To the Standing Committee on Health Aged Care and Sport

Thank you for allowing me the opportunity to submit this submission. I would like to make three recommendations,

1. There should be more Community Services for allied health for children so children don't end up with mobility and functioning capacity abilities like me when they are an adult

2. More funding in research for arthritis (both juvenile and adult)

3. The Government should invest in increasing paediatric rheumatology services for children to ensure so that children with arthritis get timely care as well as the best possible case available.

My name is Shirani and I have had juvenile arthritis for the last 43 years. I have had it since I was 3. I have arthritis in nearly all my joints and I get inflammation in my lungs as well. In fact, that's where it started for me was in my lungs; which is unusual. It took at least 2 months to get my diagnosis. Having had arthritis and still having it along with other health problems, which are associated with my arthritis, has effected my life in a number a major ways. Some of them I'm so used to, I don't even realise now.

One way my arthritis has effected my life is as a child, there was a lot to deal with. Taking daily medication for the age of 3, seeing doctors regularly, being in pain and probably not understanding why at that age, having painful (for a child) blood tests, having others tests, missing school and being in hospital just to name some things. This is a lot to deal with as a child. Your friend's don't deal with this. Being in hospital and being away from your family is not easy. This also I imagine would have been hard for my parents and my sister. My being sick, having a chronic illness, effected the whole family. It still does now as an adult, effect my own family as a whole.

I also remember having to wait in out patient clinics for what seemed like ages as a child. I remember not being able to go on a particular school camp as I wouldn't be able to do the activities such as rope climbing. As a child, this is upsetting. My twin sister (who didn't have arthritis) got to go on the camp. My twin sister was also in a basketball team as a teenager and I was not, as I could not really run.

The other thing that effect's children in adulthood with arthritis can be side effects of medication. One major impact I have had from being on prednisone for 43 years, is it has stunted my growth. I am only 147cm, about 4foot, 9 and a half inches. It has also given me a weak muscle in my lungs and this muscle doesn't expand like it should either.

Also because I have had arthritis for so long, I have de conditioned muscles as I'm not that fit due to pain etc. Because of this, I get muscle pain as well as joint pain. Again, because I have had it for so long, I have Oseto Arthritis as well as Rheumatoid Arthritis. I also have chronic pain. I need a team of specialists to look after me. I see a GP, a Rheumatologist, a pain management specialist and an Endocralist. I also attend allied health services through a Community Health Centre where I do group exercises for people with chronic pain run by the physio, and I see the podiatrist. In the past, I have also seen the O.T. and the dietitian. I self referred myself to these services as I had read an article about services provided by Community Health Centres. The Rheumatologist or GP did NOT refer me to these services. There needs to be more Community health services around and the public needs to know what they do.

During my life, I have also had to have both my hips replaced and my right knee. My first hip operation I was 30, which is quite young for a hip replacement. This is as a result of having arthritis as a child. I was working at the time and had to stop work for about 6 months as I was in too much pain. I was living with my mum and step father at the time so they were able to look after me. This puts pressure on families as luckily my mum worked part time so she could drive me to out patient physio after my operation. From memory, I had to do this twice a week.

After my knee replacement, after 9 days in hospital, I had to go to a rehabilitation centre for a week which is not much fun for a 30 something year old.

Also, because I having arthritis I do not work. I did work full time for about a year and a half but ended up in hospital and was told by my doc to reduce my hours. I then worked part time for a few years but stopped working when I was 12 weeks pregnant with my first child. I could not work and be pregnant and have my health issues. After my 2 children, I did not return to work, my arthritis and the pain and disability I get from it is too bad to work. My husband works full time.

Because I’ve had arthritis for such a long time and there wasn’t as many medications around then, I have a lot of permanent damage done to my joints and you can’t replace all of them so I struggle with house work, standing for long periods of time, walking for more than 5 mins. Because of this I am on NDIS. This is another way my arthritis has effected me.

Moreover, having arthritis from such a young age has had a major impact on my life and will continue. I urge the committee to make the government aware of the huge life long impact of pain and disability on the many of thousands of adults who got arthritis as children and urge the government to invest in better services to avoid and reduce this in the future. Thanks.

Shirani