



**Hon Amber-Jade Sanderson MLA
Minister for Health; Mental Health**

Our Ref: 76-30479

Ms Leonie Axton-Hooper
Founder and Coordinator
The Arachnoid Cyst Awareness Australian Support Group
acystawraustralia@gmail.com

Dear Ms Axton-Hooper

Thank you for your email of 12 March 2024 to the Minister for Health regarding improved awareness of symptomatic brain and spinal arachnoid cysts. The Minister has asked me to respond to you on her behalf.

The Western Australian Government has a longstanding interest in rare diseases and the special aspects pertaining to patients and their families living with the estimated seven thousand different conditions that are considered rare. The Western Australian Department of Health (DOH) paved the way for the *National Strategic Action Plan for Rare Diseases* released in 2020, after having developed the first government policy for rare diseases in the southern hemisphere (the *WA Rare Diseases Strategic Framework 2015-2018*).

Due to the sheer number of rare diseases that exist, the Western Australian Government recognises the impact of rare diseases collectively. Although there can be unique aspects to many rare diseases, there are also commonalities including many patients experiencing a long diagnostic odyssey (often after seeing multiple medical professionals), and a lack of understanding and awareness of their disease among health professionals.

The Parliamentary Friends of People with Rare and Undiagnosed Diseases was established by the Parliament of Western Australia to raise awareness of rare and undiagnosed diseases collectively and increase liaison between people and organisations working in a range of rare diseases and Members of Parliament. The Western Australian Government also continues to support and promote international Rare Disease Day.

The DOH played a crucial role in establishing Rare Voices Australia in 2012, which as you mention is the national peak body to provide a strong, unified voice to advocate for health, disability and other system improvements for people living with a rare disease. The DOH has collaborated and is still working closely with Rare Voices Australia on multiple projects, including on implementing within the state aspects of the *National Strategic Action Plan for Rare Diseases*.

Additionally, the DOH financially supports a range of initiatives aimed at addressing the needs of people living with a rare disease, taking a combined approach to rare diseases to maximise impact and ensure consistency and equity throughout the State. You may also be aware of the Rare Care Centre at Perth Children's Hospital, which has been established to address the needs of children living with rare diseases who enter their dedicated program.

The Future Health Research and Innovation Fund was established by the Western Australian Government to improve the health and prosperity of Western Australians by funding medical research and innovation projects, programs and people. One of the Funds current priority goals is to "enhance clinical trial capacity and expertise to improve the quality of clinical trials in Western Australia and make the state more attractive to funders of clinical trials (grant funding and commercial sponsors)". Clinical trials are often an option that brings hope for patients with rare diseases, due to the extremely limited existing treatment and management options for this collection of conditions.

Dr Kristen Nowak, Director, Office of Population Health Genomics at the DOH, leads a team that considers policy aspects of rare diseases. Dr Nowak is also a member of the Scientific and Medical Advisory Committee for Rare Voices Australia. Dr Nowak will soon be in contact with you to offer to meet via telephone or videoconference to discuss your concerns pertaining to the care and management in the Western Australian health system of patients with symptomatic arachnoid cysts.

Thank you for bringing these matters to the Minister's attention.

Kind regards



Stacey Hearn
CHIEF OF STAFF

1 MAY 2024