APR Consent Form

Study Title	**A**ustralasian Paediatric Endocrine Group **P**atient **R**egistry (**APR**)
Principal Investigators	**Coordinating PI:** A/Prof Andrew Biggin; Sydney Children's Hospital Network; The University of Sydney
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Research Governance Office/Complaints	Research Governance Office, NSLHD. **Study Reference:** 2021/STE03449 **P:** 9926 4590 **E:** NSLHD-Research@health.nsw.gov.au

Declaration by Parent/Guardian (please select all of the below to indicate your agreement)

☐ I have read the Parent/Guardian Information Sheet or someone has read it to me in a language I understand.

☐ I understand that the APR will share de-identified pooled data with approved users of the registry for research.

☐ I give permission for my child's treating doctor to release the described information to the APR concerning my child's condition and treatment for the purposes of research. I understand that such information will remain private and confidential, and I am free to withdraw it at any time without affecting the child's care.

☐ I have had an opportunity to ask questions and I am satisfied with the answers I have received.

☐ I understand that I will be given a signed copy of this document to keep.

Study Options (please select ONE)

Option 1 ☐ I give permission for my child's doctor to release personal information concerning my child's health to the APR. I understand that such information will remain private and confidential.

Option 2 ☐ I give permission for my child's doctor to provide **only de-identified** data to the APR. Information like my child's name and medical record number will not be sent to the registry. I understand that my child's doctor will not be able to update my registry records during our visit.

Future contact (please indicate your preferences by selecting YES or NO for each item)

Yes	No	
☐	☐	The APR may contact me at the email address below to report on the child's health via survey.
☐	☐	The child's hospital doctor may contact me to invite us to take part in future APR studies.

Email: _____

Name of Child (please print):_____

Signature of Child: _____Date: _____

Name of Parent / Guardian (please print): _____

Signature of Parent / Guardian: _____Date: _____

Under certain circumstances (see Note for Guidance on Good Clinical Practice CPMP/ICH/135/95 at 4.8.9) a witness to informed consent is required.*

Name of Witness* to Parent / Guardian's Signature (please print): _____

Signature of Witness: _____ Date: _____

* The Witness is not to be the investigator, a member of the study team or their delegate. In the event that an interpreter is used, the interpreter may not act as a witness to the consent process. Witnesses must be over 18 years of age