

CreakyJoints Australia 2nd Patient Council Summit Summary

Melbourne 16–18 November 2018



About Us

“The CreakyJoints Australia Patient Council and team embody the spirit of living well despite these conditions.”

The CreakyJoints Australia Patient Council is a team of inspiring individuals from states and territories across Australia and New Zealand living with various forms of arthritis and drawn together by a common mission. Our mission is to empower Australians living with arthritis to put themselves at the centre of their own care by vocalising their treatment preferences and working in partnership with their healthcare providers. CreakyJoints Australia connects arthritis patients with current and relevant disease-specific information and support, across a spectrum of arthritis conditions via digital media.

Our second annual summit, held in Melbourne in November, was also attended by members of the CreakyJoints Australia management team and representatives from our US-based parent organisation, CreakyJoints, part of the Global Healthy Living Foundation (GHLF).

Attendees

CreakyJoints Australia Patient Council: Kasey Gardiner (Qld), Kate Grimwood (WA), Neen Monty (ACT), Sarah Clark (NZ), Alice Jones (NZ), Chrissy Maurice (NSW), Nicole Black (SA), Mel Boyd (Vic). **Absent:** Shannyn Meloncelli (Qld)

CreakyJoints Australia Management Team: Naomi Creek (National Coordinator), Rosemary Ainley (Writer and Editor)

CreakyJoints/GHLF US Management Team: Seth Ginsberg (GHLF Co-founder and President), Joe Coe (GHLF Director, Education and Digital Strategy)

Presenters: Seth Ginsberg, Naomi Creek (CJA National Coordinator), Joe Coe, Kasey Gardiner, Shilpa Venkatasalam (GHLF Associate Director, Patient-centered Research) (via conference call).



Summit Goals

- To ensure that the voices of the CJA Patient Council and team are leading the efforts in Australia and New Zealand. It is about us saying, "These are the issues we are addressing" and "These are the things we are going to do about them".
- To work out how best to communicate with the patient community in Australia and New Zealand and to leverage the digital landscape and networks we already use.
- To learn what the council members want to focus on, to discover everyone's strengths, and to explore ways that they can become active in their own countries, states, or territories.
- To help us to identify actionable areas.

"We are laying the groundwork so when things do take off, we are all ready." Seth

What we've been up to

Seth Ginsberg, Cofounder of Creakyjoints and GHLF, and Naomi Creek, National Coordinator of Creakyjoints Australia, opened the summit by welcoming all new and returning participants, introducing Joe Coe, GHLF Director of Education and Digital Strategy, and recapping on our achievements over the last year.

The Creakyjoints Australia team have been very busy. We now have around 2,000 members and our own [CJA Instagram page](#) alongside a dedicated national audience for CJA content published on the Creakyjoints global Facebook page.

Some of our key activities over the past year included:

- Establishing strong media exposure via TV, the internet, and print media for World Arthritis Day and arthritis awareness in general. Bringing our personal perspectives and experiences to the public via the media is a dominating objective for CJA and a great way for us to raise the profile of these conditions.
- Attending the 4-day Australian Rheumatology Association Annual Scientific Meeting in May as consumer/media representatives and having a CJA information stand in the main hall.
- Attending industry and health sector events in Melbourne, Sydney, and Canberra as CJA representatives.
- Planning and creating a host of new literature and resources for Australians and New Zealanders with arthritis and their families to be released in stages over the coming few years.

"Our name is getting out there. We appeared on Nine Extra, in Women's Day, and in a variety of other publications which was very exciting for us." Naomi



Health

4 WAYS TO MANAGE ARTHRITIS PAIN

National coordinator of CreakyJoints Australia
NAOMI CREEK reveals the top tricks

1 FIND YOUR 'PAIN TOOLBOX'
Learn to recognise your body's pain triggers and warning signals so you can have a range of coping strategies – a toolbox – for different scenarios.

"[T]hat hot and cold packs, stretching, meditation, or medication if you need it," says Naomi. "When your pain levels are low, it can be tempting to do too much. Learn to stop before you reach your limit."

2 EXERCISE

helpful ways to manage pain. "Be sure to wear supportive footwear and allow rest to aid recovery," says Naomi.

3 USE HOT & COLD THERAPY
"Generally speaking, if you have inflammation, cold therapy is best," says Naomi. "If your joints are stiff or you have strained muscles, heat works well to relax the area. Without bags, hot water bottles or stick-on heat pads are great for warmth, and ice spray, ice blocks or a frozen bag of peas wrapped in a tea towel are always handy."

4 HAVE SEX
"Yes, you read that right! The endorphins released during sex are a natural pain reliever," says Naomi. "However, chronic pain can make both sex and intimacy difficult to get excited about. Open communication with your partner is key – using

Summit Highlights

The summit weekend was jam-packed with exciting presentations and roundtable conversations on the key focus areas. These are some of the highlights.

Patient Empowerment in Doctor/Patient Relationships

Often, doctors say one thing and patients hear something else and vice versa. We looked at the possible ways we can act to get doctors and patients communicating better in meaningful ways. Some of the barriers to communication we discussed included:

- Gender bias in diagnosis and treatment and common perceptions of invisible illnesses.
- The lack of adequate training and education of health professionals about arthritic conditions. We trust them, but many don't have adequate knowledge to provide us with optimal care.
- Access to rheumatologists. The long gaps between visits can prevent strong relationships forming.
- Differences in perception of what effective communication and disease control should look like.

Our Plans

- Focus on educating patients about the symptoms to look for, the questions to ask, and the tests to request.
- Increase awareness of comorbidities such as mental health issues and fibromyalgia.
- Get our own stories out there to inspire others to advocate for themselves.
- Create a range of high-quality accessible resources for different parts of the arthritis community.

“It is not just our conditions that we need to educate ourselves about, it's how other aspects influence how we present ourselves, how we request information, and what we need to arm ourselves with. So, it's a real holistic education process.” Kate

Using Social Media Channels Effectively for Patient Advocacy and Education

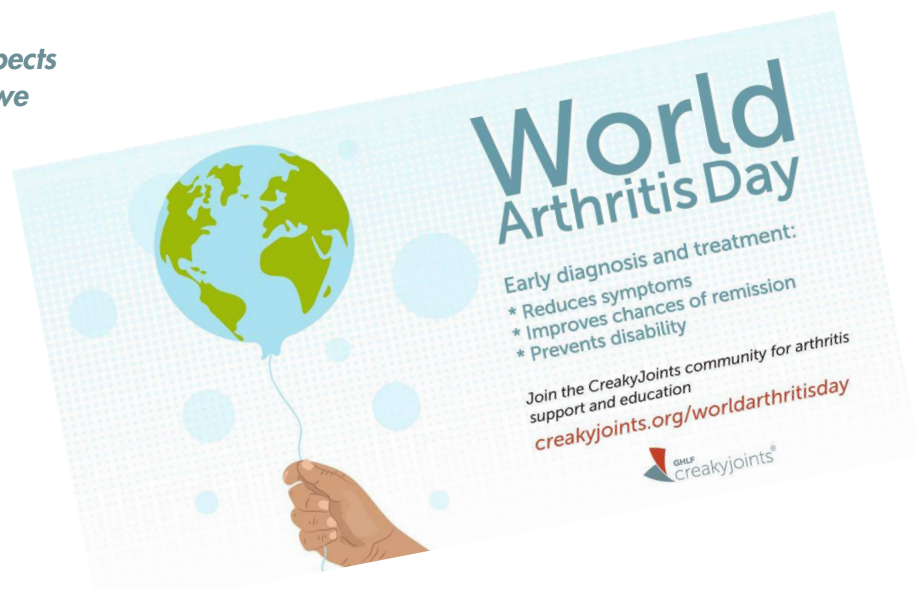
As people with chronic conditions, we want to see what we can do that creates the biggest impact using the least amount of energy. We can reach the people closest to us, those we know through social media, and then the larger population. We also want to reach the people that are furthest from us and that we have no connection to.

Creakyjoints already has a substantial global social media presence. Aside from specific healthcare and medication information, there is a lot more that connects us than doesn't. However, we want to create more opportunities for Australian and New Zealand voices to come through and to empower our own patient communities:

Our Plans

- Create a landscape analysis of what this aspect of the social media scene is like in Australia and New Zealand. This will help us formulate a plan to tap into the social media here in a meaningful way.
- Look for potential synergies with people and organisations already active in this space.
- Select some of the successful US social media strategies and adapt them appropriately for Australia and New Zealand.

“Everything we do starts with the question, ‘How does this benefit the patient and why does this matter to them?’” Joe



Raising The Voice of CJA Patient Council Members and Others Through Media and the Government

This workshop was presented by Kasey Gardiner, one of our Patient Council Representatives from Queensland. Kasey has an extensive background in high-level media roles for government departments and is currently studying a postgraduate degree in digital communications.

Kasey asked us to list the things that are important to us as people with arthritis. Other people will share the same priorities and be trying to navigate the same barriers we have faced. By sharing our stories with the media, politicians, and via our own social media networks we can inspire and empower them.

Our Plans

- Map out a calendar of affiliated events to promote awareness stories around them.
- Develop key messages and press releases for a handful of events we want to target each year.
- Have a focus on stories about people that have found successful ways to get on with daily life when faced with chronic illness challenges.

“We need to promote the message that we have these conditions, but we can live positive and happy lives regardless. That is why our stories are so powerful.” Kasey

Exploring the Barriers and Opportunities Around Patient-Centered Research, Data Privacy, and Digital Health Records in Australia and NZ.

CreakyJoints and the Global Healthy Living Foundation are already a globally-respected source of patient-centered research. We can use our shared infrastructure to capitalise on the amazing research opportunities available in Australia and New Zealand.

There are a number of registries that doctors can register their patients for, however, they can only write from their perspective, not ours. In the past, the voice of the patient has been largely absent in this area, but there is growing support for it now.

The research, security, and ethics regulations here are rigorous, but we respect that. We need to take the time to explore the best ways for us to become active in the arthritis research space.

Our Plans

- Develop a CreakyJoints Australia charter for our principles, research, and privacy. This would be included with all advocacy research submission documents we create.
- Explore a variety of innovative ways to work with arthritis researchers in Australia and New Zealand.
- Initiate action plans for pathways we want to pursue.

“We are changing it up. We’re saying, ‘No! We are patient-centred! We are all about how we feel and what we think and what our perspectives are!’” Seth

This is just a taste of the ideas that abounded at our patient summit. Other topics we discussed included what’s missing in manufacturer-provided patient support programs and the rheumatology nursing workforce shortage. These will also feature in our CreakyJoints Australia plans for 2019.

Where to from here?

After the summit, we were all filled with excitement and optimism for the year ahead. We now have a list of aggressive but appropriate tasks to work on. We’ve reinforced our core values and bonded even closer as a team. And, above all, we’ve created concrete goals to help us further stem the gaps between patients, communities, health professionals, researchers, and governments.

Follow the work of CreakyJoints Australia by visiting our website and signing up for our free membership. Contact our team for more information about CreakyJoints Australia and our Patient Council.

creakyjoints.org.au