10 May 2022

**RE: FEDERAL ELECTION – 21 MAY 2022**

Dear

Genetic Undiagnosed And Rare Disease (GUARD) Collaborative Australia, is comprised of the peak body organisations; Genetic Support Network of Victoria, Genetic Alliance Australia (NSW), Syndromes Without A Name (SWAN) Australia. Together, we represent the voice of people living with genetic, undiagnosed and rare diseases and those who support them. We strive for a fair, equitable and collaborative approach to health, disability, education and the well-being of all of our community. Our focus is consistent with the National Strategic Action Plan for Rare Diseases, national and state genomics and precision health policies and our individual organisational objectives.

GUARD members work independently of each other, fulfilling their own responsibilities and roles and come together to provide systemic national advocacy and support for people living with genetic, undiagnosed and rare conditions and those who support them. Our advocacy is driven by values of fairness, equity and quality of life and focuses on positive change in the health and disability sectors.

Together we offer our united collaborative strength and provide assistance, support and services for genetic, undiagnosed and rare condition support groups, their communities and the wider community seeking to influence and change current health, mental health, support services and disability policy and practice impacting our community. 'It is the right of every human being, without distinction of any kind, to have access to the enjoyment of the highest attainable standard of physical and mental health and to a standard of living adequate for the health and well-being of oneself and one's family.' GUARD strives to see this happen and we need your support to achieve this. That is why we call on the government to address the challenges of persons living with a rare disease and the communities that support them.

We have addressed the key issues of concern on behalf of the families we represent.

## 1. Diagnosis

**a) For every patient to have equal access to the support they need on their diagnostic journey, by way of testing, care plans, counselling and peer support groups**

## 2. Access to Healthcare

a) **Implementation of The New Frontier Delivering better health for all Australians - Inquiry into approval processes for new drugs and novel medical technologies in Australia.**

b) **Continuation of funding for the Patient Pathways Telehealth Nurse Program.**

c) **Timely access to mental health care supports.**

d) **Address the workforce shortage for genetic services**

## 3. National Disability Insurance Scheme (NDIS)

a) **Mandatory training and education for Early Childhood Partners, Local Area Coordinators and NDIA Planners, so they gain a better understanding of genetic, undiagnosed and rare diseases.**

b) **Establish a Genetic Undiagnosed and Rare Disease Reference Group as one of the Independent Advisory Council's Reference Groups.**

## 4. Support Groups

a) **Funding to ensure peer support groups remain sustainable and continue to provide services linking health and the community.**

We have expanded on the key issues on subsequent pages.

Thank you for your time acknowledging the challenges member of our GUARD community face. We look forward to working with you to address these significant issues and welcome the opportunity to discuss them in more detail with you.

Yours sincerely

**The GUARD Collaborative Australia**

Jan Mumford – Director - Genetic Alliance Australia
T: 0417 087 414 or E: director@geneticalliance.org.au

Monica Ferrie – Chief Executive Officer – Genetic Support Network Victoria
T: 0403 909 748 or E: monica.ferrie@vcgs.org.au

Heather Renton – Chief Executive Officer – Syndromes Without A Name (SWAN) Australia
T: 0404 280 441 or E: heather@swanaus.org.au

## 1. Diagnosis

### a) For every patient to have equal access to the support they need on their diagnostic journey, by way of testing, care plans, counselling and peer support groups

Delayed diagnosis and misdiagnosis are common among our community and can negatively impact healthcare, mental health, and social support. Without a diagnosis, it is difficult to plan for the future, gain the supports you need and understand what the future holds in terms of how a condition may progress, regress or develop.

All patients should have the right to timely, equitable access to genetic and genomic testing and information, services and supports that are culturally appropriate (if they exist).

Genetic counselling should be available to all who would benefit from it at no cost

A diagnosis can change the way rare diseases are managed and lead to better health outcomes for patients.

A diagnosis can lead to a connection with a peer support group where information and knowledge can be shared and isolation among members can decrease, leading to better mental health outcomes for patients.

## 2. Access to Healthcare

### a) Implementation of The New Frontier Delivering better health for all Australians - Inquiry into approval processes for new drugs and novel medical technologies in Australia.

- Implement the priorities of the Rare Disease Action Plan.
- Adopt a new Health Technology Assessment (HTA) pathway to be developed for cell and gene therapy in Australia.
- Adopt novel health technology development such as cell and gene therapy and treatments and implement pathways to allow for seamless regulations.
- Establish a 'Centre for Precision Medicine and Rare Disease within the Department of Health.
- Ensure genomic testing is equitably accessible across the country and included provisions for genetic counsellors for all patients.
- Ensure the HTA decision-making process includes patient evidence and lived experience as a valued input.
- Re-establish the Australian National Congenital Anomalies Register (NCAR) and utilise it to capture appropriate data for rare diseases.
- Streamline the regulatory pathway to safely allow the use of lifesaving therapies and treatments for children sooner.
- Link orphan drugs to the priority review pathway for children so they can access medicines for rare diseases faster.
- Provide faster access for patients to have access to the life savings drugs program
- Drug manufacturers and the Australian Government to work together in funding and sharing risks for novel medicines for rare disease patients.
- Adopt a national newborn screening approach to ensure that every state and territory receives the same newborn screening tests.

**b) Continuation of funding for the Patient Pathways Telehealth Nurse Program.**
The Patient Pathways Telehealth Nurse Program provides much-needed navigation services through complex health and other services to optimise health outcomes.

**c) Timely access to mental health care supports.**
We require timely access to targeted and specialised mental health services for the undiagnosed and rare disease community, no matter the geographical location.

**d) Address the workforce shortage for genetic services**
Strategies and measures need to be taken to address the workforce shortage in genetic services, to ensure there are enough geneticists, genetic counsellors, pathologists, scientific curators, and bioinformaticians to service the growing demand for genomic testing.

## 3. National Disability Insurance Scheme (NDIS)

**a) Mandatory training and education for Early Childhood Partners, Local Area Coordinators and NDIA Planners, so they gain a better understanding of genetic, undiagnosed and rare diseases.**
Our communities report not receiving NDIS plans that support their needs to enable them to meet their NDIS goals.

**b) Establish a Genetic Undiagnosed and Rare Disease Reference Group as one of the Independent Advisory Council's Reference Groups.**
A Genetic Undiagnosed and Rare Disease Reference Group needs to be established as one of the Independent Advisory Council's Reference Groups to provide a better understanding within the NDIA of people living with genetic, undiagnosed and rare diseases.

## 4. Support Groups

**a) Funding to ensure peer support groups remain sustainable and continue to provide services linking health and the community.**
Invest in peer support groups so they can build the capacity to provide wellbeing and mental health support as identified in priority 2.5.3 of the National Strategic Action Plan for Rare Diseases.

Support groups provide a community for those with rare and undiagnosed conditions, offering peer support by sharing information, knowledge and lived experience to optimise health and social outcomes for patients. Support groups provide a link between clinical health services and the community providing education and resources not available elsewhere.

Some support groups have the capacity to provide necessary funds for research into conditions that would not receive funding from government funding programs. This does not take away from the need for Government to fund rare disease research directly.

Support groups provide systemic and individual advocacy around a variety of services and supports to obtain better outcomes for their members in the areas of: disability, education, employment and social opportunities.

Support groups provide vital connectivity for families and individuals supporting better health and wellbeing outcomes.