PARLIAMENTARY FRIENDS OF PEOPLE WITH RARE AND UNDIAGNOSED DISEASES

Statement

HON MATTHEW SWINBOURN (East Metropolitan — Parliamentary Secretary) [5.20 pm]: I rise tonight to announce the formation of the Parliamentary Friends of People with Rare and Undiagnosed Diseases. I have convened this new group in conjunction with Hon Donna Faragher and Hon Stephen Pratt, and I would like to thank them at the outset for their willing involvement and collaboration in this new parliamentary friendship group.

As the majority of members in this place know, the issue of rare diseases is very close to my heart. I have spoken on a number of occasions of my family's journey in living with a rare disease—in fact, with multiple rare diseases. Rare and undiagnosed diseases are usually characterised by poorly managed pain; both intellectual and physical disabilities; mental health burdens on both the person suffering the disease and those close to them; and, unfortunately, premature death. Although WA Health estimates that there are between 5 000 and 8 000 rare diseases, rare diseases collectively are not uncommon, affecting between six per cent and eight per cent of the population. This includes close to 200 000 Western Australians, of whom approximately 63 000 are children. It also affects their families and the broader community in terms of the impact and the cost on our health system.

My family's experience with rare diseases has given me a personal and detailed insight into the fight many people experience in receiving a correct diagnosis and appropriate care and treatment for their disease. One of the big issues with rare and undiagnosed diseases is the lack of community and clinical awareness of the nature and depth of the issues associated with these diseases, and many people with a rare disease struggle to get a diagnosis, hence the reason that we have included both rare and undiagnosed diseases, because a large proportion of people are still fighting for recognition of what they are suffering.

We hope through this friendship group to provide opportunities for members of Parliament to learn about the needs of people with rare and undiagnosed diseases, and the challenges and opportunities involved in providing care and services to them. We hope to facilitate communication between members of Parliament and people and organisations working with people with rare and undiagnosed diseases. We hope to increase community awareness and raise the profile of rare and undiagnosed diseases in the community generally. We hope to raise awareness of the role and opportunity for innovation, data, research, policy and national and international partnerships on rare diseases. We hope to promote an understanding of the work undertaken by health professionals, researchers and organisations who provide care and services to people who live with rare and undiagnosed diseases. We also hope to champion initiatives that seek to deliver improved outcomes for people with rare and undiagnosed diseases, and their families.

We are working closely with a number of figures and groups in the WA rare diseases community, including Kane Blackman, the deputy chair of Rare Voices Australia; Dr Gareth Baynam, head of the Western Australian Register of Developmental Anomalies, which is the combined Western Australian Birth Defects Registry and the Western Australian Cerebral Palsy Register; and my friend Andrew Bannister, a wonderful and prominent rare diseases campaigner in Perth. Members may recall that I have spoken about Andrew before. He has organised lighting significant sites around Perth, the state and internationally for Rare Disease Day. Andrew is a tireless campaigner for raising awareness of rare diseases and suffers from his own rare disease.

The group will be officially launched during the dinner break in the courtyard by the Premier and the Leader of the Opposition on Tuesday, 19 October 2021. We will be joined at Parliament by many figures from the rare diseases community, and I sincerely hope that members will take up the opportunity to meet them and learn about how important it is that we continue working to address rare and undiagnosed diseases.