

As a recently retired paediatric rheumatologist I can reflect on 40 years working in this field, with particular reference to terms 3, 4 and 5 of this inquiry into childhood rheumatic diseases.

When I started it was not unusual to see juvenile arthritis patients in wheelchairs or requiring some form of assistance with their day-to-day tasks. The advances in management made over this time, however, has seen a former patient of mine fulfil her dream of studying medicine and become a paediatrician in Melbourne. Another was a top 10 pick in the AFL draft and has now played 50 games in the senior team (sadly not for Collingwood!). Importantly, it must be stressed that the actual diseases managed by paediatric rheumatologists have not, by their innate nature, changed over this time. An inadequately treated child, usually through lack of access to specialist care, will potentially experience exactly the same damaging circumstances as those children I saw in the early 1980's.

So what has changed? There are a number of reasons. Advances in medications have been dramatic over this time with the development of what are called "disease modifying anti-rheumatic drugs". International studies of many of these agents have included Australian paediatric rheumatology centres in this research placing our units at the very cutting edge in the field. Importantly these agents are not without their potential issues underlining the importance of having specialists experienced with the managing, monitoring and overall supervision of their use. There is an often-used term in managing paediatric conditions – "*Children are not just little adults*", so that overseeing care needs to take in all aspects of child health.

Over these years we have also seen the establishment of multidisciplinary clinics including specialist physiotherapists, occupational therapists and nurses each with their own role in optimizing the care of a child with arthritis, and it should be stressed the impact of the child's disease on the whole family. The funding, staffing, and training of of these roles are key in considering term 3 and 5 of this inquiry. A child cannot be considered to be receiving best quality care without the input of this whole multidisciplinary team. Ironically the one field requiring a reduced role in juvenile arthritis management these days has been with our orthopaedic surgical colleagues in that children are no longer coming to require joint related surgery during their child/adolescent years due to improved early disease management.

Finally, it should be mentioned that caring for children with juvenile arthritis is only part of the role of a specialist paediatric rheumatologist and their team. There are a number of other conditions listed under the umbrella term of "Autoimmune Connective Tissue Diseases" requiring specialist care eg systemic lupus erythematosus, juvenile dermatomyositis, polyarteritis nodosa etc, which also fall under term 3 of the terms of reference in diagnosis and access to care. Also with our increasingly multicultural society, we have seen the need for a paediatric rheumatologist's role in managing what are called the "Autoinflammatory diseases" for which certain ethnic groups eg those from the Middle Eastern countries are, for genetic reasons, more prone.

I am certainly excited by the opportunity this governmental review offers for the field of paediatric rheumatology and the benefits for Australian children with rheumatic diseases which may follow.

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