JOINT SUPPORT

Living well with arthritis

Arthritis NZ
Mateponapona Aotearoa

IN THIS ISSUE · SPRING /SUMMER 2024

REBECCA'S Column

As we welcome the warmth of spring and reflect on the past year, I am grateful for our donors and supporters. Your generosity has been instrumental in our mission to help people with arthritis live well.

The demand for our services has surged, with our Arthritis Assist team managing 48% more cases than last year. Our digital presence has also flourished, with an 18% increase in both E-News subscribers and website visits, and a remarkable 26% growth in our YouTube channel audience.

In the community, we continue to forge valuable partnerships at national, regional, and local levels. We're deepening our understanding of health equity issues and working to address them while integrating Te Kawa o Mateponapona into our approach.

A highlight of the past year was the formation of our Youth Advisory Committee in late 2023. This eight-member group serves as a crucial link between young people affected by arthritis and our board, with the goal that our efforts resonate with and meet the needs of our younger members.

Collaboration has been a key theme this year. Arthritis NZ, alongside other agencies supporting people with long-term conditions, is intensifying its advocacy efforts. A recent meeting in July brought together representatives from various organisations, including the Stroke Foundation, Age Concern, Age Care Association, and Rare Disorders NZ. Discussions included ways to enhance inter-agency cooperation through joint submissions, unified government communications, and resource sharing. Common issues such as pain management and healthcare access were identified, with plans to involve more interested groups in the future.

As we look ahead, I'm excited about the potential these collaborations hold for improving the lives of those affected by arthritis. Our growing reach, both digitally and in the community, positions us well to make an even greater impact in the coming year.

Thank you for your continued support. Together, we're making significant strides in arthritis care and advocacy in New Zealand.

Warmest regards,

Rebecca Roberts
Chair of the Board

NOTICE OF Annual General Meeting 2024

The Arthritis New Zealand – Mateponapona Aotearoa stakeholders are formally notified of the details for the FY2024 Annual General Meeting.

Wednesday 27 November 2024

3 pm to 3.30 pm

Online via Zoom

If you would like to attend, please scan the QR code and register your interest by **Friday 22 November 2024**, and we will send you a Zoom link to join the meeting.

Representatives from Arthritis NZ, Aged Care, Rare Disorders NZ, Stroke Foundation, Aged Care Association

HEALTH AGENCIES UNITE TO strengthen voice for long-term condition patients

Collaboration with other agencies is an important aspect of Arthritis NZ's advocacy programme and is becoming increasingly important for a number of other organisations too.

In July, representatives from agencies working on policy and advocacy for people living with long-term conditions met to look at how they could improve inter-agency cooperation. Topics discussed included looking at what submissions are called for, how to work towards making joint submissions and meeting with the government so that we speak with a combined voice and exchanging information and resources.

The agencies recognised that several issues that arise are common to all of us - pain management, access to pharmaceuticals and primary health care, promotion of the importance of a healthy diet and exercise to name a few.

Those attending the first meeting to discuss such collaboration included Arthritis NZ, Stroke Foundation, Age Concern, Aged Care Association and Rare Disorders NZ. Contact has also been made with other groups who are interested in developing improved collaborations.

ACTIVITY WITH Arthritis programme

Patricia Thompson

Te Whatu Ora/Health NZ has funded an initiative to help people manage osteoarthritis without surgery. The Activity with Arthritis (AWA) programme offers free education, exercise, and community support to those living with this condition. We explore how this programme was trialled in Taranaki, its success and the positive impact it's having on participants' lives.

The AWA programme offers non-surgical management strategies that are proven to reduce pain, improve function, and delay and even avoid the need for some surgeries. The programme was initially trialled in the Bay of Plenty and Taranaki, and is proving to be highly successful.

Louise Robinson, AWA Lead Physiotherapist for Taranaki, launched the pilot programme for the region at the end of 2020.

"I run them back-to-back and there are heaps of demand for each intake. It helps to optimise people's movement and well-being, so they feel more confident in managing their arthritis," says Louise.

Each programme has around 20 people who go in twice a week for one hour over eight weeks.

"People enjoy the group. However, some might have difficulty attending at set times or have particular needs such as deafness - so, where needed, I can see people one-on-one. It's ideal for people with hip or knee arthritis, as that is the most common, but we also get people with arthritis in their back."

The Taranaki clinics, which include dietician support, are held at Base Hospital and Hāwera hospital as well as in the primary care setting at Tui Ora in New Plymouth. Over time, the aim is to provide the service 100% in the community to make it easier for people to attend appointments. Louise takes referrals from GPs, orthopaedic services and also from the specialist Taranaki orthopaedic triage service.

"The biggest age group is 60 to 75 years old, but we have had people in their 80s and 90s and they are amazing - very fit and inspiring to have in the group.

"Feedback from participants has been very good. One of the biggest things is the group support, people really like that. Even though arthritis is common, people can feel quite isolated, and friends may not necessarily know what they are going through.

> “If you want what you lost a few years ago with your ability to walk, to run, to move your hands, do the programme and stay at it. The first exercise might be hard, the second might be hard but the more you do it the easier it becomes. It is like a baby trying to walk. One step today, two steps tomorrow, next week is running.”
>
> – Dave Whatuira

“I usually find people are still functioning quite well in the community but with pain, so optimising movement, strength, balance and flexibility is helpful. Some people do end up having surgery but doing physio is very helpful for recovery and just feeling more confident in managing the symptoms and knowing what arthritis is.

“Some people come back to give talks, such as **Dave Whatuira**, who is such an inspirational speaker and also took part in making a short video about the programme.”

Louise says she encourages anybody with arthritis, whether they are just starting to feel the symptoms or in later stages, to talk with a physiotherapist.

“There is always something we can do. Arthritis can be very painful, but physios are very good at tailoring appropriate exercises to the individual – so having a chat is very worthwhile.”

Georgie-Anne Cox, Community Lead for Arthritis NZ, says the AWA programmes are a very good resource for people who may, for a variety of reasons, not be able to have surgery for their osteoarthritis, or face a long wait.

“We support the Taranaki programme by providing our community presentation. Outcomes of the programme have been very positive. A really important impact is that people are learning more about their condition and how to manage it.”

For a short video of Dave undertaking one of his AWA exercises see:

STAFF PROFILE

PERSONAL EXPERIENCE LEADS TO health advocacy career

Patricia Thompson

Zechariah Reuelu's journey from a concerned son to a passionate advocate for community health is a testament to the power of personal experience in driving positive change. We follow Zechariah's path from a pivotal moment with his father to his current role as Community Development Coordinator Pacific Peoples for Arthritis NZ, highlighting his dedication to improving health outcomes for Pacific communities and his innovative approaches to making complex medical information accessible to all.

Zechariah's journey to help improve health outcomes for people in vulnerable communities began with a visit to a medical centre with his late father.

Realising his father couldn't understand a health promotion poster aimed at Pacific patients led Zechariah to explore how organisations could be supported to engage with different communities and communicate clinical information in effective ways. Twenty years on, that is still a passion.

Zechariah has also undertaken his own journey of learning to live well with osteoarthritis, having been diagnosed after taking on his current role six years ago. His work includes advising Arthritis NZ on working with communities and providing input into design of information and resources.

"My particular focus is the Pacific community, including improving gout equity in New Zealand, and to support the organisation's cultural understanding around how Pacific people see things in different ways," says Zechariah.

"I also work with organisations like Whānau Ora providers because they have the relationship with families, and we can provide information so they can better support those they work with.

"People can increase their understanding of complex clinical information as long as it is delivered in simple practical ways. For instance, going along to a Cook Islands mothers' tivaevae quilting and bedsheets group to show them how to do finger exercises, because many have osteoarthritis in their hands."

Zechariah is a Samoan and Gagana Tokelau speaker. His father was from Atafu, Tokelau and his mother is from Satupaitea, Savai'i, Samoa. He was raised in Porirua, where he still lives, and is also a volunteer with a number of community organisations. While he'd have liked to have gone to university, he wanted to help his family so from school he went to work for the National Provident Fund for some years.

The career change

That visit to a medical centre, shortly before his father passed away, led to a career change.

"My father was looking at posters on the wall. I asked him which one was Tokelauan, and he pointed it out but said he couldn't understand it – this was despite him having been in New Zealand for 40 years and a translator and orator for his community."

Reflecting on that visit, Zechariah later returned to the medical centre and asked the manager if he could take the poster.

“I took it to the oldest elder in our community. He didn’t understand it either and thought it had been translated from a Western perspective – but he told me what he thought it was intended to mean.”

Together, they developed a more suitable text, validated by other elders. Zechariah’s cousin, a graphic designer, designed a new poster for Zechariah to take to the medical centre.

His motivation was purely to support others in their community, but the centre manager asked if they did any similar work.

Hoe Mua Designs

That was the beginning of a new journey, launching a design agency, Hoe Mua Designs – named for the Tokelauan term for ‘navigating unexplored territory’ - focusing on authentic approaches to health promotion, as well as other Pacific and modern New Zealand design. The agency designed the new Tokelau national flag in 2007.

“This was the early 2000s and I found there was little Pacific cultural competency in advertising at that time,” says Zechariah.

“Campaigns were approached from a Western perspective, but my experience was that if we could convey those messages in different ways then we could remove some of the barriers, resulting in improved health outcomes.

“I was able to support organisations to communicate their messages and engagement efforts with community groups and was invited on to panels advising on health campaigns, such as SmokeFree, cervical screening and breastfeeding.”

> “My particular focus is the Pacific community, including improving gout equity in New Zealand, and to support the organisation’s cultural understanding around how Pacific people see things in different ways.”

After 12 years, Zechariah left the agency to focus on his young family. He then joined the Pacific Business Trust, providing support to Pacific entrepreneurs, and studied at Victoria University during the early years at Arthritis NZ.

His own diagnosis with severe osteoarthritis led to a hip replacement and he says the knowledge and advocacy from the organisation helped equip him to engage with the health system and understand post-operative and ongoing management.

“So, my lived experience is very much part of my work with communities. My journey has made me realise how complex the design of the health system is. I look at it and think ‘how can we find levers that we can turn slightly to have better impacts?’

“The leadership of Arthritis NZ has been very supportive of the space I work in. The organisation has always been a learning space, but they are working with a more holistic approach, engaging in authentic ways that are not traditional to the health sector, to convey important messages to some of our most vulnerable communities.

“And that really goes back to our mission statement, to improve the lives of every person living with arthritis.”

RUGBY PLAYERS SUPPORTING link between ACL injury and osteoarthritis

Patricia Thompson

Rugby players are helping Arthritis NZ explore the links between sporting injuries and osteoarthritis (OA). This initiative, spearheaded by researchers from Auckland University of Technology's (AUT) Department of Physiotherapy, is challenging the traditional view of arthritis as an ailment exclusive to the elderly.

As the sports community grapples with the long-term consequences of injuries, this article explores the innovative studies, their surprising results, and the potential for early intervention that could change the game for athletes of all ages.

The project is one of a series of studies led by **Dr Daniel O'Brien**, **Professor Duncan Reid** and **Associate Professor Richard Ellis** from AUT's Department of Physiotherapy.

Their work is providing greater understanding of the link between joint injuries, particularly anterior cruciate ligament (ACL) injury, the development of post-traumatic osteoarthritis (PTOA) and how that impacts players' quality of life.

Arthritis NZ supports key strands of the research, including a survey of rugby players and an interview programme with people who have experienced an ACL injury. The studies have highlighted the impact PTOA can have on physical and mental wellbeing and even employment.

The next research phase will expand the study to the national level and will invite all rugby codes and players from other codes such as netball and football to participate.

A further study by this research group, funded by the Health Research Council (HRC) of New Zealand, aims to develop follow-up approaches to help individuals manage PTOA at an earlier stage.

Dr O'Brien's primary research focus and area of clinical speciality is in the management of chronic conditions that affect the musculoskeletal system, including OA.

"Managing people at a later stage is useful, but if we can stop them getting there in the first place, that is far more useful," he says.

"I started my career in sports physiotherapy and have worked with many people with significant injuries. The major ones were often ACL injuries and shoulder dislocations. The likelihood of having changes due to OA within 10 years of these kinds of injuries, particularly an ACL knee injury, is about 50%. If someone is injured at 16 years old, they could have the start of OA by 25 or 26, and most surgeons will not do a joint replacement until someone is 55 or 60. That's a long time to be living with a disability.

"There is a lot of research into how we manage older people with OA, but we have recognised we need to intervene earlier. We want to set up a programme that picks up people 10 years post-injury to see how they are and shares information about local providers who can help them get back into exercise in a healthy way."

Managing post-traumatic OA

Dr Richard Griffiths, Research Manager for Arthritis NZ, says while management of arthritis has traditionally focused on later stages of disease progression in older adults, it is increasingly recognised that to have a greater impact, research and clinical services should also focus on the injury experience in young adults.

"This research shows that many young sportspeople are getting these sorts of injuries. It is painting a very different picture of the impacts of OA for people who have injured themselves doing something they love. Many have surgery, but the impacts are still likely to stay with them for life," he says.

The first of the AUT studies funded by Arthritis NZ involved interviewing a sample of people aged between 25 and 65, who had suffered ACL injuries.

The second, funded by AUT, saw interviews conducted with other stakeholders, including Arthritis NZ, ACC, clinicians, physiotherapists, GPs, sports coaches and parents of young people who had been injured.

"We talked with people in their 40s still running marathons but also people of that age talking about knee replacements," says Dr O'Brien. "We met people who had lost their jobs because they could not do the work they previously did. We also found a lot of people for whom injury had impacted their mental health, and we recognised it was a bigger problem than we had thought.

"It reinforced the importance of looking at more wrap-around care for these people and how they are supported."

Wellington Rugby ACL Injury Study

Arthritis NZ facilitated AUT's Wellington Rugby ACL Injury Study with support from **Tony Giles**, CEO of the Wellington Rugby Football Union (WRFU).

The 2023 New Zealand ACL Registry Annual Report indicates the highest number of ACL injuries in New Zealand sport came from the rugby codes of league, union and touch, and comprises a combined 23% of all sports recorded in the Registry.

"60% of the respondents were under 35 years old, and 67% were male," says Richard. "It's quite hard to recruit men to studies focusing on health and wellbeing, so even this small sample is a good snapshot at a regional level.

"Something that jumped out for me was that in the initial period after injury, coming into surgery, people get good support, but after surgery and rehab that support often stops.

"Wellington Rugby is keen to better understand the impact of these lower-limb injuries and assist with strategies that give their players across different age groups a better understanding of the long-term impact of ACL injuries and how to have a better quality of life following such an injury.

"ACC will also have an interest in this research as they fund the acute rehabilitation phase post injury but will also be required to fund potential total knee replacements in the passage of time as the progression to OA occurs following the ACL injury.

"The initial survey was only a small sample and now we want to scale up and look more widely at rugby and other sport, across all codes and ages nationally, to gain a better understanding of ACL injuries and what the impacts are."

> We met people who had lost their jobs because they could not do the work they previously did. We also found a lot of people for whom injury had impacted their mental health, and we recognised it was a bigger problem than we had thought.

The next phase

Dr O'Brien says that work, aiming to recruit between 800 and 1000 respondents, will get under way in the next six to 12 months. The survey work gives a different perspective to the interviews as you can go wider and get a small amount of information from a bigger number of people.

"I suspect we will see more of the same results. For me, as a former sports physio and former rugby player myself, what is worrying is the number of respondents who had been diagnosed with OA - about 50 people. 60% of those said it had impacted their health and wellbeing and 30 of those said it had impacted their mental health at some time.

"There were a lot of people in their mid-40s who now have well-established OA in the knee that is slowing them down with work and their families."

The HRC-funded programme is underway, and the findings will be reported next year.

"We are now looking at a co-design process to look at some solutions," says Dr O'Brien.

"How can we pick up people with injuries and look after them? For instance, it could be applying booster sessions. We are looking at who could provide that service and how it would be provided. We are saying 'this is what we want to create'. It will be driven by the community, clinicians, funders and people with lived experience. It is proving to be a very interesting piece of work."

Wellington Rugby ACL Injury Study findings

130 current and former Wellington rugby players completed the online survey about their experience of ACL injury. 24% of respondents identified as Pasifika and 23% as Māori. Key findings included:

87% had suffered a serious knee injury

Nearly **80%** were under 25 years when they injured their knee, with **42%** aged 16-19 at time of injury

78% had injured their knee playing a game of rugby

53% of those with knee injuries have previously had surgery

56% had pre- and/or post-operative rehabilitation, with only 42% getting post-operative rehabilitation

Since surgery, **37%** had reinjured their knee

42% of the respondents had been diagnosed with knee OA

Only 42% had a health professional talk to them about the potential of getting OA in the future

While **23%** felt OA had had a significant impact on their quality of life, 53% felt it had at least some or a moderate impact on their mental health and wellbeing

38% reported having poor to very poor knowledge of OA

84% stated they would like to learn more about OA

HOW CAN A PHARMACIST help you?

Linda Caddick, Registered Pharmacist

An important thing you can do to improve your health is to have a good support team. One of them is your pharmacist and they are keen to ensure you get the best out of any medications prescribed to you. They can also advise on medications you buy in the pharmacy.

Pharmacists are medication experts. For many people, they are the healthcare professionals you see most often. You can usually talk to your pharmacist without an appointment and for free, but only about medicines you get from that pharmacy.

Always use the same pharmacy

Pharmacists can only see the prescriptions you bring to their pharmacy. This is why always using the same pharmacy whenever possible is so important. This way, when they receive any new prescriptions for you, they will check your new medicines against your prescription history from that pharmacy plus any medication allergies you have reported to them. They cannot see prescriptions you received from other pharmacies. They do not know about an allergy you reported to your GP, hospital or another pharmacy. Due to New Zealand privacy laws, each pharmacy keeps its own database of what you get from them. Keep them informed of any new allergies or medication changes. You can then buy medicines in the shop and ask the pharmacist to check them against your prescription history.

Prescriptions from different health professionals

It is not uncommon for someone to have prescriptions from many different health professionals, such as your GP, rheumatologist, dentist, skin specialist, eye specialist, or a hospital discharge prescription after an operation or an accident. Sometimes, there are conflicts between what one health professional prescribes to another, and maybe a hospital discharge script is for a different strength than the usual script from the GP. The pharmacist will phone the latest prescriber and sort out any queries. The pharmacist might talk to you and check that any dose changes were what you were expecting.

Hospital discharge prescriptions and hospital discharge notes often differ from one another. If you have discharge notes, hand them and the prescription to the pharmacist so that they can work out any discrepancies before they dispense your medicine.

Pharmacists are part of your healthcare team

They spend a lot of time each day on the telephone talking to prescribers about the medications and potential interactions, side effects, and doses. They can check with your specialist if you have a query between appointments about whether to take this “as well as” or “instead of” what the GP prescribed. The pharmacist can also let you know when the special number needed to fund some medicines is about to expire. Pharmacists have access to the Pharmac funding criteria for medications. They are up-to-date with all the rule changes and can let you know if your medicine is about to change brands.

If you are not sure, check with your pharmacist

If you have a medication query, speak to the pharmacist. Never feel you are intruding. Even when the pharmacist is busy, most enjoy talking to people one-on-one about their medicines. This is what they trained for. People don’t become healthcare professionals if they aren’t interested in helping people achieve the best possible health outcomes.

OUR impact

July, August and September are busy months for our Finance and Fundraising teams as we undergo our audit and complete reporting and accountability for some of the larger contracts and grants.

We would like to share with you our community who support and donate to us, a snippet of our key highlights from our reporting. **Without you, this would not be possible.**

48.5% increase
in cases managed by Arthritis Assist Team

18% growth
in E-News subscribers

18% increase
in website visits

26% growth
in YouTube channel engagement

To meet rising demand, we've:

- **Launched a new online self-management program for people with RA (myRA)**
- **Expanded our resource library of video and written content**
- **Run more webinars and Zoom cafes**
- **Continued to strengthen our partnerships at the national, regional and local level.**

Comments from people who used our Arthritis Assist Service.

"I have suggested to two clients that they contact you for more specific information that I was not able to answer. This is in addition to GP clinic visit."

"It's a great support system. Arthritis is a cruel disease and it's hard to get support from GPs and friends and family who may not really understand how difficult and painful it can be."

4.3 star rating for our service to clients

About our webinars:

"[I liked] learning tips from each other on what works as well as knowing that I'm not the only one who has sleep issues."

About our work in the community:

"I've had gout for over 30 years and never understood when the doctor said, "your uric acid is high", he (Arthritis NZ staff member) explained it so well and now I know."

"Your ability to convey complex information about gout in a relatable and understandable manner resonated profoundly with our attendees. J and his family, in particular, were deeply moved by your explanation and shared their heartfelt gratitude for the clarity you brought to understanding uric acid and managing gout."

YOUTH COMMITTEE PROVIDES strong voice for young people and parents

Patricia Thompson

Arthritis NZ has taken a significant step towards empowering young people affected by arthritis and related conditions through the establishment of its Youth Advisory Committee. Launched in late 2023, this eight-member committee evolved from a youth advisory group formed by friendships cultivated at family and teen camps. The committee serves as a direct link to the Arthritis NZ Board, providing a platform for young people and their parents to voice their experiences and needs.

With a focus on creating youth-centric resources, planning camps, and developing initiatives to support young individuals with arthritis, the committee is making strides in addressing the unique challenges faced by youth living with these conditions.

A passion for giving back and advocating for young people is what drives the members of Arthritis NZ's Youth Advisory Committee.

The committee is spearheading a number of projects based on youth and parent feedback and also taking a lead role in designing and planning camps. **Georgie-Anne Cox**, Community Lead for Arthritis NZ, says a number of inspirational young leaders had come through the camps.

"A very solid friendship group from the 2021 camp wanted to make a resource and worked together to create a journal for young people with arthritis. We recognised there was no direct stream into the board for youth so the advisory group was formed, and ultimately the committee. It's very valuable. A lot of what they do is around resource design, making sure our resources for families and children comes from youth for youth. That is what families have said they want," explains Georgie-Anne.

When a young person is diagnosed with arthritis they and their families get a lot of clinical information from rheumatologists but not social information. Things like how to self-manage conditions so they can enjoy going to school and be included in things like sport and PE.

"It is important to learn how to explain to friends and teachers about the conditions, as every day will look different. Some days youth will feel great, other days they will have more symptoms of their condition," she says.

How it started

Committee member **Jasmine White** says that at the end of the 2021 camp, a group of friends discussed how they wanted to stay in touch through more than social media.

"On the last night we stayed up late planning the youth advisory group. We wanted to show that the youth experience is very different, the struggle is different, to someone who is diagnosed in their 60s or 70s – because you are still finding yourself and you have to deal with a lifelong illness on top of that.

"We wanted policy to come from lived experience, initiated by young people from the voice of young people. **Philip Kearney** [Arthritis NZ CEO] really took that on board, and it became a full-blown thing."

Committee member **India Heron** says: "We talked until after midnight and shared ideas about what we would like to do. Within a few weeks we had permission from Philip to set up the advisory group. That group is larger and more relaxed, and the committee is more formal and is where we talk about the funding and the logistics of what we want to achieve."

Camps

The committee is planning a one-day camp for the Christchurch region. "That is to help maintain connections in between camps and has also come out of feedback from parents," says committee member **Jacob Attwood.** "We are co-ordinating that and, if that goes well, we hope to expand to other areas."

Tessa Orange says an important aspect for her as a committee member is the ability to help get other young people involved in events.

"We all know how isolating it can be to have arthritis at a young age. When I went to teen camp at 13, I was feeling that way and definitely needed to meet other young people with arthritis. From there I just wanted to keep giving back. We've come together to share ideas about how we could reach youth with arthritis in New Zealand and be a sounding board for young people to go to. I think other young people find it easier to talk to us and share ideas and we can feed those forward to the Board."

Jasmine says that, with the launch of the committee, it feels like everything the advisory group has worked towards has been set in stone.

"Whether it's regional or national, such as an awareness campaign for youth, we know we have the Board's guidance and backing to be able to drive what we are trying to do. We are currently looking at a youth strategy. It is really good to know we are changing things so young people with arthritis don't have to face the barriers of understanding that were there in the past. I count myself very fortunate to be able to work with this group and be part of creating change. In three years, we have built a solid youth focus in the organisation. Arthritis NZ is pioneering in that way, and it is a huge privilege to be part of it," says Jasmine.

Jacob Attwood AGED 19

Jacob was diagnosed with arthritis when he was 11 and attended two family camps before becoming a camp leader. He is studying for a commerce degree at the University of Auckland.

Thomas Flashoff AGED 17

Thomas was diagnosed with arthritis at 11. He attended teen camps and became a camp leader. He is undertaking a beef and sheep farming cadetship through the Growing Future Farmers programme.

"The committee and group provide valuable lived experience to provide input into ideas and decisions. I love that we are able to help other kids and teens to have the resources that we didn't necessarily have – and that we can help them."

India Heron AGED 19

India was diagnosed with arthritis when she was 11 and has since been diagnosed with a number of other comorbidities and rare disorders. She attended family camps and got involved with volunteering with Arthritis NZ. India aims to become an advocacy journalist and has contributed a number of articles to publications. She is also a volunteer for several other organisations including Parafed Bay of Plenty.

Tessa Orange AGED 22

Tessa was diagnosed with arthritis at the age of 4 and attended family and teen camps. She gained a nursing degree in Christchurch, inspired by her experiences in healthcare. She's now in her first full year of nursing.

Jasmine White AGED 22

Jasmine was diagnosed with arthritis at 16, rheumatoid arthritis at 17 and secondary osteoarthritis at 19. She graduated from the University of Canterbury with a Bachelor of Youth and Community degree with a minor in health education and is now doing a Masters of Teaching and Learning.

Rihanna Gaskell AGED 17

Rihanna was diagnosed with Chronic Recurrent Multifocal Osteomyelitis at the age of 3 and attended a family camp and then teen camps. She is planning to study for either a Bachelor of Sport or Bachelor of Applied Science, majoring in sport and exercise.

Matthew Hutton AGED 17

Matthew was diagnosed with arthritis at the age of 8, and then attended family and teens camps. He is in his final year at high school and planning to start a building apprenticeship.

Gabby Shepherd AGED 18

Gabby was diagnosed with arthritis at birth. She is in her final year at high school and hoping to begin studying for a Bachelor of Medical Imaging next year. She attended families and teens camps.

"I enjoy keeping in touch with people who are going through the same things I am. We all get on very well and have longstanding friendships. The benefit of the committee is that we can all relate to the things other young people and their parents are sharing with us and help them with what they might go through."

Need help with your arthritis?

Arthritis Assist can support you with managing pain, staying active, and understanding your arthritis.

Call: 0800 663 463
Email: info@arthritis.org.nz

FIVE-YEAR-OLD LUCAS faces arthritis with courage

Originally published in Getting Out There 2024-2025

In the world of childhood adventures and growing up, some journeys are more challenging than others. This is the story of Lucas Duinkerke, a remarkable young boy who faced an unexpected hurdle in his early years. At just one year old, Lucas encountered a formidable opponent that most people associate only with older adults: arthritis.

"My name is Lucas. Papa, Mama and I would like to tell you a special story about me:

When I was about one year old my immune system stopped working properly. Instead of staying quiet when I had no illness my immune system decided to start attacking my joints. I stopped trying to crawl and would sit around, but even that got sore too. I would wake up several times a night crying in pain. I could not walk or even stand. My knees started to look like tennis balls, it was hard to open my mouth and then it became hard to stretch out my arms to take hold of things. I was sore all the time. Mama and Papa couldn't figure out what was wrong.

I had to see lots of doctors and have lots of different tests. Finally, when I was two years and nine months old, a special doctor called a paediatric rheumatologist figured out something unique about me... I have a special type of arthritis called polyarticular juvenile idiopathic arthritis (JIA). I know that this might sound surprising, but kids get arthritis too! My Mama and Papa did not know this either when I was diagnosed.

Arthritis is a disease, but you don't need to worry because you and my friends can't catch it from me. It's like my body's immune system is having a party in my joints and it doesn't know when to stop.

Getting injections

At first each week I would have a homecare nurse come and give me two injections. Then I had to stop one of my medicines as it was too hard on my body. My Mama learnt how to give me my injection, so the homecare nurse didn't need to come. The special medicine in the injection is to calm my immune system down. My Papa would hold me in a big strong cuddle and my Mama would give me the injection in my upper leg. I do not like injections! They are very sore, and I would get scared at the thought of needing to have them. Just this year I had a port-a-cath (port) inserted into my chest wall. Now I go into the hospital every three or four weeks to have my medicine via an IV infusion. The IV line is hooked up to my port. Now I don't need injections. I can even have my blood tests taken through the port!

Learning to walk

When I was first diagnosed, I couldn't walk, and I would use special equipment like walking frames to help me move. A month after I started on my medicines, I took my first steps and then began walking by myself. By the time I was four years old I didn't need my walking frame anymore. Walking and moving still made me tired, and I needed lots of physio help and swimming lessons to get my body stronger. I then had splints on my feet to help them be strong, but now I don't need those anymore either!

My family likes to go on lots of walks and climb all the mountains around Whangarei. For a long time, Papa or my oldest brother Caleb would carry me ALL the way. This year I managed to climb part way up Mt Manaia and Mt Parihaka by myself. Then Papa or Caleb helped carry me the rest of the way up and down. Last year we met **Justin Hill** for the first time. He also has arthritis, but it is not the same one as mine. I walked The Loop with him three times when he was doing his walk for Arthritis NZ.

I ran in my school cross country for the first time this year. It was hard work, and I got even sorer doing it; but I still did it and everyone was cheering for me at the finish line.

Families Camp

This year Arthritis NZ sponsored Mama and I to go to the Families Camp. I got to fly in an aeroplane for the first time and ride on a big bus. The camp was in Matamata. I had fun meeting other children who also have arthritis. I got to go on the super big hydro slide – even Mama went on it with me!

Thank you for reading my story and understanding."

Together we can transform lives and ensure all New Zealanders with arthritis can live well.

People we love are suffering from arthritis. Many forms of arthritis can be managed well with the right support, education, and resources.

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