

A STATEMENT FROM THE GENETIC, UNDIAGNOSED AND RARE DISEASE (GUARD) COLLABORATIVE



We, the peak state bodies for genetic, undiagnosed and rare disease communities and the national body for people without a diagnosis present this document outlining our position for care, protection and support during the COVID-19 crisis.



Our statement is informed by the National Strategic Action Plan for Rare Diseases, the National Genomics Health Policy Framework and State Policies and calls for the delivery of person centred and integrated care at this time as outlined by these important guiding documents for our sector.



Our position is underpinned by our common values:

- **Fairness and Equity**
- **Empowerment**
- **Respect**
- **Integrity**
- **Connectedness**



This statement has been supported by those organisations whose logos appear at the end of the document.

In this time of rapid change and decision making we urge policy makers and authorities in Australia and around the world to ensure that people living with severe chronic diseases, genetic, undiagnosed and rare diseases or disabilities are part of decision making and that policy and action protect these populations. Our recommendations for this are in line with the proposals developed by our European colleagues and outlined below.

We praise the efforts of and are deeply grateful to all healthcare professionals currently fighting COVID-19 on the frontline. We also acknowledge the efforts of policy makers in a challenging environment.

People living with a genetic, rare, undiagnosed disease and disabilities are amongst the most vulnerable groups in society. Their conditions are highly complex, often chronic and severely disabling, which generate specific care needs. They are even more vulnerable during the current COVID-19 pandemic.

We are concerned for people living with genetic, undiagnosed and rare disease in the coming weeks and months where it is suggested the number of people with severe COVID-19 symptoms may exceed ICU bed and respiratory aid capacities.

To ensure equity for this vulnerable population of people living with genetic, undiagnosed and rare conditions and disabilities, special measures need to be applied to ensure their best health outcomes. GUARD is urging health professionals to use their experience, expertise, resources, observations, and their own ethics to influence how the medical system prioritises vulnerable patients in the triage process.

GUARD urges all hospitals to include representation from the rare disease community in whatever platforms they are convening to create triage protocols. We support the Australian and New Zealand Intensive Care Society Guidance which states patients should be included in decision making.

To stop the spread of COVID-19 for all Australians and to reduce the need to triage in Intensive Care Units, a primary objective should be to prevent vulnerable populations being infected with COVID-19 in the first place. This is especially critical for the health and wellbeing of people living with genetic, undiagnosed and rare disease.

Amanda Samanek
Executive Director
GaRDN

Monica Ferrie
Chief Executive Officer
GSNV

Jan Mumford
Director
GAA

Heather Renton
Chief Executive Officer
SWAN

We propose the following special measures to medical bodies, national health authorities, as well as healthcare providers on the ground fighting against COVID-19 to provide optimal care:

- 1. Consideration in decision making about ICU admission guidance that co-morbidities for people living with genetic, undiagnosed or rare conditions and disabilities should not limit their treatment options for COVID-19. Guidance should limit the potential for discrimination or de-prioritisation of people living with these conditions.**

Critical care guidelines must be non-discriminatory and should be respectful of fundamental ethical principles and based on “clinical appropriateness and proportionality of the treatments”¹. They should be aligned with international law, notably the UN Convention on the Rights of Persons with Disabilities (article 11 & 25) and the UNESCO Universal Declaration on Bioethics and Human Rights, as well as disaster medicine ethical guidelines.

- 2. The immediate adoption of concrete measures/ protocols in the provision of emergency healthcare during the COVID-19 crisis, warranted by the complex needs of genetic, undiagnosed or rare disease patients, for example:**

- Lead efforts to ensure **sufficient ICU beds** (including in **temporary hospitals**) and **respiratory aid equipment** are available in order to avoid triage.
- When a genetic, rare or undiagnosed condition person presents with COVID-19 symptoms, the **patient’s medical practitioner** should be contacted to understand the specific disease history and treatment plan of the patient.
- For people living with a rare disease, family members play a crucial role in the treatment, care and support of their loved one. **Carers are experts on the disease and the specific needs of the individual patient and should therefore be permitted to attend the ICU** and support doctors in their relative’s treatment plan and care.
- **Temporary special hospital wards dedicated to particularly vulnerable rare disease patients affected by COVID-19 should be considered whenever possible** (for example, for patients affected by neuromuscular, pulmonary or immunodeficiency diseases). These should be located in hospitals that already have highly specialised expertise in rare diseases.
- The use of whatever means necessary to **expedite information exchange between experts** for those patients affected by COVID-19.

People living with a genetic, rare or undiagnosed conditions or disabilities should be included as a **priority population in preventative measures** to stop the spread of COVID-19. During the isolation period, carers of rare disease patients most vulnerable to COVID-19 should be **systematically tested**. They should receive **masks/ personal protective equipment** as a priority when quantities allow for this beyond priority health/ social care professionals.

Adapted from EURORDIS Rare Disease Europe COVID-19 Statement

¹ Bioethics Committee of the San Marino Republic, Answer to the request for urgent opinion on ethical issues regarding the use of invasive assisted ventilation in patients all age with serious disabilities in relation to Covid-19 pandemic, 16 March 2020:<http://www.sanita.sm/on-line/home/bioetica/comitato-sammarinese-di-bioetica/documents-in-english/documento2116023.html>

<https://www.anzics.com.au/wp-content/uploads/2020/03/ANZICS-COVID-19-Guidelines-Version-1.pdf>

We strongly encourage governments and support agencies to consider and address the following critical issues:

- **Clear, transparent and appropriate channels for ongoing engagement** with genetic, undiagnosed and rare disease communities and other vulnerable populations to monitor their needs, safety and requirements.
- **Agile, Timely and Flexible solutions developed and implemented** through **ongoing monitoring** of the needs of the genetic, undiagnosed and rare disease communities and other vulnerable populations.
- **Targeted support** to ensure the existence and sustainability of **not-for-profits and charities** with limited capacity and resources to generate funding as traditional funding streams become unavailable.
- **Flexibility** with timeframes attached to **delivery of grant outcomes** for funding already received, acknowledging that delivery may not be possible in the current environment
- Targeted and readily **available support for carers** now unable to access the respite, home support or services they usually depend on.
- **Access** to more than one **support worker** to come into a home and/or to a hospital/medical centre to support where there is a **clear and identifiable need** and all parties are acting (where possible) within social isolation guidelines.
- Support for people with disabilities and their families with **online learning supports** in the event of **school closures and/or learning method changes** in accordance with the Disability Education Standards outlined in the Disability Discrimination Act.
- **Secure supplies** and **equitable access** to feeding and continence products, and personal protective equipment (gloves, masks, hand sanitiser) for people with disabilities and their carers' and support workers.
- **Secure supplies** and **equitable access** for ongoing treatment needs of people with chronic care needs, including blood/blood products, specialised medicines (including those listed in the Life Saving Drugs program), and other medicines or medical technologies.
- In addition to getting background information on medical history they **specifically request information on psychiatric history and complex behaviours that may be present**. Encourage staff to refer to parents/ support providers regarding strategies to assist with behaviour management and strategies to gain maximum patient cooperation. Lack of insight into the complexities of behaviours may compromise the effectiveness of the medical care.
- **Flexibility for NDIS Plans** to allow for the purchase of devices and internet plans so that people can equitably access telehealth services.
- **Accessible information services and channels** for all information about service changes and COVID-19 updates. Information delivery must be through 'Easy Read', translations for hearing impaired and with access to language translations.

The following support organisations have indicated their support for this statement:



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