



**NORTHERN TERRITORY**  
***of* AUSTRALIA**

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*Member for Fong Lim*

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**HANSARD EXTRACT**

**WORLD AUTOIMMUNE & ARTHRITIS  
DISEASE DAY**

TUESDAY 20 MAY 2025

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*This extract is taken from the Official Hansard of the Legislative Assembly of the Northern Territory*

Julie was there with The Silver Brumby Coffee Caravan. MeeMa's Kitchen, Lolly & Craft Shop with Sylvanna entertained the children with her amazing arts and crafts. The baked goods were something that had to be seen to be believed.

Rowie Schulz from my office should be commended on her efforts to ensure the event could go ahead. It truly is a massive thing to put on a public event these days.

Local builder Blueprint Construction assisted with a temporary fence. Darren Burton builders then assisted in putting up the exterior fence with the local Man Walk group on the day helping with what we commonly call the playpen, the entertainment arena where kids can safely interact with the entertainment on the day and parents can keep a close eye on what is happening without having to worry about their kids running off.

Rex from the reptile centre came along and put on a reptile display that the kids loved. Alice Springs Family Daycare helped out with games for the children after the beginning of the event.

This culminated in the Teddy Bear parade. What a job it was to judge that.

I cooked pancakes for the masses, and the Treasurer's sausage sizzle was a hit as always.

Michelle Bell and many other volunteered their time on the day to ensure its success. Once again, I give a huge thank you to Rowie Schulz from my office, and David Koch, Ashley and Shane from the Member for Namatjira's office.

It was a wonderful event put on for the community with all money raised going towards a local community group to support the work of Alice Springs Family Daycare.

I also mention the Bangtail Muster. I thank the combined Rotary Clubs of Alice Springs, along with event organiser, Eli Melky, who ensured everyone was where they needed to be. This year was exceptionally special, with Lilly-Marie taking part in her first-ever Bangtail Muster, following in her mum and dad's footsteps. My mum often recalls me being on the back of a truck as a gumnut baby. To see Lilly-Marie dressed as a unicorn will be something I will never forget.

Thank you to the educators at Braitling Preschool—Ms Nikki, Ms Heleena and Ms Lilly—along with all the other mums and dads who came to assist on the morning. The Magic of Friendship was the theme for this year's event. It is the sort of wonderful event that reminds everyone in town why we choose to live in The Alice.

**Dr RAHMAN (Fong Lim):** Madam Speaker, today, 20 May, is World Autoimmune and Autoinflammatory Arthritis Day. The day is dedicated to raising awareness about autoimmune and inflammatory arthritis diseases, which are systemic conditions affecting multiple parts of the body.

The day was established in 2012 by the International Foundation for Autoimmune and Autoinflammatory Arthritis to raise global awareness of these conditions and forms of arthritis like rheumatoid arthritis, lupus, ankylosing spondylitis and juvenile idiopathic arthritis. The initiative arose from the recognition that these chronic and often debilitating conditions are frequently misunderstood, widely under-diagnosed and sometimes overshadowed by more familiar forms of arthritis like osteoarthritis.

The day serves as a global platform for patients, healthcare professionals and advocacy groups to come together, share resources and educate the public about the early signs, systemic nature and long-term impacts of autoimmune diseases. Through virtual events, social media campaigns and international collaboration, World Autoimmune and Autoinflammatory Arthritis Day has fostered a sense of solidarity within the global patient community, whilst advocating for improved diagnostics, access to care and increased research funding.

What are autoimmune diseases? First of all, autoimmune diseases are considered to be one of the least understood areas of medicine. Although scientists know of about 80 of these diseases, the exact causes and triggers of them remain largely elusive. This makes diagnosis, treatment and ultimately prevention of these conditions extremely challenging. Our lack of understanding is compounded by the fact that autoimmune diseases vary in their symptoms and diagnosis, and they lack definitive diagnostic tests. There is limited understanding of triggers, a focus on symptom management and under-recognition and a lack of awareness globally.

What we do know, in simple terms, is that autoimmune diseases impact the body by causing our immune systems to mistakenly attack our own body tissues and organs. Instead of protecting the body from harmful invaders like viruses and bacteria, the immune system targets cells, proteins or entire systems as if they were threats. This misdirected immune response can lead to chronic inflammation, tissue damage and impaired function of affected areas like joints, skin, nerves, glands and internal organs. Likewise, common impacts include debilitating fatigue and pain, particularly in the muscle and joints, skin rashes, digestive issues and hormonal imbalances. Over time these diseases can lead to permanent damage if they are not properly managed, potentially resulting in disability and/or life-threatening complications.

Equally significant and often under-recognised is the impact that these diseases can have on people's families. The chronic nature of these conditions means loved ones may need to take on caregiving roles, adapt their work schedules and provide emotional support, often over many years. This can place strain—as with many other conditions—on relationships, finances and the overall family wellbeing, particularly when people are affected by experiences such as unpredictable flare-ups and ongoing pain and fatigue. For families with young children and young adults, there may be additional stress in regard to schooling, social life and future independence. Partners, likewise, often report feelings of helplessness, burnout and anxiety as they try to support loved ones whilst maintaining household stability.

The cumulative effect can be a reduced quality of life for not just the patient but also the family unit as a whole. Support groups, flexible employment options and access to reliable healthcare and counselling are critical in helping families to manage the long-term impacts of diseases such as these. This is where the critical services of our healthcare providers become so pivotal.

In the NT health and hospital system an important role is played by a broad delivery of services to try to support autoimmune care. These institutions provide access to multidisciplinary teams comprising rheumatologists, immunologists, neurologists and allied health professionals, all of whom work collaboratively to offer comprehensive treatment in a difficult area. These services help to ensure that autoimmune healthcare is accessible to Territorians.

I thank our healthcare workers, clinicians and researchers for working on these difficult-to-pin-down diseases and their dedication to patients and advancing treatment options in this field. I thank them, not least, because I am the beneficiary of their efforts and because my late grandfather, Muhammad Nurul Huq OAM, whom I spoke about at length in my maiden speech, also was the beneficiary of their diligent work.

My grandfather, as I mentioned previously, was a prolific man but one whose working life was cut short by rheumatoid arthritis.

For the uninitiated, osteoarthritis is a degenerative condition where cartilage breaks down due to wear and tear on your body, often affecting larger joints like your hips and knees. Rheumatoid arthritis is an autoimmune disease, the likes of which I am speaking about today, where the immune system attacks the joints, primarily the synovial membrane, leading to inflammation and pain that can affect joints and smaller joints in the hands and feet.

I watched my grandfather's decline in mobility over many years, his increasing pain and the impact on my grandmother and family over many years. I watched him go through four knee replacements; each time they would come up with a novel material trying to solve the problem. He went from steel to plastic to titanium to carbon fibre, which was something of an ordeal in and of itself. The point I am making is that in his day there was less public awareness, less support, less sympathy and fewer treatment options available for autoimmune diseases, which are one of the vanguard areas for medical research in the modern era. I am glad that things are better in 2025 than they were in 1985 and 1995 for him in managing those conditions.

The other reason I mention this is that I too manage an autoimmune condition, which I mentioned in my maiden speech—myasthenia gravis. It is a random condition that no-one interesting or famous has except for the godfather of Indian cinema, Amitabh Bachchan. Indians frequently will recall exactly who he is and what the condition is. I am no Bollywood film star, as we all know, but we have in common the chronic autoimmune disorder where the immune system attacks neuromuscular junctions throughout our body, disrupting communication between nerves and muscles. This leads to fluctuating muscle weakness and fatigue which worsens with activity and improves with rest.

The disease can affect muscles controlling eyes, facial expression, chewing, swallowing and speaking. However, I am pleased to report, as you can all attest to, that although many in this House may have noticed me winking at them on a regular basis because of my variable vision, I clearly have not lost control of my capacity to speak. I probably will not be able to hit a cricket ball very well ever again, though.

In all seriousness, I thank all those who have helped me on my health journey, noting that it is only with the help of others that you can overcome the myriad challenges that life presents you. That includes, no less, the lovely people at RDH and within our neurology services.

Although there is no cure per se for my ailment, treatments such as medication, thymectomy—a complicated surgery which was performed successfully on a mouse some 80 years ago, so people continue that process—and blood transfusions help people like me to manage the symptoms of an autoimmune condition and lead relatively normal lives. On that note, I thank the staff at the day surgery clinic at RDH whom I periodically see for, as my friends euphemistically call it, an oil change.

I raise this tonight, in all seriousness, not for pity but to raise awareness and, moreover, to express gratitude and take a moment to appreciate our health system and modern medicine and perhaps also to be reminded that behind the scenes we are all struggling with the innumerate complexities of life. Gratitude sustains optimism, as I noted in my maiden speech, and it is a good outlook to have in general. Likewise, we all face trials and tribulations, and it is worth occasionally reinforcing in places like this and at times like this the importance of being kind and considerate to one another, even in our sometimes combative workplace.

With that sentiment in mind, I will continue to draw attention to the ever-increasingly obscure, such as World Autoimmune and Autoinflammatory Arthritis Day, and support awareness initiatives. It is important to shine a light on it not only in the abstract but also in terms of how these things impact us in our place and context. I encourage all of you likewise to do the same and to consider some of the ways in which the Northern Territory is part of a bigger ecosystem of a country and a world, sharing common challenges and predicaments.

On that note, thank you for your indulgence. Happy, in so far as it can be, World Autoimmune and Autoinflammatory Arthritis Day to everyone.

**Mr KERLE (Blain):** Madam Speaker, I will close the loop on some matters we have discussed in this Chamber, where we debate and pass Bills which become Acts in this wonderful Northern Territory of ours. This is important work. However, it is not so often that we get to evaluate, in almost real time, the effects that the Bills we pass have.

I draw attention to a decision of the Supreme Court in Alice Springs by His Honour Justice John Reeves in *The King v EM* [2025] NTSC 31, dated 9 May 2025. This decision deals directly with the two signature pieces of legislation of this Assembly. The first is Declan's law, which changed the presumption of bail, and the second is the *Bail Act* amendments that we passed on urgency recently.

I will read certain extracts. There is a lot that I will not read because there are matters to do with the offending, even though the offender is still on bail. I will not identify the offender, but the nature of the offending is not relevant to this discussion. What is relevant is that His Honour, when considering granting bail to this individual, was in the position that the defence and the prosecution appeared to be in favour of bail. He wrote in his decision:

*Even though that was the agreed position of the parties, because ...*

The defendant:

*... had pleaded guilty to a very serious offence, I was not willing to act on it.*

He went on to discuss the effect of the amendments. He wrote:

*In considering the matters in ss 24 and 24A, the amendments ...*

Meaning the amendments that we passed recently:

*... have made two important changes. First, the risk (if any) to the 'safety of the community' that would result if a person were released on bail is 'the paramount consideration' of the criteria prescribed by those provisions. A 'paramount consideration' is one that 'must be treated as the highest level of importance'.*

These are the words of a justice of the Supreme Court of the Northern Territory:

*Nonetheless, 'other considerations are not entirely excluded...[they]...are only subordinated'. Secondly, remanding a youth in custody is no longer to be considered as the option of last resort.*