

Consent for inclusion on the Victorian Prader-Willi Syndrome Register

I, _____

hereby give consent to the inclusion of

Name: _____ Date of birth: _____

on the Victorian Prader-Willi Syndrome Register.

I have received information about the Register. I understand that an individual may not directly benefit from membership of the Register and that no payment will be made for joining the Register.

I consent to:

- Yes No The collection, recording and permanent storage of information about the person with Prader-Willi Syndrome. This may involve consulting medical records of birth and current health.
- Yes No Receiving periodic questionnaires about the person with Prader-Willi Syndrome that will provide information for the Register.
- Yes No Health professionals completing separate questionnaires relating to the health details of the person with Prader-Willi Syndrome.
- Yes No Receiving invitations from time to time to participate in other research studies. There is no obligation to participate.
- Yes No Sharing information with other PWS registers

Signed: _____ Date: _____

Relationship to child: _____

Address: _____ PC: _____

Phone: _____ Mobile: _____

Email: _____

Health professionals who may be able to provide information e.g. paediatrician or therapist
(include name and contact details):

1. _____

2. _____

For more information, please contact Tess Lioni
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