GUARD COLLABORATIVE AUSTRALIA

STATEMENT REGARDING NEWBORN SCREENING

The Department of Health announced changes to the assessment process for nominated conditions conducted under the Newborn Bloodspot Screening (NBS) National Policy Framework on 9th June 2021.

There has been no consultation with our rare disease communities about newborn screening assessments, applications, expectations, deliverables or outcomes. The design or implementation of a new process deserves broad consultation particularly as the previously responsible Standing Committee has been inactive for months. People living with genetic, undiagnosed and rare conditions, their families and communities and patient support organisations across Australia continue to be dismissed by our Federal Government. There are more than half a million rare disease families asking why our decision makers are increasing complexity, increasing burden, decreasing options and decreasing outcomes.

We are concerned that the decision for any newborn screening application to progress is now the responsibility of one person alone – the Chief Medical Officer. We worry that the new assessment process includes Health Technology Assessment (HTA) as part of approval to recommend the inclusion of a condition by the Medical Services Advisory Committee (MSAC) to the federal health minister. This process continues and amplifies the practice of placing the burden of proof, the burden to share the most private lived experience, the re-living of the darkest days that are expected to come from patients, families and patient support organisations as evidence of personal cost. A previously complex process has been replaced by an even more complex, bureaucratic and burdensome process for our community. How many years will be added while children die? This process will further fuel inequity of access to screening as those with the greatest capacity to advocate are heard, and others of equal need excluded. This process is at odds with world health practices of inclusion and commitment to leave no-one behind.

Under the current MSAC processes, evidence of personal cost and quality of life value, doesn't even equal the evidence value of economic cost. How is it that in 2021, we are implementing processes that promote inequity and increase burden? How is it in 2021, that we are introducing a system that favours well-resourced and high-capacity patient groups? Why are we implementing systems that leave people behind while the rest of the world is actively working to bring everyone along? Every person deserves a fair chance, every condition a level playing field. This new system fails the equitability test.

This new announcement fails to address the implementation challenge where newborn screening recommendations and inclusion are ultimately state and territory based decisions. Our assessment process is all care and no responsibility. Australia currently loses approximately 2,500 children each year[1], to many conditions, which may have totally different treatable outcomes if they are screened for. This doesn't include those children with degenerative conditions who are waiting for diagnosis later in life. These facts are not a surprise, our governments know them already and sadly so do many Australian families.

The genetic, undiagnosed and rare disease community is calling on our Federal, State and Territory Governments to work with our collective communities including those that have access to screening, current and future applicants so that a fairer and more equitable process can be implemented. We urge national collaboration across jurisdictions to implement a consistent and fair approach. We are calling on the Federal and State Governments to work collaboratively and with consumers for a resolution to newborn screening discrimination and inequity. Quality of life and life itself cannot depend on the luck of where you were born because governments cannot agree. The application process must be addressed and implementation inequity resolved quickly so we do not lose any more children to treatable conditions that can be diagnosed through newborn screening.

[1] Mortality over the twentieth century in Australia: Trends and patterns in major causes of death