

JOINT SUPPORT

ARTHRITIS NEW ZEALAND NEWSLETTER DECEMBER 2016



Acknowledging the different faces of arthritis

Missing, presumed alive

How we found a missing arthritis star 38 years later

Older New Zealanders would remember Telethons.

They were like a huge nationwide party where celebrities and the general public joined to perform all kinds of antics to raise money for a needy cause, on television. The first Telethon ran in 1975 on what was the brand new channel South Pacific Television/TV2.

Telethons ran right into the early 1990s, when changing technology meant that free-to-air TV was ceasing to become the exclusive visual media of the people and no longer had quite the power and pull that it once did.

The young star of the 1978 Telethon was 12 year old Antoinette Black. The cause that year was arthritis, and the money raised was to be given to the Arthritis Foundation of New Zealand.

Antoinette was living with arthritis despite her young age, proof that arthritis is not exclusively a disease of the older person. She sat patiently with front man Peter Sinclair through many sequences in the 24 hour show.

38 years later, in 2016, Arthritis New Zealand was writing a digital book about its 50 years of service to New Zealanders with arthritis. But no-one knew where Antoinette was, in 2016. We had last met with Antoinette when she cut the 25th anniversary birthday cake.

The TV3 prime time evening show Story agreed to help find her if possible.

The show played footage of the 1978 Telethon and asked viewers if anyone could put them in touch with Antoinette.

She ... is a mother and grandmother, and has been on top of her arthritis for many years.

Left to right – Sandra Kirby and Antoinette Hutton



Response was immediate and the first call came in 20 minutes after the end of the show. She now works in the finance industry, is a mother and grandmother, and has been on top of her arthritis for many years. This despite two hip replacements.

The Story programme ran footage of Antoinette and the surprise visit of Sandra Kirby, CEO the following week.

Antoinette was presented with a bouquet that included orange gerberas, which are the emblem of the organisation, and shown the digital book containing the Telethon clips.

Her grandchildren crowded around the screen to watch grandma in action as a 12 year old.

Antoinette Black is a walking, talking example of how arthritis can be managed, and that the person living with it can lead a successful and rewarding life. If Antoinette's becoming a mother and a grandmother, and holding down a job she enjoys, isn't proof enough that people can live with arthritis when it is managed well, then may be nothing is.



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Parliamentary Friends of Arthritis

On Tuesday 20th September friends and colleagues of Arthritis New Zealand, were hosted to a Parliamentary Friends of Arthritis function by Dr Shane Reti, MP.

The function had a two fold purpose, to launch the start of Annual Appeal week and also our 50th Anniversary Digital History Book.

Steven Renata was able to show guests snippets of the book and it is available to download from

<http://tinyurl.com/qcsx3sq>

or alternatively, search the App Store on your Apple device for 'Arthritis NZ'



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Governing Body for 2016/17

There are two new faces on the Arthritis New Zealand Governing Body following the AGM held in Auckland on November 26th.

Cate Grace is the new Southern Regional Representative. Cate is well known within the organisation having been a supporter for many years and received the President's Award at this year's Arthritis New Zealand Awards function. Cate has been living with arthritis since her early 20s. She describes her relationship with Arthritis New Zealand as an important part of her wellness. Cate says "It has always struck me that Arthritis New Zealand is an organisation full of amazing resources, and supports a wide reaching audience. I believe I can offer a personal and professional perspective on managing arthritis, while also representing the organisation into the next strategic phase."

Elly Crispin was elected as the MidlandCentral Regional Representative. Elly works as a Fitness Instructor and Elder Volunteer Coordinator for the YMCA in Tauranga. Elly has helped out with our with street appeals and hosted fundraising events for Arthritis New Zealand. She has worked with other large organisations to create policies and work on community initiatives. "I have the determination and passion to help Arthritis New Zealand grow, promote health to help the community and target all ages." says Elly.

The Governing Body for 2016/17 is:

Peter Larmer	President
Digna Toresen	National Representative
Joe Stanton	Northern Regional Representative
Elly Crispin	MidlandCentral Regional Representative
Cate Grace	Southern Regional Representative
Rebecca Grainger	Appointed Member NZRA
Roy Tiffin	Appointed Member
Martin Lenart	Appointed Member
Steven Renata	Appointed Member

At the AGM outgoing members of the Governing Body were farewelled. Deirdre Lusby ended her term as Southern Regional Representative. President Peter Larmer thanked Deirdre for her passion for the members and supporters of Arthritis New Zealand in the South Island. Laurie Breadmore, former MidlandCentral Regional Representative, has also been an advocate for the community water based exercise classes.

Immediate Past President Alan Henwood ended his term at the AGM. "Alan's legal mind and extensive experience on the Governing Body will be missed. We are grateful for his ongoing commitment to the Fundraising Committee" said Peter.

From the Chief Executive

This time last year we predicted that 2016 would be a busy year – and our predictions were right. From our Awards function at Government House in February right through to our young people performing the ORANGE play at the Tapac Performing Arts Centre in November we have celebrated many events marking the history of this great organisation. We have been incredibly fortunate to have been the recipient of many grants to cover these special events.

Having celebrated the past we now look to the future. The Governing Body have adopted a new Strategic Plan to guide us over the next five years. To be able to achieve these ambitious goals we will be reshaping the way we work.

The review of service delivery undertaken by KPMG and the feedback from the consultation on the Strategic Plan have confirmed that raising awareness of arthritis and advocating for the needs of people with arthritis are key functions for Arthritis New Zealand. We cannot further build our awareness and advocacy functions without directing resources to these functions.

We have been steadily building our phone and digital services. Our 0800 call service operates nationally and we recognise there are some changes required to ensure we provide a timely response to callers.

Our digital service is currently limited to website and Facebook. We intend to extend our capacity to deliver self management programmes online. The contract with the Ministry of Health as part of the Mobility Action Programme will signal a new development in our online services. We also have some funding to deliver online education in specific areas such as pain management. The Department of Internal Affairs is supporting us with a salary for an intern to build this capacity.

While we are signaling a move towards digital services this is not intended as

excluding people who have no access to the internet. Everything that can be accessed on line can also be accessed by calling our 0800 number and having a staff member respond directly.

We are moving from our regional service delivery model to a national service delivery framework. While this could be seen as a significant change in our operations it reflects the transition that has already commenced. Change is not easy but it is the reality of moving forward. John F Kennedy famously said “Change is the law of life. And those who look only to the past or present are certain to miss the future.”

We must prepare ourselves and Arthritis New Zealand for the future if we are to succeed in ensuring that we can achieve our goal of improving the lives of every person affected by arthritis.

The Christmas and New Year season are ones we can reflect on the good things of the past and look forward to the future – I hope that the summer holiday season brings you good company, good cheer and a sense of optimism for the years ahead.

Nga mihi o te Kirihimete me te Tau Hōu



Sandra Kirby
Chief Executive



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High-fat diet results in growth cartilage lesions in a laboratory animal model.

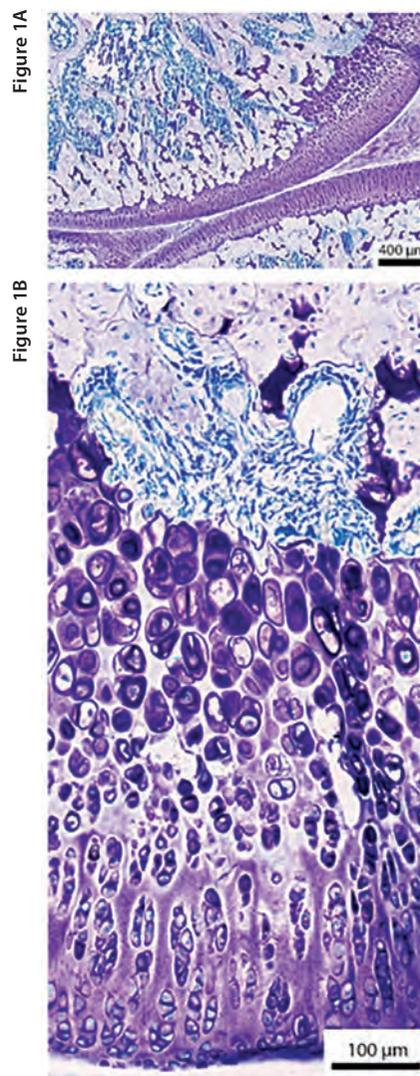
A research project funded by Arthritis New Zealand has yielded some interesting results. The study involves feeding rats a high-fat diet from very early in life. This is because of the large amount of attention now being given to overweight/obese status becoming the most common risk factor associated with metabolic osteoarthritis (OA) in middle-aged people.

Clear research shows a higher risk of OA being due to not only the increased biomechanical load on the knees, but also the presence of the chronic inflammatory state throughout the body; in wrist OA this metabolic component is more dominant. But it is also becoming evident that many of our overweight adolescent youth have knee discomfort or pain, which discourages their being normally active.

In the Arthritis New Zealand study a high-fat diet or the control chow diet was fed to male rats immediately after weaning, at 22 days of age, when they are growing rapidly, and the cartilages of the joint are forming. As young adults (4 months old) the effects of the diet were assessed by measuring blood plasma concentration of hormones associated with the body's general inflammation status, measuring the body composition (fat and muscle content) by DEXA scanning, and by scoring the state of the cartilages in the knee joint. For all these, the values of the group fed the hi-fat diet were compared with those of the group fed only the normal chow diet.

The amount of feed consumed by the two groups was not different, but the body weight and amount of body fat at 4 months was higher in the high-fat than the chow diet, and the concentration of pro-inflammatory hormones were moderately but significantly higher as well. So the diet had induced an overweight-obese metabolic state.

Assessing the joint cartilage under the microscope showed no evidence of OA in the surface layer or sub-surface zones of the joint cartilage. But there were lesions



in the growth cartilage tissue, which by dividing increases the number of cells and the size of the bone end and the joint; this is typical of the growth period in young mammals, when these rats were ingesting the hi-fat diet.

The lesions occurring are shown in Figure 1. The cartilage cells are enlarged, and have not turned into bone, and the retained cartilage becomes thicker, making it unstable and likely to split.

Figure 1A: Microscopic view of (above) the femur (above) and the tibia (T) separated by the joint space, and the triangular shaped sections of the meniscus. The cartilage is stained purple, the focal thickening contrasts with the normal thickness of the young adult cartilage.

Figure 1B: In this enlarged view of the growth cartilage of the femur age, the grossly enlargement and staining intensity of the cartilage cells is variable, and there is space between the cells, indicating diseased cells that are producing little or no normal matrix around them. In the bone tissue (pink above) the bone marrow between bone plates is replaced by fibrous tissue (blue), and a small cyst-like space (white) has formed. The changes indicate abnormal growth cartilage and its early effects on the underlying bone.

There were statistically significant correlations of the retained cartilage lesion scores and body composition, and the elevated concentrations of leptin, TNF α and INF γ , all of which are related to abnormal metabolic and inflammatory status.

Some retained cartilage lesions may be painful, others not; some lesions heal spontaneously but other retained lesions can lead to secondary osteoarthritis, which does lead to pain. The possibility thus exists that young people with knee pain who are overweight or obese may have such retained cartilage lesions. We intend searching for evidence of this in scans of such people.

The research was conducted at the University of Auckland with the awarding of ArthritisNZ funding in August 2014 to Elwyn Firth (Department of Exercise Sciences and Liggins Institute) Sue McGlashan (School of Medical Sciences) and Mark Vickers (Liggins Institute). The experiment was conducted in summer of 2014–15, under authority of University of Auckland Animal Ethics Committee. The laboratory data were assembled by Sam Haysom, supported by a Liggins Institute masters scholarship. Other investigators analysed other samples related to the effect of diet on cell and tissue metabolism. The results are being prepared for publication in a peer-reviewed scientific journal.

Young people meeting their peers who also have arthritis

On Friday 14th October 10 young people aged from 14-19 years old arrived in Wellington from around New Zealand for the Youth Leaders Development weekend.



These young New Zealanders all have arthritis!

The major struggle for all these young people is that they look perfectly normal; their condition and the associated pain is invisible. One day they can be well and the next struggle to move.

They are gathering to spend this weekend developing their skills and knowledge as potential Arthritis New Zealand Youth leaders. Their activities will include discussion about their experience of growing up with arthritis, and dealing with the entrenched myth that arthritis only affects the elderly.

One of the most important features of this weekend was giving these teenagers a chance to meet with and learn from others of the same age who have arthritis. The weekend also involved young adults now in the paid workforce who have grown up with arthritis who can share their experiences of leaving

school and moving to the worlds of work and study while managing their arthritis.

In addition to the fun activities there were also interactive conversations with Evolve, Youthline and a session on Self-care and Wellbeing.

Some experience bullying, others are challenged with the loss of career dreams and are being encouraged to understand that 'you can do anything!'

"I think having the paediatric and adult nurses and mentor was my favourite because it was good to learn about moving to adult doctors."

"My favourite session was Zealandia".

"I found the events extremely fun because I got to talk to others and who were the same as me who I can now call friends."

"Make the camp longer."

Contribution to research acknowledged

Arthritis New Zealand has been honoured by the University of Auckland for significant contributions to research on arthritis conducted by researchers at the university.

The Chancellor welcomed Arthritis New Zealand to the Sir George Fowlds Society of the Chancellor's Circle. Arthritis New Zealand is now inscribed in their Book of Recognition. The entry reads "Arthritis New Zealand has supported research into the causes and treatment of arthritis for many years. This has included diverse projects such as the effects of exercise on osteoarthritis, the examination of the role of neuro-receptors and most recently, using MRI scanning to investigate whether joints of patients with rheumatoid arthritis improve as a result of changing therapy. We are grateful for their ongoing support."

Digna Toresen, Vice President and Kathie Smith Chair of the Research Grants Committee were delighted to join the Chancellor for this occasion along with Arthritis New Zealand staff members.

This article was provided with the support of Pfizer.

Getting the most out of your specialist

Time with your Rheumatologist is valuable, and being well-prepared for your appointment is easier than you realise says Dr Martin of Auckland Hospital's Rheumatology Department.

In this article, Dr Martin shares tips and tricks to help you get the most out of your time with the person who manages your arthritis treatments. The goal of your Rheumatologist is to help relieve your symptoms and enable you to get on with living your life.

Many people experience arthritis and need treatment, so clinics are often very busy says Dr Martin, "During your appointment our focus is to ensure you, as a patient, are getting the best therapy for your condition."

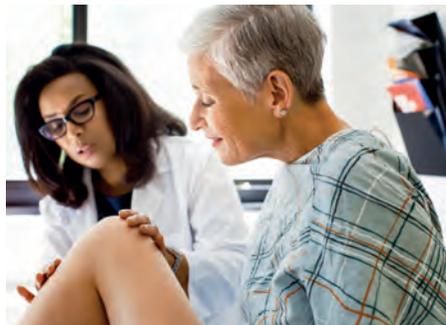
"The more time we have to talk about how you are functioning day-to-day the better we can work with you to reduce symptoms and in turn improve your mobility and quality of life.

"Arriving 15 minutes before your appointment gives you time to fill out forms telling us about your health before we see you. This frees up clinic time so we can assess you thoroughly."

When you are seen, sometimes we may need to examine all your joints says Dr Martin, "A lot of useful information is gained by checking joints that aren't painful and also your nails – so please remove nail polish before your appointment."

"Wearing loose clothing with few layers for ease of removal means you spend less time getting undressed in order to look at the joints we need to check. We then have more time to talk about your symptoms, assess how you're doing and what your quality of life is like."

It's important to be honest with your specialist about how you are doing says Dr Martin, "Better understanding of how you are managing your arthritis day to



Key tips for making the most of your appointment:

- Allow plenty of travel time
- Arrive early
- Wear loose clothing
- Always remove nail polish
- Know your medications
- Write your questions down
- Bring a support person

day helps us figure out if your treatment schedule is working as best it can for you."

Dr Martin also emphasised the need to bring your medications with you or a list of what you are currently taking, "People often forget to do this as they believe the medication list is on our hospital records. The reality is that different doctors in the hospital and in general practice make changes to your medications and it is not always accurately reflected on your records. People also don't always take what is prescribed so it is really important we have an up to date list from you of what you actually take every day."

Dr Martin recommends bringing a support person along to your appointment. "We sometimes give

patients a lot of information to digest and a diagnosis of rheumatoid arthritis or lupus can be a shock to people so having a friend or relative there can help support the patient and be a second pair of ears."

It's also important to allow enough time to get to your appointment says Dr Martin, "Hospitals are busy places and traffic and parking can be unpredictable. We want to ensure all patients get the care they deserve and, after we noticed many patients had to wait because others were running late, we introduced a standard lateness policy in our Auckland clinic. This means that anyone who is over 15 minutes late needs to make another appointment. Unfortunately as our clinics are so busy that can be several months away."

"Due to our extensive wait list we take it very seriously when patients don't attend an appointment. After all this is a missed opportunity to see someone in need. We allow a reschedule once but if you fail to attend clinic for two occasions in a row you will need to be referred once again by your GP before you can receive another specialist appointment.

"Please let your clinic know at least a few days ahead if you think you cannot make your allocated appointment as there is often a long list of people waiting to get last minute slots."

From the President

At the last Governing Body meeting we adopted the 2017-2021 Strategic Plan – you can see the key themes over the page.

Our vision is to improve the life of every person affected by arthritis. There are currently 620,000 kiwis affected by arthritis, with a growing number of younger people impacted by the conditions. The trends indicate the growth will continue. The impact is not only on those living with arthritis, but their families/whanau and the wider community. We cannot achieve our vision alone, and our partnerships with our stakeholders will be even more important in the coming years.

Arthritis is the leading cause of disability in New Zealand, and our vision is ambitious. I have met with both the Minister of Health and the Minister of Disability in recent weeks. These Ministers have stressed the value we have in being one organisation to represent all people with arthritis.

Arthritis New Zealand has always kept people at the heart of what it does, and that commitment will not change – but the evolving healthcare environment means that it is increasingly important that the organisation focus on being a strong advocate for the needs of people living with arthritis, and to grow awareness and understanding of the challenges people face in their day to day lives. Since 2010 people have told us that we need to increase our focus on awareness and advocacy. We have done this with limited resourcing. This plan signals the next step in committing to these important programmes.

As a small organisation, we are proud that 80% of New Zealanders know who we are. We need to build on this so that people know to engage with us. We must ensure that Government, employers, healthcare providers and the community know and understand the impact of

arthritis on people's lives. A single strong voice can be heard – my conversations with government stakeholders confirm that we are known and trusted.

There is a growing reliance on digital technology for information and advice, Arthritis New Zealand needs to ensure that it is in the best position to ensure people with arthritis receive the assistance and services they need, in a way that they can readily access. Our online services need to adapt and grow to meet the demand. Digital technology will allow people to access us at a time that suits them. This does not mean people without mobile phones or computers won't be able to access services – our 0800 telephone line will ensure access to all people.

The healthcare system of both today, and in the future, has patients with a far stronger voice than ever before in their choices and treatment, and the patient voice will continue to become more powerful with advances in technology and faster access to information. We will be part of that future.

We are proud that we have built the support for Māori and Pacific people, who live with arthritis, to 40% of the services now being delivered to those communities. We are committed to continuing to work with the providers of services to Māori and Pacific Island people to ensure equity in accessing support.

Arthritis New Zealand has always ensured it is financially sustainable through evolving how it operates to provide support to those affected by arthritis. There will be changes to the staffing to ensure we can deliver this ambitious vision within a constrained resource environment. These are tough but necessary decisions. I know that other Presidents before me also had to make



similar decisions. Our longevity testifies to this.

2016 has been a significant year for Arthritis New Zealand. Along with the other members of the Governing Body I thank you for your ongoing support and wish you all the compliments of the season.

Peter Larmer
President

IMPROVING THE LIFE OF EVERY PERSON AFFECTED BY



WORKING TOGETHER TO ENSURE	Arthritis is recognised as the leading cause of disability among adult New Zealanders	All people affected by arthritis have access to the services they need
WHAT DOES SUCCESS LOOK LIKE?	<ul style="list-style-type: none"> • Arthritis & musculoskeletal health is a national health priority • The public understands arthritis is a chronic health condition, & its impact on individuals and the community • Health & community services are provided to meet the needs of people with arthritis • People diagnosed with arthritis are provided with evidence based treatment by all healthcare professionals 	<ul style="list-style-type: none"> • People's health, employment & lifestyle needs are met to enable them to live well with arthritis • Māori and Pacific people diagnosed with gout and other forms of arthritis have access to the support and services they need • Health & recreational services within communities meet the needs of people affected by arthritis • Decisions made about services and locations provided are evidence based
WHAT DO WE NEED TO DO TO ACHIEVE SUCCESS?	<ul style="list-style-type: none"> • Engage with key policy & political decision makers to educate about the condition and impact • Utilise all multiple communications channels to educate the public, Māori and Pacific and other target groups on the conditions & their impact • Profile the experiences of people living with arthritis, including Māori and Pacific, to raise awareness • Be an active contributor to musculoskeletal health policy • Arthritis New Zealand is an active leader and contributor in multi-disciplinary sector advocating for joint health initiatives • Championing the issues that affect people with arthritis, including Māori, Pacific and other target groups through a solutions based approach • Support healthcare professionals to ensure models of care for all forms of arthritis are developed and followed 	<ul style="list-style-type: none"> • Linking people to appropriate & credible programmes in their communities • Working with employers, policy makers & people with arthritis to reduce barriers to employment • Provide information to the families of children with arthritis to enable self management at school • Advocate for services that meet the needs of people with arthritis at community level • Utilise community gout champions & partner with Māori and Pacific health providers to raise awareness of gout to support better screening, diagnosis and treatment of gout • Arthritis New Zealand website provides easily accessible information and support • Arthritis New Zealand develops criteria for community based providers including social, health and exercise groups. • Exercise and other community providers work with Arthritis NZ to ensure services are available across the country.

D BY ARTHRITIS



New Zealand research will contribute to finding a cure for arthritis

- New Zealand researchers investigate causes, prevention and treatment for arthritis
- Patients have access to evidence based information about arthritis
- People diagnosed with arthritis are actively involved in research

Arthritis New Zealand is the go-to organisation for information, advice & advocacy

- People diagnosed with arthritis know to contact Arthritis NZ for support, information & advice
- Healthcare professionals endorse Arthritis NZ as a provider of self-management support
- Government seeks input from Arthritis NZ on musculoskeletal health
- Arthritis NZ has the resources it needs to ensure the delivery of sustainable services
- High staff and volunteer satisfaction demonstrates that Arthritis NZ is a good employer

- Ensure research findings are disseminated
- Fund New Zealand research
- Generate research to support our advocacy and awareness priorities, enhance service and good practice guidelines
- Promote patient participation in research planning and implementation
- Collaborate with researchers on New Zealand research initiatives
- Engage with collaborative initiatives with government agencies, tertiary institutions, health, community, Māori and Pacific providers to ensure our services and information is relevant and accessible

- Evidence based information and advice is provided predominantly through telephone, and online mean
- Peer to peer support offered for newly diagnosed
- Increase awareness of Arthritis NZ services in primary care, including Māori and Pacific community providers
- Support Māori and Pacific providers with training and information to ensure Māori and Pacific people with arthritis have access to culturally appropriate services
- Seek out and foster collaborative relationships with government, community, health, Māori and Pacific providers to ensure all our services are responsive to current and future needs
- Organisation is sustainable with sufficient reserves to meet future needs



Advocacy in Action

Advocacy is one of our organisational priorities but at times it can seem to be slow and behind the scenes.

This has certainly been the case with our work on ACC claims. It has been 4 years since we were alerted to the problems that clients were experiencing with ACC claims and now 4 years down the track we are seeing some progress being made.

In 2012 our Osteoarthritis Awareness campaign sparked a number of calls from clients who had had accidents and when they claimed for ACC cover were declined on the grounds that their injury was due to osteoarthritis rather than an accident. Clients reported that they found the ACC systems complex and demanding and a number of them felt they had been shortchanged especially if they could not afford a lawyer to represent them in the review and appeals process.

We took these concerns on board and started looking at what the problems were and how we could make suggestions for improvement. First step was holding a workshop on *Arthritis or Injury? The ACC Challenge* in early 2013. This workshop had input from a number of professional

bodies, ACC, and MPs plus several clients who told their stories. This workshop helped identify some key issues and Arthritis New Zealand then decided to focus on the appeals and review process where we could make constructive suggestions for improvements.

Following this workshop we researched and produced a paper on the appeals and review processes and began a dialogue with ACC, lawyers and ACC advocates and other interested organisations such as ACCclaim Otago, ACC Futures, and politicians including then ACC Minister Nikki Kaye.

Following a report from ACCclaim Otago which was very critical of the ACC review and appeal processes Minister Kaye commissioned Miriam Dean QC to undertake an independent review of ACC dispute processes – Arthritis New Zealand was one of the organisations who met with Ms Dean. The report released this year made a range of recommendations which accurately reflected the concerns

that our clients had been expressing. In particular the Dean Report included recommendations that

- ACC explores ways to better collect and analyse data about claims and disputes
- ACC consider funding a free nationwide advocacy service modeled broadly on the Health and Disability Commission Advocacy Service
- Review costs that can be awarded to successful claimants be increased by more than the rate of inflation
- ACC convenes a working group to address policy and process related problems with accessing medical evidence.

Government have accepted in principle the recommendations made in this report.

Yes – it has taken 4 years and is not over as we now make further submissions and monitor the implementation of the Dean Report but we can see solid progress has been made.

Advocacy results may not happen overnight but they will happen.

Peer to peer fundraising

Peer to peer fundraising has enjoyed spectacular growth over the past five years thanks to the creation of websites such as Everyday Hero and Givealittle.

Peer to Peer fundraising has grown exponentially over recent years and is now a fundraising tool for most charities. This platform allows individuals to connect with the causes they love in a way they prefer, and in helping these wonderful people support Arthritis New Zealand, we've learned that giving isn't just about money. With the everyday hero platform used by Arthritis New Zealand, people can not only fundraise, donate and volunteer for us, but they can also see and track the voice, time and effort they put in.

We recently had a number of Auckland marathon competitors establish everyday hero pages. Penelope who ran the New York marathon and Debbie competing in the West Coast marathon have also set up pages.

If you are thinking of entering an event and would like to raise awareness and perhaps funds for Arthritis New Zealand then please chat to **Emma.Barker@arthritis.org.nz** or call **0800 663 463**.

"The time has come to finally set another running challenge to raise funds for Arthritis New Zealand – a charity so very close to my heart. My late Nanna suffered from terrible rheumatoid arthritis and every step, every movement caused her pain. My beautiful cousin Rosie also suffers from rheumatoid arthritis, and she now lives in Darwin to help reduce and manage the effects of its crippling pain. My wonderful dad Duncan has had two hip replacements from osteoarthritis..."; said Sophie Barr.

And another Sophie: *"Hi, my name is Sophie and up until 6 months ago I had been a competitive middle distance runner and I had raced for New Zealand. In March this year I was diagnosed with chronic psoriatic arthritis and had to give up competitive running because my joints were sore and swollen."*

Student walks the length of the country for arthritis

As the final edition of Joint Support for 2016 hits your letter box, and if all has gone to plan, an Otago Polytechnic student will be in his final days of an epic walk from Bluff to Cape Reinga in the name of arthritis awareness.

Kazushi Noiri, originally from Japan, is near the end of his second year of a nursing degree. With studies completed for the academic year, he decided to set out on his walk on World Arthritis Day, 16 October. Explains Kaz: "I am a volunteer with an aged care organisation in Dunedin. Working with patients has shown me how hard everyday life can be for people with arthritis. So I decided to put some effort into spreading awareness and to support Arthritis New Zealand. I hope to raise \$5,000 from sponsorship and donations. I have learned that there are 620,000

New Zealanders who have a diagnosis of arthritis, including a surprising number of children. There are 140 types of arthritis." Kaz trained for several weeks prior to his walk of 2,244kms. He estimates that it will take 66 days, walking 13 hours each day, reaching Cape Reinga a couple of weeks before Christmas. Otago Polytechnic fully supports Kaz's efforts. The Institute says Kaz is the latest face of its *Explore More New Zealand* campaign which promotes New Zealand internationally as a study destination.



Navjeet & Dee from Wellington office seeing Kaz off from Wellington

When this issue of *Joint Support* went to press, Kaz was doing well and if things have worked out for him, he should by now be in the top half of the North Island. If you see him, wish him well, and maybe walk with him for an hour, because he will appreciate the company given the loneliness of his task. Naturally the offer of a meal and a bed would go down well, too. Thank you Kaz. Arthritis New Zealand salutes you and the people of New Zealand who support you. He has a fund raising website: <https://give.everydayhero.com/nz/exploremoregive>

Thank you New Zealand for your support!

Once again New Zealand you have supported our annual appeal and your donations will support our services for the 620,000 New Zealanders with a diagnosis of arthritis.

"For that I would like to extend a heart-felt thank you" said Sandra Kirby CEO, to the thousands of volunteers, members and donors who helped to make our 2016 Arthritis Appeal Week a success. I know that while you were collecting you were also able to have conversations with people about their arthritis and refer them to our 0800 663 463 help line."

We are proud to report that thanks to your ongoing generosity and support our total income stands at nearly \$250,000.

We depend on fundraising for 75 per cent of our income; it is paramount to our success. Without your generous donations, we wouldn't be able to help the over 620,000 New Zealanders who live with the pain of arthritis everyday.

We were delighted to again have the support of BNZ Closed for Good volunteers helping us pack material. Their laughter and sometimes catering brought a day of fun to our offices.

Although this year's street appeal has concluded, our work to improve the health and well being of people who are affected by arthritis continues, and we still need your help. If you missed our collectors, you can still support us by making a donation via our website of a \$20 donation by calling 0900 333 20

If you would like to learn more about the services we offer, how to volunteer, or make a donation, ring 0800 663 463 or visit www.arthritis.org.nz.

Sandra Kirby, *Chief Executive, Arthritis NZ*



JOINT SUPPORT



Judy & Karen from Cambridge Support Group



Arthritis New Zealand recognised the contribution of Gloria Simpson over many years to the Otaki Arthritis Support Group, which has now closed.

A large audience once again enjoyed the music from the 50's Up Brass band on Thursday 27 October in Christchurch. The band has been running these concerts in support of Arthritis New Zealand for more than 10 years. The oldest member of the band was in his late 90's and it was wonderful to view the pleasure they derive from performing.

Equidays 2016

As the partner charity for this event at Mystery Creek in Hamilton we spent a weekend in miserable weather with thousands of riders and their families. A huge village was created with motor homes and horse floats surrounded by external and internal display areas.

It was great to meet the para-riders who have arthritis and they came and shared their stories. As always lots of questions on how to deal with arthritis and fun spent with visitors to our stand trying to guess the number of gerberas in the jar ... well in the plastic bag after an accident with the jar.

Arthritis Educator Trevor Fredricks provided advice on Friday supported by Cambridge's Support Group volunteers, Karen & Judy. Great visibility.

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Ask your doctor or contact our clinic for more information.



Being employed makes people with arthritis healthier

There is plenty of research that demonstrates that being in paid employment helps people stay healthier, including the New Zealand Fit for Work research undertaken by the Work Foundation and released by Arthritis New Zealand in 2013.

We have been passionate advocates for employment to be included in considering health outcomes. The evidence supports this and so do people's experiences. We see this from the comments made by people to Arthritis Educators; in the responses made to our employment surveys and the questions that come from employers and employees about employment.

In many countries including New Zealand and Britain the two most common health concerns that prevent people from working are mental health issues and musculoskeletal health. Musculoskeletal health includes arthritis. The Social Development Minister, Hon Anne Tolley, recently announced the "Work to Wellness" trial that supports beneficiaries with mental health conditions into work. Many people diagnosed with a mental health condition also have arthritis.

People currently receiving the Supported Living Benefit are also able to join *Opt In* – a programme that enables disabled people to prepare for work and then supports them to find work through Work and Income. A dedicated case manager will work with *Opt In* clients for six months providing coaching and mentoring, job search services and assistance to help clients into work. This may include referring them to services such as counselling, additional GP visits or skills training.

One of the world's most eminent experts on work place wellness visited New Zealand in October. He is Dr Paul Litchfield, the senior medical officer for the British Telecom group. He is also the chairperson of an organisation called the *What Works Centre for Wellbeing*. Dr Litchfield talked about the differences in the way governments see work place health and wellbeing compared to how employers see it, and the different goals between the two. While both government and businesses want mentally and physically well people for government the driver is to make best use of scarce health and welfare

resources while businesses are interested in increased productivity and worker engagement.

We were especially intrigued by Dr Litchfield's definition of work in our current era.

"Work," he said, "used to be a noun. People would say that they were off to work now, which meant they were leaving home for an office or factory, a definite place and defined hours. Now, going to work is a verb. Work can be something that's done from home, on a plane, from a hotel....anywhere and at any time."

The evidence for what helps support people with long term health conditions stay in work shows that flexibility is the biggest single change that works. Flexible hours and for some flexible work place does help keep people with arthritis in the workforce. The other key is supportive manager.

One of the challenges for an ageing workforce – and most OECD countries have an ageing workforce – is that jobs that involve physical labour do get harder if you have osteoarthritis. For some people re-training for a less physical job may be the way to stay in work.

Minimising barriers to participation in paid employment is one of the priority issues for Arthritis New Zealand and we have established an online forum to discuss these barriers and possible solutions – if you are interested call us on 0800 663 463.

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The Walking Stick Tree

by Trish Harris | Illustrations by Sarah Laing

How does a child deal with acute pain?

Trish Harris answers this question and others you didn't even know you had in her memoir about pain and loss, identity and living creatively. With essays, illustrations and her personal story of living with arthritis, this memoir is a unique experience for readers.

With a wry eye on the world this remarkable memoir tells the story of a six-year-old girl developing acute arthritis and navigating her way through childhood into adulthood.

She forms a relationship with pain and treads a fine line with loss. As an adult she reaches for a 'normal' life by developing her own 'adapted' version.

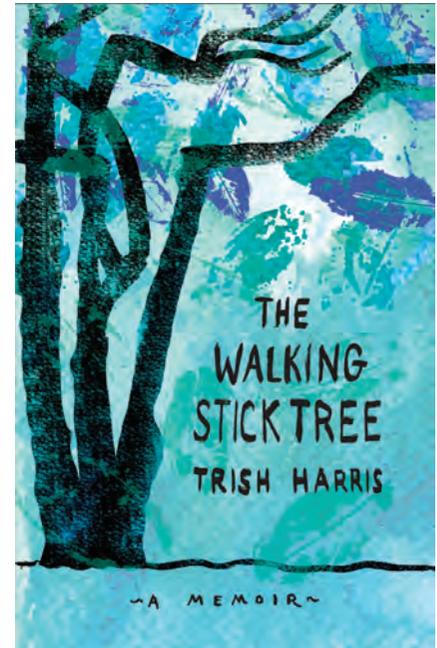
Renowned children's author, Joy Cowley, comments, 'It is often said that the body is the house in which the true self dwells. Trish Harris's "house" has arthritis written

all over it, but her true self has expanded beyond its walls to embrace the universe. In *The Walking Stick Tree* Trish has given us a beautifully written memoir that will bring hope to those living with disability, and encouragement to everyone.'

The four essays on 'Exploring loss, sadness and grief', 'The dance of identity', 'Body and soul' and 'The nature of pain' show the vision of someone writing from the inside of the experience, rather than a person writing as an outsider looking in.

'Finding a quality New Zealand book on the experience of disability is like finding water in a desert: eagerly consumed and leaving me wanting more.' says Robyn Hunt, leading disability expert in New Zealand.

This warm, perceptive and insightful book is for those who have a disability, who live



with or care for a disabled person, and those who want to live life fully regardless of the circumstances.

Mary-Jane Duffy, publisher at Escalator Press says, 'At Escalator Press we want to publish books that are not only a great read, but also bring voices not often heard into the New Zealand writing landscape. *The Walking Stick Tree* is a compelling story that shines light on a personal experience of disability, but also puts it

Bequest

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

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

Once you have taken care of those who are close to you, you might like to remember Arthritis New Zealand. We are always overwhelmed when we receive advice of a bequest. These gifts ensure our work continues for generations and confirms the importance of supporting the 620,000 New Zealanders with arthritis.

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

Saying goodbye is never easy. Arthritis New Zealand is grateful to those who ask friends and family to donate to us in lieu of flowers. These generous thoughts and donations assist in the funding of our work for the 620,000 New Zealanders with arthritis.



What's on-line?

Arthritis New Zealand has the latest tidbits for your mouse.

The cyber world offers a great way for people to share their problems, solutions, burdens and observations, and those living with arthritis get a great deal of benefit, amusement, entertainment, but most importantly, information... from many on-line sources and contributors.

You can start, of course, with Arthritis New Zealand's own website.

The website address, if you haven't already got it, is: www.arthritis.org.nz

Also, follow us on Twitter. Find us on Facebook.

But we would like to give you a few links to some of the more interesting on-line videos and blogs that we've seen in the last few weeks from overseas. The American Facebook page *Creaky Joints* asked followers to describe fatigue in three words or less. You might be interested in what some of the respondents came up with. <http://tinyurl.com/pglq4q5>



Entertainer Robbie Williams is changing his dance routine due to arthritis in his back. Take a look at an article about it in *The Daily Mail*. <http://tinyurl.com/qhyuobe>

And take a peek at a Twitter piece that the National Rheumatoid Arthritis Society of the UK posted on World Arthritis day, October 16th. <http://tinyurl.com/pg37dah>

And another piece that we found intriguing was about how to give a decent hand shake when your hand or wrist hurts like hell. It's a blog from Canada.

<http://tinyurl.com/ouuojsw>



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

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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 (new address)

Level 2, 120 Featherston Street, PO Box 10 020, The Terrace, Wellington 6143
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