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## **CreakyJoints Australia submission for the Parliamentary Inquiry into Childhood Rheumatic Diseases**

To whom it may concern,

Thank you for the opportunity to provide input into the Parliamentary Inquiry into Childhood Rheumatic Diseases.

### **About CreakyJoints Australia**

[CreakyJoints Australia](#) is a leading source of information for Australian arthritis patients and their families. Our website helps people find reliable information and support, offers opportunities to become involved in advocacy and also helps link patients to patient-centred research opportunities as they become available.

Our mission is to empower Australians living with arthritis to put themselves at the centre of their own care by talking about their treatment preferences and working in partnership with their healthcare providers. CreakyJoints Australia connects arthritis patients and their families with current and relevant disease-specific information and support across a spectrum of arthritis conditions (of which there are more than 100), using a diverse set of digital platforms. CreakyJoints Australia provides opportunities for members to proactively advocate for themselves and their families and to participate in research that will broaden the global understanding of arthritis management.

### **About the Global Healthy Living Foundation (GHLF)**

CreakyJoints was co-founded in 1999 in the US by arthritis patient and advocate Seth Ginsberg (diagnosed with spondyloarthritis at age 13) and social entrepreneur Louis Tharp. In 2007, the [Global Healthy Living Foundation \(GHLF\)](#) was established.

Founded in 2015, CreakyJoints Australia is part of parent company [GHLF Australia](#) and both are proud to be part of the Global Healthy Living Foundation.

GHLF advocates for improved access to healthcare locally and nationally, amplifying education and awareness efforts within its social media framework.

Central to this advocacy is the GHLF commitment to educate the community about the importance of early diagnosis and intervention, optimal condition management and long-term lifestyle improvements for improved health outcomes.

## About our team

GHLF prides itself on being a patient-led organisation. To us, this includes both being led by the needs and voices of our community and having people with chronic conditions in all of our leadership roles.

The CreakyJoints Australia team is led by Naomi Creek and Rosemary Ainley.

### Naomi Creek

Diagnosed at age 12, Naomi's personal experience living with rheumatoid arthritis has made her a passionate advocate for others living with arthritis and chronic pain. Her lived experience includes nine joint replacements, chronic joint infections, chronic pain and dissuading doctors. She believes patients must have access to the right resources to understand their condition and feel empowered to manage their own health.

Naomi spent many years volunteering with Arthritis Victoria (now Musculoskeletal Australia) as a community guest speaker, telephone helpline operator, consumer advisory committee member and board member. She spent 10 years leading the Young Women's Arthritis Support Group in Melbourne and is the inaugural National Coordinator for CreakyJoints Australia, a role she has held since early 2015.

### Rosemary Ainley

After being diagnosed with rheumatoid arthritis in 2007 (at 37), Rosemary now lives with several chronic health conditions including ankylosing spondylitis, fibromyalgia and type 2 diabetes. She joined the Young Women's Arthritis Support Group in Melbourne in 2008 and has been a co-leader of the group since 2014. Rosemary has been an active part of the CreakyJoints Australia team since it was formed.

Rosemary is a member of several online arthritis support groups and is passionate about empowering people with chronic illness by making health information accessible and spreading more awareness about both physical and mental health conditions.

Over the years, Naomi and Rosemary have been privileged to meet many adults who developed arthritis as children. It is their stories we now draw on to shape this submission.

Some members of our wider community have opted to share their own comments for this submission. We have included these in the appendix.

## Our responses to the Terms of Reference

### **TOR 1: Research into the causes of childhood rheumatic diseases, including prevalence levels of childhood rheumatic diseases in Australia**

The [Australian and New Zealand Childhood Arthritis Risk factor Identification Study \(ANZ CLARITY\)](#) states that around 6000 Australian children have a form of childhood arthritis.

We know that many people with autoimmune arthritis are genetically predisposed, yet we still have a lot to learn before we can confidently predict who will develop these conditions and when this might occur.

Through increased understanding of the genetic factors leading to autoimmune arthritis, we can develop targeted treatments for early disease stages to slow or prevent disease progression.

For these 6,000 children, better understanding of the causes of their condition and subsequent access to targeted treatments will help to reduce the ongoing impact of their arthritis on their quality of life.

Therefore we call for increased and ongoing funding from government and non-government organisations to support research into childhood rheumatic diseases.

**TOR 2: The health, social, educational and economic health impacts on children and adults who developed rheumatic diseases in childhood, their families and the broader community**

Most of the members of our extended community who developed arthritis as children did so at a time when there were few treatment options available in Australia and almost no support systems for children and their families. This was also in the pre-internet days, so access to reliable and up-to-date information about juvenile arthritis was extremely limited.

Challenges many have told us they faced as children include:

- Anxiety and isolation associated with missing out on things other kids were doing or feeling stigmatised for being the odd one out due to their pain and fatigue levels.
- Reluctance to disclose their condition or admit to the level of pain they were in.
- Doubt from others that they really were in pain and weren't just making it up for attention.
- Constantly being told that they were "too young to have arthritis".
- Very little support was available through schools and community organisations to help accommodate their individual needs.
- Bullying from other children.
- Jealousy from siblings due to the attention they received.
- Trauma from treatments, attitudes of health professionals and poor understanding of what was happening to their bodies.

On the positive side, some people shared happy memories of attending camps for children with arthritis and their families. This was often the first time many had met other children with these conditions and they felt a sense of acceptance and belonging.

As they transitioned from childhood through to adulthood, many people recalled:

- Feeling frustrated that they couldn't go out and party like other teens. They were often in too much pain to dance or too tired to stay up late. Some were also frustrated that they couldn't drink alcohol due to the medications they were on or they drank it anyway almost to rebel against their condition.
- Most had never met other children with similar conditions so they didn't get to share experiences with peers who understood what they were going through.

- Social support to help them transition to the adult healthcare system were scarce. Few knew how to access arthritis support groups for adults. Those that did often found that such support groups were focused on seniors with very different needs and experiences.

An issue that they faced, that isn't often spoken about, is the difficulty many had as young adults forming and maintaining close relationships, including sexual relationships. Some had issues with partners who did not understand their condition and treated them poorly. For example, some were told they were too needy or boring. Others already had significant joint damage and found sex very uncomfortable but didn't know what to do about it.

Some people had hip replacements in their early 20s and spoke of how this affected their sexual relationships and family planning dreams. Some women made the decision to not have children. The factors that influenced their decision included (but were not limited to) concerns about:

- The stress this would place on their body during pregnancy and childbirth.
- Possibly having to stop or change their arthritis treatments before and during pregnancy.
- Their ability to safely care for a child if their hands were too sore or weak to hold them or if they were too fatigued to manage the child's daily needs.
- Their potential to pass on the genetic predisposition for autoimmune conditions to their child.

We know of at least one lady who was told she could not have children due to the damage already done to her body and the treatments she was on. However, her desire to have children was so strong that she pushed for proper medical support throughout her family planning and pregnancy stages. She and her husband now have two happy and healthy girls.

The medical and financial challenges the families of our community members faced included:

- Lost earnings for parents who needed to reduce their hours or stop work to be a carer for their child.
- The transport and time costs to get their child to regular medical appointments, especially for families from rural or regional areas.
- The limited treatment options available for children at that time. For many children, treatment was often just aspirin or non-medicinal treatments such as hot-water bottles and rest. We know of one family that took their child to live with relatives in Europe while they sought more advanced treatment there.

Many of those who developed arthritis as children experienced flow-on complications from joint replacements (including further revisions and sometimes infections). We know this is a direct consequence of not having access to effective medicines when they were young.

Today, we know that medical costs for children with chronic rheumatic conditions are generally covered by Medicare. However, the number of medical treatment options (such as biologics) available through the Pharmaceutical Benefits Scheme (PBS) is far fewer than the number of options available to adults.

The more treatment options available, the more likely individuals are to find ones that work effectively for them. This means less pain and stress, improved physical function and a reduced chance of long-term joint damage.

To address some of the impacts we have outlined above, we also recommend:

- Financial assistance in the form of a chronic disease card or access to a health care card for ALL adults with chronic conditions so they can afford to be well enough to work, study and socialise. Such a card should not be limited to those on Centrelink benefits and should not be income tested.
- Ongoing funding for annual camps for children with arthritis and their families to be held in multiple locations across Australia.
- Counselling for children and teens related to body image.
- Counselling for teens related to developing personal relationships (including sexual relationships).
- Support services for teens and young adults interested in exploring their family planning and life planning options.
- Career guidance for teens to help them make optimal choices at employment age and beyond.
- Providing multidisciplinary support to ensure children with these conditions feel empowered about managing their condition so when they transition to adulthood they are well equipped.
- Ensuring that all supports and services related to childhood rheumatic disease are patient-centred (even for young children) as opposed to parent-centred.

**TOR 3: Access to medical services, including diagnosis, treatment and ongoing management and support including patient information, with a focus on rural and remote communities**

In most cases, testing for autoimmune biomarkers does not occur until after people present to their doctors with symptoms, by which time joint damage may have already occurred.

Early diagnosis is vital as it enables treatment with disease-modifying anti-rheumatic drugs (DMARDs) to be initiated in the initial stages of disease. Effective treatment with DMARDs slows disease progression and reduces the likelihood of significant long-term joint damage. Early diagnosis and treatment is especially important for children. Therefore, we call for more genetic investigations and more detailed family histories to be taken by rheumatologists to achieve earlier diagnosis.

Access to up-to-date information on conditions, treatments and daily living supports is vital for all people with chronic conditions. This information can, and should, be provided though multiple channels including:

- Rheumatologists
- GPs and community health centres
- Practice nurses
- Hospital outpatient clinics
- Local councils
- Relevant health care organisations/peak bodies, including CreakyJoints Australia
- Peer support groups (in-person and online)

While these channels are already used, information about childhood rheumatic diseases has gone from non-existent in previous decades to insufficient and poorly distributed now. We believe dedicated national plans, such as the [National Strategic Action Plan for Arthritis](#) and the [National Digital Health Strategy and Framework for Action](#) should be used to shape how and where information about these conditions is shared across the country.

#### **TOR 4: Best practice quality of care and availability of treatments, including emerging treatments with a focus on equitable access to effective drugs**

In addition to Increased access for children to biologics and other medical treatments via the PBS, we call for the following:

- Dedicated funding to ensure children in regional/remote areas and their families have equitable access to care. This may include more use of digital technologies and more face-to-face outreach services in those communities.
- Increased focus on multidisciplinary care for children including improved communication between healthcare professionals in order to provide a holistic treatment approach.
- National programs focused on helping children and their families follow healthy lifestyle practices such as appropriate exercise and nutritional diets to minimise symptoms and prevent long term issues.

#### **TOR 5: The adequacy and consistency of professional education, training and awareness amongst healthcare professionals and community awareness of the disease.**

As we see it, the quality of care provided by paediatric rheumatologists and related healthcare professionals is very high. The problem is there are so few of them in the country. This means, other healthcare professionals such as adult rheumatologists, GPs and practices nurses often need to fill the gaps and they are often not specifically trained in paediatric rheumatology.

Other professionals that may provide incidental care for children with rheumatic diseases include physiotherapists, pharmacists, counsellors and teachers. Many of these have had no training in this area but they can be the most convenient people for parents to access for help.

To address these issues, we call for:

- Increased funding, incentives and training to increase the number of paediatric rheumatologists and rheumatology nurses across the country.
- Ongoing paediatric training for adult rheumatologists.
- Ongoing rheumatology training for GPs so they can recognise and diagnose early signs of rheumatic disease in both children and adults.
- Extra training for allied health professionals to increase their ability to recognise rheumatic conditions and be able to treat patients more effectively.
- Funding for dedicated awareness programs for kindergarten and primary teachers and parents to recognise early symptoms of rheumatic disease in children.
- Increased funding for rheumatic condition health care organisations/peak bodies to expand community awareness of their services and resources.

### **Appendix: Additional comments from members of our community**

***The comments below include the personal opinions of the contributors and are not the views of GHLF Australia and CreakyJoints Australia.***

#### **Michelle**

To whom it may concern,

I am writing to you to include my comments in the submission for the Parliamentary Inquiry into Childhood Rheumatic Diseases.

I am 31 years old and was diagnosed with Juvenile Arthritis when I was 8 years old. I continue to battle the disease and have significant deformities as a result.

I have two children and am studying for my Bachelor of Psychology to hopefully one day be able to make a difference in the lives of young people diagnosed with chronic illnesses. I have written a brief summary of my experiences related to each of the Terms of Reference.

**1. Research into the causes of childhood rheumatic diseases, including prevalence levels of childhood rheumatic diseases in Australia:**

My disease was classified as Idiopathic, with no known cause. I would like to see research into genetic testing to be able to catch the disease as early as possible. Particularly with an interest in immune health, gut health from pregnancy onwards and any other factors contributing to the immune response.

**2. The health, social, educational and economic health impacts on children and adults who developed rheumatic diseases in childhood, their families and the broader community:**

As a child, I was heavily impacted socially and in my education due to my illness. I developed quite severe mental health issues such as depression and anxiety, lack of awareness for my parents about associated mental health issues and bullying from children at school as a result of my illness. I missed most of my high school years and was asked to leave in year 11 due to not fitting into the mainstream catholic education requirements, despite being a grade A student. I was unable to participate in most sport and activities my friends were doing and felt very isolated and alone.

As an adult, I have never been able to have a normal job and I rely on my partner for the main income. At 31 years old, I still do not own a car or have a mortgage and live week to week.

My health has always been impacted significantly. From mental health to chronic fatigue and vulnerability to common infections.

**3. Access to medical services, including diagnosis, treatment and ongoing management and support including patient information, with a focus on rural and remote communities:**

Living near the city, I have had access to the medical services and treatments I have needed.

**4. Best practice quality of care and of treatments, including emerging treatments with a focus on equitable access to effective drugs:**

As a child, I suffered an extreme lack of quality of care. I had a specialist who was very unkind, lacked understanding and was very forceful. Due to his treatment, I suffered severe anxiety, developed phobias of medical treatments and medications and have not had the best outcome of my illness possible as an adult.

I was withheld from top of the line treatments until later in life which once I started was life changing.

I would like to see more accessibility to biologic drugs for younger patients and an easier process to obtain these (such as repeat prescriptions from the GP).

### **5. The adequacy and consistency of professional education, training and awareness amongst healthcare professionals and community awareness of the disease:**

There needs to be much more education and awareness for rheumatic diseases in children. Local GPs have no knowledge besides the bare basics.

There needs to be more research into the comorbid factors that are associated with these diseases. The mental health of children diagnosed with chronic illnesses needs to be at the forefront of holistic care.

#### **Simone**

My only real comments are about the acceptance, funding and support for those with less well-known chronic health conditions. I feel that some conditions receive more support, grants, discounts, welfare services, funding and recognition.

I have been living with this illness since my teens and I am severely compromised at the moment, requiring a couple of surgeries and other expensive services. COVID isn't the only disease of this moment. However, being of a convict background and not having a more well-known condition, I don't seem to matter with government support. My health requirements and medical needs will cost the same no matter what my husband earns, but there is ZERO support for our illness. I have been told for decades now "you're too young for that", because society has treated us like mushrooms and left us in the dark.

Our health issues need total recognition. It is a lifelong condition. It is expensive. It is chronic. It is painful. It is degenerative. It is socially misunderstood and, as a result, completely disrespected. All autoimmune conditions and patients with these conditions deserve a whole lot better and a whole lot more.

#### **Anne**

The following provides information about my experience of having juvenile-onset rheumatoid arthritis. I have addressed 2) and 5) in the Inquiry Terms of Reference.

I have had RA for almost 50 years. My earliest memory of having rheumatoid arthritis (RA) or Stills disease as known then, was between 8 and 10 years old. I developed a swollen knee that would become hot/ red and painful especially after exercise. My absolute love in life was horse riding and my parents would blame this or "growing pains" for my early knee problems and overall stiffness, after the weekend riding.

Finally, after seeing the GP (whose investigations included ruling out gout!), at fifteen I had a biopsy on the knee. I had a huge incision that was unnecessary given the diagnosis, something the orthopaedic surgeon probably was not expecting. I think he was expecting an injury rather than a medical reason for my swollen knee. Interestingly, his pre-assessment did not ask any other questions/ observations — he just focused on my knee.



Later the anaesthetist admitted suspecting I may have other issues when she asked me to straighten my arm (to view my veins). Apparently, my elbow was also affected by the RA (unbeknown to me), making it difficult for me to straighten my arm. It seems that growing up with chronic pain as a young person influences the brain's ability to either "turn off/endure " or cope/reframe the pain". Both no doubt impact on psychological/emotional and certainly physical development.

The staff in the hospital appeared in shock that I had RA, by their kind and empathic responses. The rest of my family and I were in denial. I remember being told at that stage that I would either "Grow out of it — or possibly be in a wheelchair permanently, by 21". It really was too much to accept for all, but equally a confusing, frightening, and uncertain diagnosis.

Once there was a diagnosis, the trial and error, roller-coaster of treatments and subsequent side effects started. I was lucky in not having too many issues — other than the expected ones (e.g., mouth ulcers, skin infections, digestion issues, hair loss, sun sensitivity) and/or them simply not working. Plaquenil, penicillamine, gold tablets and Arava, were some, but certainly not all, of the medications tried.

Having the diagnosis as an adolescent (or at any young age) of what was then thought to be an "old person" condition, was extremely difficult. It had enormous ramifications on my social and emotional development and life options.

As most people with RA will agree, it is frustratingly unpredictable in terms of symptoms and pain — one never can predict a flare-up or rapid joint deterioration. One minute plans are set and the next minute we can't walk and must cancel or postpone plans. It was a regular occurrence and a recipe for social isolation that at times led to anxiety and depression. The fact that I had a wonderful boyfriend at the time of diagnosis and for another five years, certainly protected me and built my resilience. He and his family were incredibly supportive, as was my own mother.

In my late teens and early twenties, I rejected conventional medication and tried alternative medicine, including admitting myself into a Melbourne allergy clinic — which did nothing to alleviate any of the disease activity. My desire to try another approach was maybe because I was exploring my independence, feared that the medication would cause side effects or had a healthy desire to question conventional approaches. More so, until I was admitted to hospital with severe anaemia, I had no idea that RA was a serious disease that, if left untreated or not probably treated, could be life-threatening.

Having juvenile rheumatoid disease had an enormous impact on my middle and adolescent years. The journey through early onset, the unpredictable painful and deforming symptoms, diagnosis, treatment and long term "mechanical damage" caused by chronic inflammation had a huge impact on my family and was certainly life-limiting for me.

However, the support that I had from some family members and friends was crucial for my coping and resilience. The toll on those around me as they saw me in pain, my joints swollen and deformed, was obvious. Their constant sense of helplessness understandably led to occasional compassion fatigue.

It wasn't until biologic drugs became available many years later that treatment really made a big difference. Unfortunately, this was too late to rectify the damage caused by years of inflammation and slowly dislocating, deformed joints. Over the last ten years, I have had a total cervical neck fusion

(C1-T2), a total knee replacement and a hip replacement. Over a longer period, I have also had thumb reconstructions and revisions on dislocated shoulders.

Thankfully the RA has not hugely impacted my ability to have a career as a social worker and now planner — albeit a very difficult journey at times. This is entirely due to support from a supportive rheumatologist, good luck that I can tolerate medications (prednisolone, methotrexate and Orencia), resources to afford allied health practitioners when needed, my family (while at school/ university) and until his death in 2020, my gorgeous carer/ partner of 30 years.

The biologics have also made an enormous difference to the disease activity, making it easier in terms of controlling the symptoms and allowing me to be more active. I am so grateful for the support I receive now, including the NDIS, without which I would not be able to be independent and so fulfilled in life — albeit with a severe form of the disease.