

The Honorable Mark Butler  
Federal Member for Hindmarsh  
Minister for Health and Aged Care  
Parliament House  
Canberra, ACT 2600  
minister.butler@health.gov.au

7 March 2025

Dear Minister Butler,

### **Support for Funding Request – National Patient Registry for CDH**

We the undersigned strongly support Hypersomnolence Australia's request for \$50,000 in funding to establish a national patient registry for Central Disorders of Hypersomnolence (CDH). These debilitating sleep disorders, including narcolepsy, idiopathic hypersomnia, and Kleine-Levin syndrome, have a profound impact on affected individuals, their families, and the broader community.

Currently, there is no systematic way to collect and analyse data on Australians living with these conditions. Establishing a national registry is a small but critical step toward improving research, diagnosis, and treatment options for CDH. This investment would lay the foundation for better healthcare outcomes and future advancements in this field.

This \$50,000 in funding would support:

- ✓ Initial database development
- ✓ Secure data storage
- ✓ Outreach to healthcare providers and patients to ensure widespread participation
- ✓ Collection of an initial dataset as a proof-of-concept, strengthening future applications for larger funding opportunities (e.g., NHMRC)

We urge you to give serious consideration to this important request.

Sincerely,