

I have prepared this submission to the Parliament of Australia's Inquiry into Childhood Rheumatic Diseases and wish to present my recommendations in relation to the following **Terms of Reference**:

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

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

Access to medical services, including diagnosis, treatment, and ongoing management and support is crucial to the health of children diagnosed with various childhood rheumatic illnesses and the current level of resource is, in my experience, inadequate to the needs of Australian children.

Our family has experience with diagnosis of childhood rheumatic diseases and we offer the following observations of particular concern:

- there is limited awareness of conditions such as juvenile arthritis amongst general practitioners and so a swift diagnosis and referral to specialists is uncertain for many children;
- there are only a few specialists and so access to them is not easy and can mean that children do not have the immediate treatment that their illness might require;
- as children grow up with the illness, their needs for support and treatment change but the current delineation of paediatric and adult services means that transitioning from a 'childhood' illness to management of a chronic, life-long condition is very poorly supported;
- adult specialists in rheumatology largely work with an older, mature patient group and so a young person can find being shunted into an adult practice very confronting. Accordingly, they are at particular risk of dropping out of proper management of their condition and at risk of severe, life-long health impacts.

In light of these observations, I make the following **Recommendations**:

1. It is recommended that a public information and professional education campaign on childhood rheumatic diseases be a regular part of general practice professional development.
2. It is recommended that resources be made available to expand the number and range of specialists available to children and young adults diagnosed with rheumatic diseases.
3. It is recommended that Transition Clinics be established to allow older teenagers and young adults to have their unique and serious needs addressed by specialists versed in the particular complications of rheumatic illnesses and who are trained to assist young people learn the management, monitoring, and daily practice skills needed to optimise their well-being and disease control.

This third recommendation is one of particular concern. As soon as a child turns 18, it is very easy for them to find themselves somewhat adrift in the adult medical services system. Whilst it might be of bureaucratic ease to cut a hard dividing line between childhood and adult life, reality is that young people — especially those managing potentially crippling conditions with chronic pain and

physiotherapeutic needs — are being denied world-class support and advice at this important, foundational stage of their lives.

Thank you for your time and attention to this Submission. I am grateful that the Minister and Members of Parliament are open to addressing the truly desperate needs of children who have been diagnosed with a rheumatic illness.

Yours sincerely

Dr. S. T. McClean

