JOINT SUPPORT



Living well with arthritis



IN THIS ISSUE - AUTUMN/WINTER 2024

QE Health: from illness to wellness

Teens and Families Camps change lives

Summer Scholarships

PHILIP'S Column



Welcome to our autumn edition of Joint Support.

As we approach the middle of the year, I look forward to clarity of Arthritis NZ's increasing role in the ever-changing health sector.

We are looking to work closely with a range of partners to ensure our support for those with arthritis grows. We will continue to advocate for increased services and shorter wait times for those with Osteoarthritis and Rheumatoid Arthritis and increase awareness of the needs of people with Gout arthritis, including simplifying the process to obtain medication to those who suffer from it.

On page 4 we feature the QE Health Centre (formally QE Hospital), which will I am sure bring back many memories for those who received treatment at this iconic facility in Rotorua. Shortly after I started with Arthritis NZ, I attended a reunion in Lower Hutt for those who had received care at QE. We would love

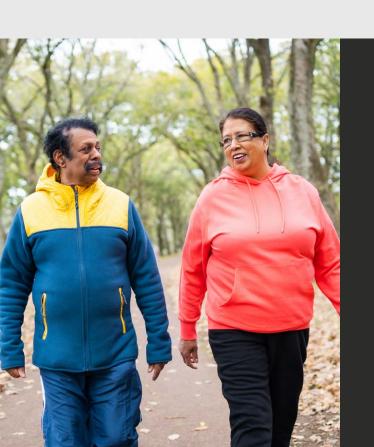
to hear of your experiences and memories of the facility. You can send us an email with your recollections to info@arthritis.org.nz.

As ever we greatly appreciate your support for our work. Our last appeal raised just over \$36,000 which helped us provide services for young people with arthritis to support them as they transition to adulthood. This work wouldn't be possible without your support. If you have received Joint Support for a few years, you may remember Phoebe Nielsen from previous editions. We've included an update on how Phoebe is managing adulthood as well as arthritis.

I wish you all the best of health as we head into winter. It's a chance to dust off those winter woollies and keep moving as much as you can.

Warmest regards

Philip KearneyCEO Arthritis NZ



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

WELCOME TO ARTHRITIS ASSIST How can we help you?

Our team of health coaches, a pharmacist, and a healthcare educator are here to help and support you.

We provide free compassionate and empathetic assistance and can help guide you through navigating the healthcare system, managing pain,

offering wellbeing support, providing nutrition advice, and recommending suitable exercises tailored to your needs.

Don't hesitate to reach out - we're here to support you every step of the way.

Call us on 0800 663 463 or email at info@arthritis.org.nz

MEET THE TEAM:



ALAINA our Healthcare Educator

What strategies do you find most effective to provide relief and support for people with arthritis?

"Supporting individuals with arthritis involves a holistic approach focused on lifestyle adjustments, education, and access to resources. I also recommend heat and cold therapy for pain relief, incorporating antiinflammatory foods into their diet, and suggesting stress management techniques like meditation or yoga can contribute to overall well-being."



REBECCA our Health Coach

What motivated you to specialise in helping individuals with arthritis and how does this passion reflect in your approach as a health coach?

"My passion to specialise in arthritis was fueled from my own personal journey to living well with Rheumatoid Arthritis. I am a big advocate for lifestyle medicine such as wholefood nutrition, exercise and movement, good sleep hygiene and mindfulness. Addressing these factors in your life can really help determine how well you can live with arthritis. "



LINDA our Pharmacist

In your view, what are the most rewarding aspects of being a pharmacist?

"Most of the examples are very personal or very low points for someone and it is an honour to be there for them. All I can do is listen, be their sounding board, be that safe place to complain about the unfairness of the world and agree that the world is an unfair place. Those are the days when I come home and think: I am pleased it was me who got to be there for that person."



QE HEALTH CENTRE: FROM ILLNESS to wellness and health

"A safe place" is how **India Heron** describes the unique QE Health Centre in Rotorua. Unique in New Zealand, the centre offers a holistic approach, with rheumatology specialists, pain management educators, physiotherapists, occupational therapists, dieticians and psychologists all working under one roof.

The clinic has residential facilities so people can stay at the centre when needed and takes advantage of the natural thermal wonders offering mud and heat therapies.

For India, who lives with Juvenile Idiopathic Arthritis (JIA) and a number of other conditions, it has been life-changing.

"I suffered PTSD (post-traumatic stress disorder) due to my hospital experiences over the years. I've had instances where my pain hasn't been believed, and at times, the treatment has made things worse. But QE Health Centre has taken the stress out of my condition. It's like walking into a lovely home, where you know everyone, they know you, and they all work together to help you manage your condition".

India's sentiments are echoed by QE Health Centre Nurse Practitioner Coordinator Rachel Gregory:

"For some people, it's the first time they have felt listened to. For

many people who attend our two-week course, they've already seen doctors and specialists. They feel like coming to our clinic is the end of the road. But it's not long before they feel truly supported, often for the first time."

The two-week course covers therapeutic and educational topics such as understanding what pain is, the role the brain plays in our experience of pain and how that can be changed. It also covers pain medications and includes information on alternative medicines such as Cannabidiol (CBD) oils and various vitamin regimes that can help reduce inflammation.

Patients set goals, learn how to manage stress, change their diet so they can reduce inflammation, incorporate movement into their daily routine, and build healthy routines they can take home with them.



"QE Health Centre has taken the stress out of my condition. It's like walking into a lovely home, where you know everyone, they know you and they all work together to help you manage your condition."

- India Heron, patient

One of the biggest challenges Rachel sees people struggle with when they first come to the clinic is accepting their condition. "There is a grief process that people have to go through. Many may have been fit and healthy before they got their condition, and some may have had to leave their jobs. We help people reach acceptance and help them understand that they can still have a rich and rewarding life. I love seeing people leave empowered and positive after their two weeks with us," says Rachel.

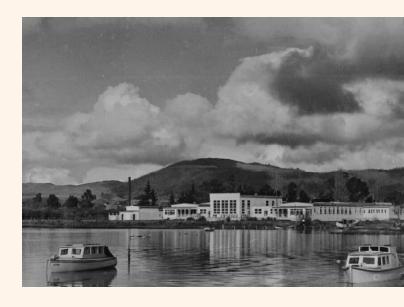
The QE Health Centre started in 1942 as a hospital for returning members of the Second New Zealand Expeditionary Force offering physio and occupational therapy to heal and assist servicemen back into civilian life.

In 1948, the hospital changed its name to Queen Elizabeth Hospital and started treating patients with arthritis, rheumatism and associated complaints.

In 1993, the hospital became a private company called QE Hospital and the Trust represented various stakeholders including Arthritis NZ.

In 2003, the hospital changed it's name to QE Health and Wellness with the focus shifting from 'illness' and towards 'wellness'. In February 2023, a new 3000sqm facility opened, delivering a unique holistic health and wellness service.

With the current health changes in place, the clinic can no longer take referrals from outside the region, but does accept private clients from anywhere in New Zealand.





Have you benefitted from care at QE Health Centre?

We would love to hear your story. You can email us: info@arthritis. org.nz or send us your story in the enclosed postage paid envelope.

SEX, DRUGS AND ROCK 'N' ROLL:

Meet Arthritis NZ's Research Manager

Arthritis NZ Research Manager Dr Richard Griffiths says his own research career "covered sex, drugs and rock and roll" and he isn't joking.



Richard, who joined the organisation in 2021, has worked on a wide range of research projects over the past two decades. However, he says his current role is the best.

"I love it," says Richard. "It allows me to draw on every experience at every level as a researcher and it is dealing with very interesting and evidence-based knowledge.

"I learn something new every day. It is so rewarding and when you have that connection with a job you get very passionate about it."

The 'rock 'n' roll' experience came through Richard's Master's and PhD studies which included researching New Zealand's punk culture, and 'moral panic' and media coverage around the Goth movement in young people.

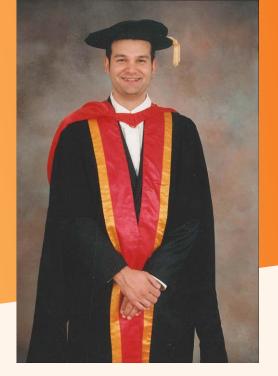
Then there were 16 years working in research, evaluation and as a consultant including around youth, community development, transport, health, undiagnosed HIV, dementia daycare programmes, methamphetamine and MDMA use.

Richard feels a strong personal connection to his role. Seven years ago he was diagnosed with Gout arthritis and now takes allopurinol daily.

"When I saw this role advertised, I felt like it could have been written for me," he says. "I had been working in the commercial research industry but, during lockdowns, looked critically at what I wanted to be.









"I decided I wanted to go back into a not-for-profit or charity space, because that's where I had done my best work and met the most amazing people."

He manages stakeholder engagement and research funding applications and works to challenge potentially harmful misconceptions and misinformation around arthritis.

"Misinformation is something I deal with every day. I worry that people are not getting the best advice. If someone can't afford to go to the GP there is a risk they may go online and find misleading advice and make decisions that are not good for them.

"It is very important that people know to look at information that is evidence based. All information on our website comes from working with specialists, allied health professionals and researchers."

Richard attends, and gives presentations at events and conferences, including specialised symposiums for rheumatologists and rheumatology nurses.

"I really enjoy that. The information we gain from rheumatology professionals and from academics and health researchers enables us to say to arthritis communities: 'Have you tried this? It might help'."

Richard also led the establishment of the Arthritis NZ Lupus/SLE Postdoctoral Fellowship. The inaugural Fellowship, made possible through a bequest from the late Dorothy Ashbolt, was awarded to Dr Chunhuan Lao from the University of Waikato.

"That has been amazing. Dr Chunhuan Lao has already published three internationally peerreviewed journal articles and completed the first Lupus/SLE incidence and prevalence study for New Zealand to be undertaken in 40 years.

"That important piece of work has filled so many gaps and built a base that can be used in so many ways to better understand what is happening for Lupus patients.

"My work with Arthritis NZ enables me to build on what I have done in the past. I am not (usually) conducting my own research, but I'm still learning things every day to help us to improve the lives of people that live with arthritis.

"It's about empowering people to have better conversations about what is happening to them, to help achieve improved outcomes and to have less pain through the use of research and informed policy."





Arthritis NZ staff attended the Access Aotearoa rally in Wellington, March 2024

ADVOCACY FOR people with Arthritis

Arthritis NZ's advocacy team assists people in navigating the health and support systems and pinpoints barriers to treatment and support services, which we can raise with providers and policymakers.

Current priority advocacy issues we are working on are:

- The development of a national model of care for people with Osteoarthritis, facilitating early intervention and management rather than waiting until surgery is required;
- The implementation of a plan for healthcare for people with inflammatory arthritis; and
- Working towards making allopurinol easier to access for people with Gout arthritis by reclassifying it to enable community pharmacists to prescribe it.

Each of these issues can involve working with Health New Zealand - Te Whatu Ora, Pharmac, health professionals and members of parliament.

An important part of advocacy is telling the stories of how people are affected by arthritis - whether it be in the workforce, caring for children, or needing support with everyday tasks such as housework, and managing barriers to accessibility such as stairs and heavy doors. In the past year, access to GP services has been a significant issue and has been brought to our attention frequently. Similarly, access to home support services continues to be problematic, and we are aware that the proposed return of prescription charges is also a concern.

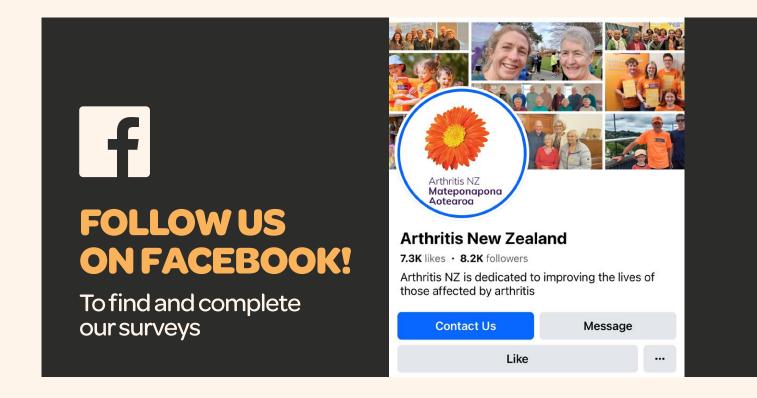
While our advocacy focuses on improving systems and policies, we also provide advocacy support for individuals. Recent cases have included:

 People living with inflammatory arthritis who have been prescribed biologic medications overseas and wish to come to Aotearoa have requested assistance with travelling with

- medications and ensuring their treatment can continue here, despite the availability and the criteria for biologic medications being more restricted in New Zealand.
- Consumers requiring support when restrictions for biologics lead them to seek information about criteria for restricted access medications or medications not vet approved by Pharmac. While Arthritis NZ cannot resolve these problems, we can raise the concerns with rheumatologists and policymakers and help people learn about how the approval process and special criteria work. We work with other organisations to highlight these issues and advocate for fewer restrictions on these medications.
- Regular contact with those on surgical waiting lists, once again, while we cannot resolve the issue of long surgical waits, we can provide advice on navigating the health system and we continue to advocate for improvements.
- Those trying to understand Work and Income procedures often find these difficult and we can assist in understanding what can be available.
- People who need advice and support in their workplaces have contacted us for help in managing employment issues, and once again, advocacy support can be available.

To help us keep our work meaningful to people with arthritis, we run regular surveys and polls online. If you do not have internet access, call us on 0800 663 463 and leave your name, address, phone number and the concern you have, and we will consider raising it

when we look at the issues brought to our attention. We also encourage you to share your stories with us so we can use them to strengthen and support our work. If you would like to share your experiences, call us or drop us a message at info@arthritis.org.nz.















TEENS CAMP

2024

From Wellington Airport to the serene landscapes of El Rancho Camp, Teens Camp 2024 was a beacon of connection and empowerment for teenagers and young adults with arthritis.

As attendees trickled in on 26 January, the air buzzed with anticipation. These teenagers and young adults travelled alone, many for the first time, navigated multiple flights, to finally meet a group of peers they had never met face to face the first of many experiences for them at Teens Camp.

The bonds formed during Teens Camp 2024 were visible from the get-go. Led by our enthusiastic youth leaders, participants dove headfirst into team-building activities, breaking the ice with laughter and shared experiences. From guessing each others ages and locations in New Zealand in a charades-type game to playing challenging team-building games, the connections made are likely to last a lifetime.

The teens enjoyed taking part in challenges, including raft building and kayaking, rock climbing, soft archery, and more, with each activity fostering a sense of accomplishment and group camaraderie.

"For me, one of the standout moments of Teens Camp 2024 was the educational session led by Nurse Specialist Nicola Gray. With a focus on self-management strategies for transitioning into adult rheumatology care, attendees displayed unprecedented engagement and curiosity. Nicola's expertise, coupled with the willingness of youth leaders to share their lived experiences, facilitated open and meaningful discussions about navigating the complexities of managing arthritis into adulthood," said Georgie-Anne Cox, Youth & Community Coordinator at Arthritis NZ.

By providing a safe and supportive space for young people with arthritis to connect, the camp not only fostered friendships but also instilled a sense of belonging and empowerment.

These gatherings have a profound impact on the mental health, self-esteem, and overall quality of life of participants, underscoring the importance of continued support and community engagement for people with arthritis.

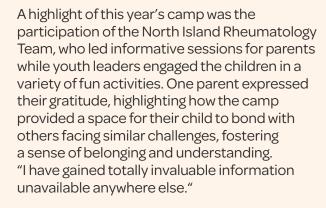
Teens Camp 2024 would not have been possible without the generous support of donors and supporters. Their contributions, alongside the dedication of our volunteers, ensure that future generations of teens and young adults with arthritis have access to transformative experiences like Teens Camp.

FAMILIES CAMP

2024

The Families Camp not only provides practical support and education but also fosters a sense of community and hope for families affected by juvenile arthritis. It is a testament to the power of connection and shared experiences in overcoming challenges and building resilience.

Held in mid-March at the picturesque Totara Springs camp in Matamata, this year the camp welcomed 17 families affected by juvenile arthritis and other autoimmune conditions.



The camp's success is made possible by the generous support of funders, allowing it to remain a free experience for families.



"*Stacy* gained so much confidence at this year's camp. She's finally met other kids on the same medication as her and it meant so much to her. She got to challenge herself and make friends which is just amazing."























LIFE IS ON THE MOVE for Phoebe Nielsen

Ten years ago in Joint Support we featured a 13-year-old, Phoebe Nielsen, who had recently been diagnosed with Juvenile Idiopathic Arthritis (JIA) and over the years we've followed her journey into adulthood.

During the 2020 lockdown Phoebe was one of our enthusiastic volunteer content creators featuring in a series

of videos for our 'Arthritis Diaries' series on YouTube.

She also volunteered her time and story for Arthritis NZ's 2020 annual appeal.

We recently caught up with her again to find out how she is managing arthritis as a young adult.

Phoebe is embarking on a new career, has a new partner and is set to visit Europe in June for the first time. Phoebe started her career in an eating disorder clinic. She saw how lonely and isolated her patients were, which she could identify with from having JIA.

"JIA is also a lonely health condition. I used to isolate myself socially and part of my wellness journey has been to push myself back into my relationships because it just helped me to feel better."

Newly graduated in occupational therapy, Phoebe is now working at North Shore Hospital's Orthopedic Department where she helps people with hip fractures and breaks, often caused by Osteoarthritis. She's also found time to complete a post-graduate certificate in mental health and addictions and is just finishing training in Eye Movement Desensitisation and Reprocessing (EMDR), a trauma therapy.





Thank you to all of our wonderful supporters who donated to our last appeal to help us support young people with arthritis as they transition to adulthood. So far we've raised just over \$36,000. Thank you!

"A lot of people with chronic health conditions can face uphill battles with their mental health and have often suffered a lot of trauma, especially if their pain is not believed or understood. I was in and out of hospitals for years, and there were definitely clinicians who were amazing and some who were unsupportive. I guess this has made me passionate about really trying to see and hear the whole person I help because getting well and staying well is a holistic journey."

As part of her journey, Phoebe decided to come off her medication as it was affecting her immune system, which meant she was often sick and had to miss out on social events. "Sometimes I need to take a different shortterm medication, and I've had to pace myself. In the past, I would go on these boom and bust cycles where I'd do too much and then spend days recovering. It's still a balance, but I'm learning, and Pilates helps a lot," she says.

She's managing so well that she and her partner Nick are planning seven weeks in Europe in June. Her relationship with Nick has also been a journey and she says that in the beginning he would joke about her condition because he didn't fully understand it, but now he has committed to understanding and is supportive and the couple have built trust and confidence together.

Her advice to anyone else with arthritis is to not give up.

"Don't hide away at home. If you want to do something figure out a way to do it. It might mean adjusting things and doing it in different ways. For me to play netball, I had to learn that I could only play half the game, I had to wear gloves and spend time in a hot bath afterward, but I could still play".

For Phoebe getting the most out of life is learning how to nuture both the mind and body because both need to be looked after for either to be ok. It's a passion she intends to share with her patients throughout her career.

STUDENTS EMPOWERED by Summer Scholarships

Arthritis NZ funds up to six summer scholarships each year, enabling academics and health professionals to fund postgraduate or final year undergraduate students to undertake research.

Arthritis NZ Research Manager Dr Richard Griffiths said many Summer Scholarships are part of larger research programmes.

"Some are small snapshots of bigger issues, and part of larger research programmes on issues or concerns that impact people living with arthritis in their everyday lives.

"It is an opportunity for student researchers to focus on something in depth over a few months. Once they have finished, we ask them to reflect on their experience and it is great to hear them say 'this has empowered me to want to do more research in this field'."

The effects of hot-water immersion on pain for those with mild to moderate hip or knee osteoarthritis.

Supervisor: Dr Brendon Roxburgh, Postdoctoral **Fellow and Practicum** Supervisor, Department of Surgical Sciences, University of Otago, Dunedin.



Scholar: Aliya Mottus

Existing evidence suggests that heat therapy, such as heat packs and balneotherapy (bathing/ spas), may provide therapeutic benefits due to the increases in blood flow and elasticity of connective tissue. However, there is a shortage of research directly investigating the effects of hot-water immersion on joint paint for those with Osteoarthritis.

Aliya's Summer Scholarship research aimed to test whether the analgesic effect of immersion in hot water at 40°C would last longer in people with mild or moderate hip or knee Osteoarthritis and if it might translate to increased physical activity, potentially preventing Osteoarthritis progression.

The study found that joint pain decreased during both types of immersion, with the positive effects of lower-leg immersion lasting longer.

"It is only a very small sample, but it is important because if this was a bigger study, with more people, what would that find?" said Richard. "Summer Scholarship funding can be a stepping stone to provide opportunities for larger-scale research."

A cross-sectional study of systemic lupus erythematosus (SLE) within the Waikato region. Lupus in the Waikato: Demographics, Diagnosis and Treatment.

Primary Supervisor: Professor Ross Lawrenson, Professor in Population Health, **Medical Research** Centre, Te Huataki Waiora School of Health, The University of Waikato.



Scholar: Daniel Darlington

Dr Chunhuan Lao, recipient of the inaugural Arthritis NZ Lupus/SLE Postdoctoral Fellowship, has estimated the incidence and prevalence of systemic lupus erythematosus (SLE) in New Zealand using the national administrative datasets. However, these did not include data on the date of diagnosis and severity of disease at diagnosis.

This project aimed to fill this information gap by providing important information such as the date of diagnosis, patient characteristics at diagnosis, disease severity, and patient experience.

Daniel was based in the rheumatology department in Waikato Hospital and used lists of Lupus patients that attended the clinic between October 2021 and February 2022, identifying 105 patients for the study.

He found that most patients could be regarded as definitely having Lupus according to standard European and American diagnostic criteria but for 29% there was a diagnostic uncertainty.

While 69% of the sample were of European descent, the remainder comprised 17% Asian, 11% Māori and 4% Pasifika patients. There was also a greater proportion of female patients, which is consistent with previous studies.

The study also highlighted that kidney disease attributed to SLE was more frequent in the Asian group compared to other ethnicities.

Results from the research will be presented at the Waikato Biannual Research Seminar and the abstract will be published in the New Zealand Medical Journal.

Intentional non-adherence in patients with inflammatory arthritis

Primary Supervisor: Dr Rachel Murdoch. Senior Lecturer -Medicine, Clinical Research Centre, **Faculty of Medical** and Health Sciences. **University of Auckland**



Scholar: Lachlan Fleck

This scholarship was part of a larger project at the University of Auckland, researching intentional non-adherence (not taking medication) with methotrexate in patients with inflammatory arthritis.

Methotrexate is the most common and preferred first-line disease-modifying antirheumatic drug used for inflammatory arthritis. This project will allow greater understanding of patients' reasons for deciding whether or not to take methotrexate and will help clinicians address patients' concerns more effectively and support people in taking methotrexate.

Lachlan conducted interviews with 42 patients and assisted the research team with their preliminary data analysis of the interviews or data.

The strongest motivation participants had for wanting to stop taking their methotrexate was the associated side effects. Of the 42 people interviewed by Lachlan, 24% agreed with the statement that methotrexate 'is harsh on my body', while a further 36% reported nausea to be a notable side effect. Most of these patients felt this was directly related to their medication.

Characterisation of the p53 isoform Δ133p53β as an inflammatory driver in osteoarthritis

Primary Supervisor: Dr Adele Woolley, Senior **Lecturer**, **Department** of Pathology, the University of Otago, Dunedin.

Scholar: Ashmita Sharma

While x-rays and MRI scans can be used to confirm an Osteoarthritis diagnosis, results can sometimes be inconclusive. Additionally, what an image shows may not necessarily reflect the level of pain or disability someone experiences daily. Getting an early diagnosis is key, along with working out what activates, drives, and accelerates inflammation.

Isoforms are proteins that are similar to each other and perform similar roles within cells. Dr Woolley and her team had already identified that the $\triangle 133$ p53 β isoform is associated with a pro-inflammatory phenotype and poor prognosis in both cancer and more recently in Rheumatoid Arthritis.

It is hoped that this Summer Scholarship project will contribute to the body of international research on Osteoarthritis and be published in peer-reviewed journals and disseminated at conferences.









THE 2024 ARTHRITIS NZ Whanganui Garden Amble

The Garden Amble was held on Wellington Anniversary Day and offered a unique opportunity to explore the hidden gems and landscapes of Whanganui gardens. There are many lovely gardens in the Whanganui area, and this occasion allows the garden owners to show with pride the hard effort they have put into making an 'oasis' for themselves and indulging in their passion.

The Amble is more than just a garden tour; it's a celebration of community, creativity, and the enduring appeal of nature. It also raises much-needed funds for Arthritis NZ to continue helping people live well with arthritis.

Each garden on the tour offers a unique perspective on gardening, inviting visitors to explore, learn, and be inspired. Whether you're a gardening enthusiast or simply looking for a peaceful escape, the Anniversary Amble in Whanganui promises a memorable journey through some of the city's most beautiful and lovingly tended gardens.

A constant stream of visitors passed through the gardens on the lovely warm day and raised over \$8,000 for Arthritis NZ.

Thank you to all who volunteered to make this event a success. We look forward to the 20th anniversary of the Garden Amble on 22 January 2025.

SHARP NZ Golf Day

Sharp NZ once again backed Arthritis NZ -Mateponapona Aotearoa as principal sponsors of our annual golf day fundraiser for a fourth year.

This year teams teed off on 1 March in the summer sun raising funds to support the Families Camp held annually in Matamata. Families Camp offers children with arthritis and their caregivers a weekend of learning, fun, and bonding. You can see this in action on page 12 of this issue.

Team entries, sponsored holes, an auction, and numerous raffles and donations fueled the fundraising efforts. Both Sharp NZ and Arthritis NZ are immensely proud of the collaborative efforts that contributed to the success of the day for everyone involved.







Proud sponsors of Arthritis New Zealand

Good health changes everything



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.

By supporting Arthritis NZ you can help improve the lives of people with arthritis.



DEEPER UNDERSTANDING

We can provide personalised information packs, with the latest medical advice.



PRACTICAL SUPPORT

Advice for people about their arthritis through our Arthritis Assist service.



PAIN MANAGEMENT

Information about how to manage pain and feel better faster.



TO DONATE, SIMPLY SCAN THE QR CODE, OR VISIT

www.arthritis.org.nz

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If you would prefer, you can donate by direct deposit or internet transfer directly into our bank account.

If you donate via direct deposit, please email us with your details so we can send you a receipt.

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