FASD Australian Registry (FASDAR) Opt-Out Form

A copy of this form is also available online on the FASDAR website (<u>www.fasdregistry.org.au</u>)

Please complete this form only if YOU WISH TO OPT OUT FROM THE FASDAR Please tick the box next to the information you do not want recorded in FASDAR

I wish to withdraw the following information from FASDAR:

□ Personal information (information including your child's name, date of birth, address, and contact details and your name address and contact details)

□ Health information about my child

□ I do not wish to be contacted by FASDAR in the future

Your name	
Your child's first name	
Your child's last name	
Your child's date of birth	
Contact number	

Signature of Parent, Legal Guardian or Authorised Proxy

Date:

Please send this completed form to

Fetal Alcohol Spectrum Disorder Australian Registry

c/o The Australian Paediatric Surveillance Unit (APSU)

Locked Bag 4001

WESTMEAD NSW 2145

OR email to SCHN-APSU@health.nsw.gov.au

OR fax to the APSU on 02 9845 3082

OR call the APSU on 02 9845 3005

Opt-Out Form for health information already collected by the Australian Paediatric Surveillance Unit (APSU) before enrolment in FASDAR

As indicated in the FASDAR Participant Information Sheet, the APSU already collects national de-identified health data on children with FASD. This APSU surveillance study has obtained ethics approval (HREC Reference: LNR/14/SCHN/441). The child's initials and date of birth are collected by the APSU to identify duplicate cases. Once duplicate cases have been detected, the initials are removed.

You may request to have this health information about your child removed if your child's initials are still in the APSU database. If these have been removed, we will not be able to determine which data set is your child's and we will therefore not be able to remove the health information that has been collected.

□ Please remove my child's health information that is already in the APSU database, if possible

Please provide the following details:

Your name		
Contact number		
Email address		
Your child's first two letters of first name		
Your child's first two letters of last name		
Your child's date of birth		
Signature of Parent, Legal Guardian or Authorised Proxy		

Date: _____

We will contact you to confirm whether or not we were able to locate your child's health data in the APSU database and to delete it.

Please send this completed form to

Fetal Alcohol Spectrum Disorder Australian Registry c/o The Australian Paediatric Surveillance Unit (APSU) The Children's Hospital at Westmead Locked Bag 4001 WESTMEAD NSW 2145 OR email it to <u>SCHN-APSU@health.nsw.gov.au</u> OR fax to the APSU on 02 9845 3082

OR call the APSU on 02 9845 3005