



11 February 2021

Dear Health Professional

RE: Fetal Alcohol Spectrum Disorder Australian Registry (FASDAR)

We ask health professionals who care for Australian children with a confirmed diagnosis of FASD to invite their families to participate in the FASDAR. This includes newly and previously diagnosed cases of FASD in children under 15 years of age. The FASDAR is funded by the Australian Government Department of Health.

The FASDAR will assist with the provision of information to families regarding new services, effective treatments, peer support, and resources when these become available. It will also enable longitudinal studies of FASD outcomes and participation in clinical trials when new treatments become available.

The FASDAR aims to support collection of national FASD data to monitor epidemiological trends and outcomes, and to maintain a central database of cases. These national FASD data will inform government departments, researchers, clinicians, and non-government bodies involved in service delivery, evaluation of treatments, and policy development for FASD. Data access will be under strict control and no identified data will be released.

We ask you to:

1. Invite families to participate in the FASDAR by providing them with the Participant Information Sheet and ask them to consider completing the Opt-In Consent Form,
2. Alternatively, ask families to contact us directly via the contact details on the Participant Information Sheet or via our website (<https://fasdregistry.org.au/index.php/contact/>)

The FASDAR has received ethical approval from the Sydney Children's Hospitals Network Human Research Ethics Committee and the Australian Institute of Aboriginal and Torres Strait Islander Studies Research Ethics Committee to allow participant recruitment nationally.

This is an exciting opportunity and is the first national registry for FASD in Australia. We encourage you to invite families to join the FASDAR. Please let us know via the below contact details if you have any questions or would like more information.

Kind regards,

Professor Elizabeth Elliott
Chief Investigator

Dr Melissa Cheung
FASDAR Manager