

This year, Abby and Scott gained as much knowledge as they could from specialist speakers and youth leaders to help overcome the feeling of helplessness in the face of a chronic disease. Briar loved the camp so much that she wants to become a youth leader herself in a couple of years.

"You just have to keep putting one foot in front of the other. Gaining more



**Briar – enjoying a balanced lifestyle.**

information on JIA gives insight that there is light at the end of the tunnel," says Abby.

Briar's JIA condition is now stabilised, thanks to fortnightly injections of the biological drug Humira. She is now learning how to lead a balanced lifestyle while dealing with chronic pain. Briar attends a supportive school – she is able to keep up with her school work and was chosen to be a team leader this year.

## Children's Camp

In early March, 26 families, 6 youth leaders and a number of volunteers gathered at Totara Springs in Matamata for the annual Children's Camp – a weekend full of fun and information.



**A helping hand is always welcome.**



**Teamwork in the Toptown activity.**



**Learning to trust on the Burma trail.**



**Rhemus, TP and Azalay whoop down the waterslide.**

## Te Matatini 2017

Among the 50,000 people who attended the four-day kapa haka festival, Te Matatini, in the Hawkes Bay were Tui Tararo (Community Development Manager) and Marion Pawson (Arthritis Educator). Tui and Marion were part of the Hauora 'Wellbeing' Village where they had conversations about arthritis with around 450 people over two days at the end of February. Joint Support asked them about their experience:

### What was your main message?

Tui: We talked about how gout is more about genetics than what you eat. It's not a 'punishment' for being greedy or enjoying your food! We also stressed the role and importance of medication. Our aim was to dispel some of the myths and entrenched guilt about gout. You could see a lot of pennies dropping as we talked to people.

Marion: What stood out for me was that we were able to restore people's dignity around something that has been shameful for them. It was humbling and inspiring to be able to contribute to people's understanding of the real causes of their condition.

### How did you present information about arthritis?

Our theme was gout and how to deal with it in the family. We couldn't give out handouts or booklets because the village had a paper-free policy so we basically just sat with people and engaged in conversations, face-to-face, which was very appropriate. We gave away gerberas with the Arthritis NZ website address on them and each day, people could go in the draw for a pamper pack of basic self-care items that help relieve pain.

### How did people respond?

Some people were amazed and asked us, "Why didn't we know this before?" Others introduced us to their whānau so we could talk to them too. Some of the men hung around but didn't approach us directly until the second day when they'd finally plucked up the courage to come and see us. In the visitor feedback, we topped the list both days as the "most memorable" aspect of the village, so that made us feel good about our efforts!

### What were the highlights for you personally?

Marion: As a pākehā it was valuable for me to be able to relate to Māori at a high-mana event and in a way that respects the oral nature of their culture. Some of the conversations ended with a hongi and that was very special.

Tui: For me, the festival highlighted that we have a lot of work to do but we're on the right track now. It reinforced how important this work is and the need to look at ways we can continue to engage with Māori and Pasifika people in their own contexts. I'm aware that we're building on the work of previous colleagues in many respects, and I'm grateful for that because it will help open doors in future.



Eve Moana with the pamper pack her twin sister Dawn Kireka won at the Arthritis New Zealand stand. The pack includes a bucket and Epsom salts for soaking feet, oil and marbles for massages, and rubber gloves for protecting the hands.



## Horowhenua pool proves its worth

A hydrotherapy pool at the Levin Aquatic Centre represents the way of the future for Arthritis New Zealand and it's already proving successful.



**Students and balloons**

Instead of running water-based exercise classes ourselves, eight pool staff have now been trained to deliver the service. Most classes are fully booked and physios are regularly taking clients to the pool for rehabilitation.

Aquatics Manager James Richmond says that as well as receiving plenty of positive feedback from the public, pool staff get a kick out of knowing the pool helps improve the quality of life of those who use it. "Being able to provide such health and social wellbeing benefits cannot be measured in dollars," he said.

Our staff and volunteers played a key role in lobbying the local council for the pool after Horowhenua Hospital closed its facility in 2006. With encouragement from Tui Tararo and the Levin Arthritis Support Group, a petition signed by 2254 local residents was presented to the then Mayor, Brendan Duffy. After lots of submissions, meetings, discussions, emails and planning, a new purpose-built hydrotherapy pool was finally approved in February 2016.

The Aquatic Centre reopened on 24 September 2016 after a 3-month major refit to include the new pool. Arthritis New Zealand raised \$980 on opening day for a disability hoist, with the help of some health and disability students from the Horowhenua Learning Centre.



**The disability hoist at the newly reopened Levin Aquatic Centre hydrotherapy pool.**



## Madeline turns 110

Former member and donor Madeline Anderson reached the grand old age of 110 on 4 May. She is believed to be the oldest living New Zealander.

"It rather surprises me that I managed to get to this old age, but here I am, feeling not so bad," she said.

*"It's been a wonderful life."*

Madeline McKenzie Orłowski was born in Dunedin in 1907, the eldest of four sisters. She and husband Harry had three children: sons Graeme and Brian both died young in road accidents; daughter Heather visits every week.

Madeline still lives in her own home in Upper Hutt, managing with the help of family, friends and support workers. "They say there's a time to be born and a time to die. My time to die apparently hasn't arrived yet. I've got a wonderful lot of friends who are so helpful and make life worthwhile. I've had so much love and friendship, it's been a wonderful life."

Happy birthday, Madeline, and congratulations from Arthritis New Zealand!

-Stuff



## Advocating for arthritis as a health policy priority

Arthritis New Zealand was delighted to see musculoskeletal health included with other long term conditions in the New Zealand Health Strategy. In meetings with Ministry of Health officials however, there was no sign that additional funding will match the promise, apart from a small amount for Mobility Action Programmes. A key priority for us, especially in election year, is to make sure that the needs of people living with arthritis also become a real priority for the Government and those involved in developing health policies. We will continue to lobby all parties in Parliament during this year and beyond.

In advocating for more funding to go towards services for people affected by arthritis, we need to consider arguments about the cost of health care, and recognise that resources are not infinite. Todd Krieble, Principal Economist at the New Zealand Institute of Economic Research (NZIER) spoke at the Medicines New Zealand Symposium recently. He asked some hard questions about how the health dollar is currently spent and whether it matches identified health needs. His presentation is summarised below.

### How effective is our health expenditure?

Our health care system is driven by supply side factors such as the physical, financial and human resources required to operate hospitals, while the demand side is driven by the desire of people to remain healthy and keep out of hospital. Given the need to achieve a balance between supply and demand we need to ask:

### Is our system effective?

Current health targets do not align with the conditions that impact the most people. For example, musculoskeletal conditions affect a significant number of people but improved access to elective surgery is the only health target that addresses this. Early intervention and treatment to help avoid the need

for surgery is not a priority at present. (Arthritis New Zealand advocates that such surgery should be a last resort). In other words, current health spending does not match health needs.

### Are we doing this at the least cost?

There is a high cost to maintaining 20 DHBs in New Zealand compared with other places that have far fewer, such as British Columbia which has a similar population to ours but only six DHB equivalents. Furthermore, significant percentages of New Zealand DHB income go to other DHBs. (For Auckland DHB the figure is 37 percent.)

Some services already operate nationally and others operate regionally, resulting in an extra layer of administrative costs. This consolidation is occurring because some services are just not viable when dispersed across 20 DHBs.

Reporting requirements add to the operational costs. Also, why are some DHB members elected? We do not elect people to oversee welfare or housing at a local level yet we spend millions on running elections for DHBs. A breakdown of overall voter turnout at DHB elections does show a higher turnout in smaller DHBs such as Whanganui and West Coast, perhaps suggesting that smaller communities feel more connected to



Todd Krieble

their DHBs than in the larger metropolitan areas (Sources: Ministry of Health, Department of Internal Affairs, State Services Commission).

### Are we making choices about equity?

Some groups are missing out in the health spend. When we look at unmet need for primary care in the past 12 months, we see that people in the most deprived neighbourhoods are missing out the most. More surprising are the reasons for needs being unmet – results show that the inability to get an appointment within 24 hours at one's usual medical centre ranks above the cost of visiting a GP. Again, unfilled prescription data shows that neighbourhood deprivation is the most common contributing factor in people not collecting their prescriptions.

*Continued on page 9*

# We did ask...

In preparation for this 'election special' issue of *Joint Support*, Arthritis New Zealand approached the main political parties for comment on their campaign health policies as they relate to musculoskeletal health issues. We asked National, Labour, the Greens, New Zealand First, the Māori Party, United Future and Act the following question:

**What will your party do to resource musculoskeletal health issues in the next three years?**

These are the replies we have received so far.



**The Green Party**

The Green Party is acutely aware that over the past nine years the Government has under-funded health services by more than \$1.7billion. We are committed to ensuring that health sector funding keeps pace with increasing health need, and in particular, to increasing resources for community-based services. The capacity and quality of many services has been eroded, including home-based support, respite and day-support services.

**Julie Anne Genter**  
Green Party health spokesperson



**New Zealand First**

New Zealand First supports the New Zealand Health Strategy recommendations. We have been calling for an independent review of the health system and its funding. All New Zealanders must be able to access good healthcare including people with musculoskeletal health issues. Investing in new technologies and medicines will shape the health sector for the coming decades so spending smarter must be a focus in the health sector.

**Barbara Stewart**  
New Zealand First spokesperson for Health, ACC, Family and Disability issues



**The Māori Party**

We share your concerns about the incidence of gout in Māori and Pacific people in Aotearoa and the inequitable treatment for gout. We also agree that more resource is required to increase access to equitable treatment for Māori and Pacific who suffer musculoskeletal health issues and we intend to continue to advocate in this area, among others, where inequalities for Māori and Pacific exist.

**Hon Te Ururoa Flavell and Marama Fox**  
Co-leaders of the Māori Party

*Continued from page 8*

Interestingly, non-collection declines as people age and the greatest non-collection rates are in age groups under 44 years (Source: NZ Health Survey, Ministry of Health).

**What next?**

Todd Kriebel argues for the need to re-think current health priorities, cut down on the administration of healthcare, and consider how some inequities may be reduced.

*Todd Kriebel has a wide ranging policy background, including interests in health, environment and cultural policy. He has held senior management positions in a number of government agencies. Todd chaired the Officials' Social Policy Committee and led work on the establishment of national health targets. He currently serves as Principal Economist for the New Zealand Institute of Economic Research. The presentation summarised above will be the subject of an upcoming NZIER Insight article.*

[www.nzier.org.nz/people/todd-kriebel](http://www.nzier.org.nz/people/todd-kriebel)

**Election advocates**

If you are interested in joining our election advocates, please call Arthritis New Zealand **0800 663 463** and leave your contact details.

## Joint damage in gout: insights from laboratory studies

Gout is the most common inflammatory arthritis affecting New Zealanders, with very high rates in Māori or Pacific men. Gout is caused by urate crystals in the joints; these crystals form when urate levels in the blood are high. If urate levels remain high and the crystals persist in the joint for a long time, gout can lead to joint damage and disability. Bone damage is commonly seen in people with a lot of urate crystals.

Dr Chhana and the team in the Bone & Joint Research Group investigated the effects of urate crystals on different bone cells. These include “bone-eating” osteoclast cells and “bone-forming” osteoblast cells. Both cell types are needed for healthy bone and usually the activity of these two cell types is balanced, so that the total amount of bone remains unchanged. In joints that are affected by gout, there are more bone-eating osteoclasts and fewer bone-forming osteoblasts present.

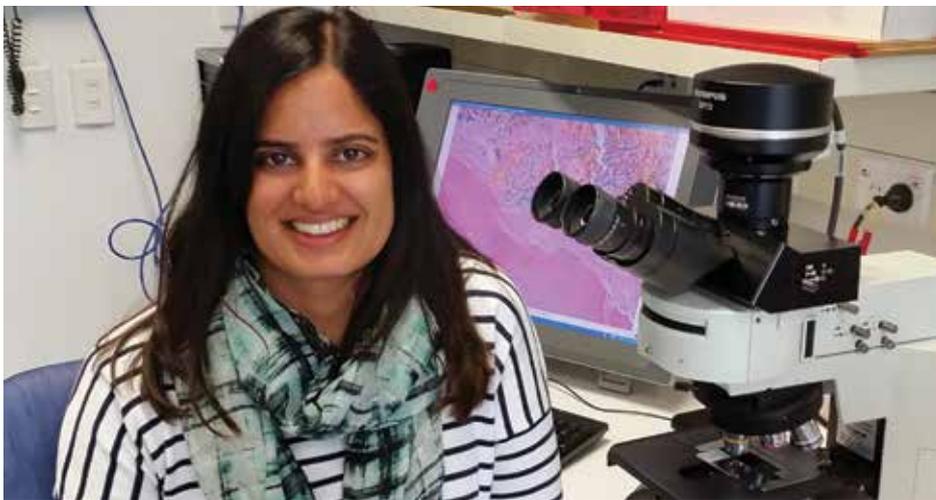
Dr Chhana has also shown that urate crystals are very toxic to the bone-

forming osteoblasts, causing them to die prematurely, and changing their behaviour so they are no longer able to make healthy new bone. Together, these findings suggest that urate crystals in gouty joints can directly contribute to bone damage by increasing the amount of bone which is eaten by osteoclast cells, at the same time as reducing the amount of new bone produced by the bone-forming osteoblast cells.

As long as urate crystals remain in the joint, bone cells will continue to be negatively affected. This limits the ability of the joint to heal and properly

repair itself once it has been damaged. Treatment that removes urate crystals from the joint (such as allopurinol) can prevent the development of joint damage and may allow the joint to start repair processes.

*Dr Ashika Chhana (PhD) is a research fellow in the Bone & Joint Research Group at the University of Auckland. Dr Chhana has been doing laboratory-based gout research for the past eight years with Professor Nicola Dalbeth. The focus of her work has been to understand how joint damage occurs in people with gout.*



Dr Ashika Chhana in her laboratory at the Department of Medicine, Auckland University.



X-rays of the hands of a patient with severe gout. Sites of bone damage are marked with arrows.

Arthritis New Zealand is grateful to be supported by:



# Reaching out to Asian communities

A key part of Arthritis Educator Jane Messer’s role is delivering education programmes to Asian communities in the Auckland region. Last year, Jane spoke to members of the Chinese, Korean, Indian and other South East Asian communities.

Jane is a Registered Nurse and often works with a translator. “A lot of people can speak English but it’s more meaningful for them and they engage more with the information if they can hear it in their own language. It’s great that we can contribute to existing Asian support networks by providing these opportunities,” she said.

The highest number of programmes was delivered to Chinese and participants said the programmes were relevant, informative, interesting, useful and helpful.

Asian people currently make up 29 percent of Auckland DHB’s population of 468,000. In the Auckland region as a whole, one in three people are likely to

identify as Asian in 2038 – up from about one in four in 2013. People of Asian origin will be the biggest ethnic group in several parts of the city.

Education programmes were delivered in partnership with the Asian Network and other services, health providers and Sport Auckland GRX (Green Prescription) programmes. They will continue to be delivered in the Auckland region as long as grant funding permits.

## References:

[www.adhb.govt.nz/About/population\\_stats.htm](http://www.adhb.govt.nz/About/population_stats.htm) (Feb 2016)

[www.stuff.co.nz/national/72557057](http://www.stuff.co.nz/national/72557057) (Sept 2015)



Arthritis Educator Jane Messer delivers education programmes to Asian communities.

# Bequests

Do you have a current Will? There are many reasons to make sure you have a valid, up-to-date Will.

The first, of course, is to protect loved ones. 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 provided for loved ones, you might like to remember Arthritis New Zealand in your Will. We are always grateful when we receive advice of a bequest. These gifts mean your legacy continues for generations as you support the 624,000 New Zealanders with arthritis.

If you would like to talk to someone about leaving a gift to Arthritis New Zealand in your Will, or would like more information, please phone Dianne Armstrong on 0800 663 463 or email [dianne.armstrong@arthritis.org.nz](mailto:dianne.armstrong@arthritis.org.nz)

*Saying goodbye is never easy. Arthritis New Zealand is grateful to those who ask family and friends to donate to us in lieu of flowers. These generous thoughts and donations help fund our work for all, young and old, who live with arthritis.*

## Wanted: Advocates for arthritis

*Would you like to become more closely involved with Arthritis New Zealand?*

Do you want to help us spread the message about the important issues for those living with arthritis?

Please call us for an advocacy registration form:

**0800 663 463**



## Hokianga gout clinics

Communities in the Hokianga welcomed Arthritis Educator Georgia Grant-Mackie and Regional Coordinator Sue Baker to their region in late March.

The pair spent a week in rural areas around the harbour, meeting locals and spreading the word, mainly about gout. They based themselves at health clinics and spoke one-to-one with patients or informally with people in waiting rooms or outside.

Georgia said the need for information and support is huge. "While our focus is gout, it was obvious that many people, especially the older ones, need help with osteo and rheumatoid arthritis as well."

*"They've spent years just putting up with the pain."*

Many benefited from hints and suggestions about things they could do to help themselves at home. One man, for example, loved the sea but had never thought of swimming as a way to exercise and relieve his pain.

The high turnover of GPs is a challenge for the area as it compromises consistency of service. Arthritis New Zealand works closely with community health workers and kaimanaki tangata to help build bridges between patients and the healthcare system.

"Our service is so important, especially for people in rural communities. The people understand that they are isolated and appreciate our efforts to visit them. They are so welcoming and generous and grateful for what they have. It was a real privilege to be able to encourage them and I felt humbled by the many stories of resilience I heard," Georgia said.

The team is exploring ways to continue to be involved with Northland communities, possibly through workplace visits or attendance at sports games.



Georgia with Uncle John and Aunty Icy from Rawene.



In Mangamuka with Redden Ogle (left) and Oneroa Pihema (right).

## Medications update

Celecoxib Pfizer (formerly known as Celebrex) will be funded by Pharmac from 1 June.

This means patients will be able to get Celecoxib Pfizer at the subsidised price from their community pharmacy. A prescription will still be required. We understand that there are no changes to the funding of other NSAIDs. Doctors can still prescribe other unfunded Cox-2 inhibitors for those patients who choose to pay for them.

See Pharmac for more information:

[www.pharmac.govt.nz](http://www.pharmac.govt.nz)

And keep an eye on the Family Health Diary at:

[www.familyhealthdiary.co.nz](http://www.familyhealthdiary.co.nz)



## What issues are important for Arthritis New Zealand?

We are running a survey to ask people for feedback on which issues should have priority in our advocacy programme. The survey is available online; this paper version is for those who do not have internet access. Please complete, cut out and return to: Arthritis New Zealand, PO Box 10 020, Wellington 6143.

**1.** These are some of the issues people have raised with us. Please select the three you think are most important for Arthritis New Zealand to focus on.

- Employment issues
- Access to rheumatology
- Accessible packaging
- Access to medications
- Reform of ACC processes
- Access to medications
- Government recognition of arthritis as a health priority

**2.** Are there other issues you would like to see Arthritis New Zealand focus on? (Please specify)

**3.** 2017 is an election year. What would you be willing to do with us to bring arthritis issues to the attention of politicians?

- Write to my MP
- Attend an election meeting and ask a question
- Use social media
- Make an appointment to see my MP and other candidates
- Sign an online petition
- Other (please specify)

**4.** Tell us about yourself. What is your age group?

- Under 20
- 20-30
- 30-40
- 40-50
- 50-65
- Over 65

**5.** What is your diagnosis?

- Osteoarthritis
- Rheumatoid arthritis
- Ankylosing spondylitis
- Reactive arthritis
- Other (please specify)
- Gout
- Fibromyalgia
- Psoriatic arthritis
- I have a child with arthritis

**6.** What is your work status?

- Employed full time
- Employed part time
- Receiving a benefit
- Other (please specify)
- Retired
- Looking for work
- Caring for family

**7.** We would like to have a pool of people available to tell their stories about living with arthritis. Would you be interested in telling your story and attending training?

- Yes
- No
- Maybe

If your answer is Yes or Maybe please enter your email and postal address:

**8.** If you are interested in joining our 2017 election work please leave your email and postal address:

## Snippets from around the world...



### Will cracking your knuckles lead to arthritis?

Cracking your knuckles may annoy other people, but it probably won't raise your risk of arthritis. The "pop" happens when bubbles of gas in the fluid around the joints are compressed. Even if it doesn't cause arthritis, it's probably a good idea to give up the habit. Chronic knuckle-crackers are more likely to have swollen hands and weaker hand grip. And you could hurt yourself, quite apart from driving the people around you crazy.

[www.health.harvard.edu/pain/does-knuckle-cracking-cause-arthritis](http://www.health.harvard.edu/pain/does-knuckle-cracking-cause-arthritis)

### Saving children from blindness

A clinical trial in England has discovered a drug combination that could help thousands of children with arthritis. Around one third of children and adolescents with juvenile idiopathic arthritis (JIA) are likely to develop uveitis, or inflammation of the eye. The drug discovery will help prevent serious complications, including blindness. The trial was the first of its kind in the world and the drug therapy has already been approved for use.

[www.eurekalert.org/pub\\_releases/2017-04/uol-1ct042717.php](http://www.eurekalert.org/pub_releases/2017-04/uol-1ct042717.php)



### Extreme treatment: Scorpion venom

Pepe Casañas, a 71-year-old Cuban peasant, eases the pain of his arthritis with an unusual remedy – scorpion venom. He keeps up to four scorpions near his house (even one in his hat!) so he can sting himself when he needs to, usually once a month. "The sting doesn't hurt me a bit," says Pepe, who is from a family of beekeepers and started using bee-stings to treat his pain. "About eight years ago, I started with this scorpion stuff. My bones were beginning to hurt me and it helped me to feel comfortable."

[www.express.co.uk/life-style/health/796465/arthritis-cure-scorpion-sting-cuba](http://www.express.co.uk/life-style/health/796465/arthritis-cure-scorpion-sting-cuba)

### Depression and knee osteoarthritis

Research from Australia explored the use of internet-based cognitive behaviour therapy for people with knee osteoarthritis and depression. Results showed that internet contact (requiring no face-to-face contact) improved depression symptoms as well

as self-efficacy, pain, stiffness and physical function after three months.

[www.onlinelibrary.wiley.com/doi/10.1002/acr.23257/abstract#](http://www.onlinelibrary.wiley.com/doi/10.1002/acr.23257/abstract#)

## Members and supporters review

Our 2016 AGM agreed to review the role and function of our Regional Liaison Groups, and a taskforce of member representatives has been formed to do this.

They will consider the ongoing decline in membership numbers; the small number of people interested in joining Regional Liaison Groups; and ways for other supporters to have a voice in the organisation.

“Like many other incorporated societies, we need to set ourselves up for the future,” says Peter Larmer, President of Arthritis New Zealand. “Members are generally very long term supporters and we value their commitment. Other supporters such as donors, volunteers and clients now greatly outnumber our members and we need to consider how they can be given a voice too.”

Check out the website [www.arthritis.org.nz](http://www.arthritis.org.nz) to see the background paper. We welcome thoughts and ideas – if you would like to be included in meetings and discussions please call 0800 663 463 and give your contact details.

## Feeling alone?

A question and answer session happens on our Facebook page every Monday evening from 7.00pm to 9.00pm.

Recent sessions have covered parenting with arthritis, managing gout, and significant issues for people with arthritis. If you have a topic you would like covered, send us suggestions on our Facebook page. [www.facebook.com/ArthritisNewZealand](http://www.facebook.com/ArthritisNewZealand)

We also now have an online Facebook group to connect people all over the country to support and learn from each other. If you would like to join this group go to our Facebook page and send a private message or contact us on 0800 663 463.



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

### My details:

First name:

Last name:

Mailing address:

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

Freepost 157311  
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](http://www.arthritis.org.nz).

Thank you for your generosity!

## For further information...

### Call free 0800 663 463

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

### Make a donation

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

### Visit [www.arthritis.org.nz](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.

### Offices

Wellington	Level 2, 120 Featherston Street, PO Box 10 020, The Terrace, Wellington 6143 Phone 04 472 1427
Auckland	Unit B, 383 Khyber Pass Road, Newmarket, Auckland 1023 Phone 09 523 8900
Christchurch	Unit 3, 15 Washington Way, Sydenham, Christchurch 8145 Phone 03 366 8383

### Facebook



[www.facebook.com/ArthritisNewZealand](http://www.facebook.com/ArthritisNewZealand)

### Twitter



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

### LinkedIn



[www.linkedin.com/company/arthritis-new-zealand](http://www.linkedin.com/company/arthritis-new-zealand)

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And our strict ingredient policy means we put the best in and leave out what you don't need – so our odourless, vanilla-flavoured capsules don't include artificial surfactants.



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