



The Sydney
children's
Hospitals Network

care. advocacy. research.

onto another (third party) researcher for use in an ethically approved project or already been published.

Your information will remain confidential, however it is important to note, as with all health information kept about you, that there may be circumstances where disclosure of your health information as kept for this study may be required by law, for example, as a result of a court order. This requirement is standard and applies to information collected in both research and non-research situations. Such requests to access information are rare; however we have an obligation to inform you of this possibility.

You will not receive any payment for your participation in this biobank. No hospital visits are required outside the blood sample collection, so that the impact on your time is minimal.

Will you or your child be provided with any results?

we will not be providing results from research conducted using biobank samples where the clinical significance is not well established.

However, there may be rare instances where information of clinical significance (i.e. information which has a significant probability of impacting on the health of you, your child or that of your family) is identified by researchers using samples from the biobank, and we will make every effort to contact you and facilitate the provision of these results using the assistance of appropriate medical channels and/or genetic counselling provided by a general practitioner (GP), clinical specialist and/or State Clinical Genetics Services.

Furthermore, there may be instances where mutations (changes in the genetic code or blue print) are discovered in biobank samples that can help provide an explanation for the cerebral palsy in the individual. In these instances it would be important to share these findings with the family.

Please indicate your wish to be made aware of such findings on the consent form provided. Information about specific research projects being undertaken using the biobank data will be available on our website (see below).

