

Supplementary Material 1 - Email to NSW/ACT CP Register

Dear Parent,

Genetic research in cerebral palsy is a relatively new but exciting area of research. Presently there are only a handful of researchers around the world who are actively researching genetics in CP, and their results so far tentatively suggest that up to 35% of CP may be attributed to underlying genetic causes. To learn more about the role of genetics in CP, they have identified the need to work together and combine CP genetic data (and the clinical information associated with that data) into one large research database.

While there has been a lot of discussion surrounding policy issues in genetics and genomics, most of the commentary has come from researchers, lawyers and policy makers. Considering your genomic data belongs to you, we would like to know your views and preferences on how your information is handled and potentially shared with researchers.

If you would like to take part in this survey, please follow this link:

<https://surveys.sydney.edu.au/surveys/?s=AnZV7tDs8p>

If you know anyone else who may be interested in completing this survey, please forward this link onto them.


Many thanks to Marelle, Saskia and Sophie our CP Quest partners who helped us to develop this survey!

The Cerebral Palsy Alliance's Human Research Ethics committees have approved this project. **It is your decision whether or not you participate in this project.**


Thank you for your time, sincerely,

Supplementary Material 2 - Facebook Invite

Draft | **DESKTOP PREVIEW** | **MOBILE PREVIEW** ✕

**Cerebral Palsy Alliance** Just now · 🌐

We need your feedback! We want to find out what people with CP and your family think about genomic research. What's that? simply it's the study of genes, their functions, and related techniques. Complete the 15 minute survey and let us know what you think!



Genomics Survey

You have been invited to participate in a research study to explore the attitudes and perceptions of people with CP and their families about genomic research, international data sharing and sample biobanking. This study is being conducted...

[SURVEYS.SYDNEY.EDU.AU](https://surveys.sydney.edu.au)

👍 Like 💬 Comment ➦ Share

Edit ▼

Supplementary Material 3 - Survey

You have been invited to participate in a research study to explore the attitudes and perceptions of people with CP and their families about genomic research, international data sharing and sample biobanking. This study is being conducted by Yana Wilson and Sarah McIntyre from the Cerebral Palsy Alliance Research Institute, The University of Sydney, and Marelle Thornton, Sophie Marmont, and Saskia van Otterloo from CP Quest.

There are no known risks if you decide to participate in this research study. There are no costs to you for participating in the study. The information you provide will help guide policy and administration of the International CP Genomics Consortium and the results will be published later this year. The questionnaire will take about 15-30mins to complete. If you are unable to finish the survey in one sitting, the survey will save your answers and you can return to where you left off at a later time. The information collected may not benefit you directly, but the information learned in this study should provide more general benefits.

This survey is anonymous. No one will be able to identify you or your answers, and no one will know whether or not you participated in the study. Participation (or not) will have no effect on your relationship with Cerebral Palsy Alliance. Should the data be published, no individual information will be disclosed.

Your participation in this study is voluntary. By answering the questions and completing the survey, you are voluntarily agreeing to participate. You are free to decline to answer any question you do not want to answer and may withdraw from the survey at any time. This survey is open until May 31, 2017.

If you have any questions about the study, please contact Yana Wilson, ywilson@cerebralpalsy.org.au

Thank you!

DEMOGRAPHICS

This survey contains a number of complex terms that are defined in this attached document. Please feel free to use this glossary at any time throughout the survey.

[Attachment: "glossary.pdf"]

How old are you?

What is your gender?

- ☐ Female
☐ Male

What country do you live in?

What is the highest level of education you have achieved?

- ☐ Completed primary/elementary school
☐ Currently studying secondary/high school
☐ Completed secondary/high school
☐ Currently studying at university/college/other tertiary education
☐ Completed university/college/other tertiary education
☐ Other

Please clarify

I identify as:

- ☐ A person with CP
- ☐ A parent of a child with CP
- ☐ A family member of someone with CP
- ☐ A carer of someone with CP
- ☐ Other

Please clarify

BIOBANKING

Biobanks play a crucial role in medical research. You can think of a biobank as a library of biological samples that are maintained to help improve our understanding of health and disease. Researchers in CP genomics have recognised the need for a CP-specific biobank for their future genomic research. For more information, please refer to the attachment.

[Attachment: "biobank.pdf"]

Have you heard of a biobank or biorepository?

- ☐ Yes
☐ No
☐ Unsure

Have you ever donated a biological sample to a biobank?

- ☐ Yes
☐ No
☐ Unsure

If yes, what is the main reason you gave a sample to a biobank?

- ☐ I was/am interested in contributing to future scientific research
☐ I/my family could benefit from this type of research
☐ Other

Please clarify

BIOBANKING (continued)**If you were invited to take part in a CP genomics study:**

Would you be interested in donating a biological sample for a CP genomics study?

- ☐ Yes
☐ No
☐ Unsure

If yes, what is the main reason you would be interested in being involved in a CP genomics study?

- ☐ I want to contribute to the scientific knowledge of cerebral palsy
☐ I/my family could benefit from this type of research
☐ I want my genetic results
☐ Other

Please clarify

If no, what is the main reason you are not interested in being involved in a CP genomics study?

- ☐ I do not want to know my results
☐ I am concerned about privacy
☐ I do not understand how genetics are involved in CP
☐ I do not see how my results can have any impact
☐ I do not feel comfortable with people having access to a sample of my DNA
☐ Other

Please clarify

Would you be happy for your de-identified sample to be stored in a biobank to be used for future genomics studies or follow-up studies?

- ☐ Yes
☐ No
☐ Unsure

If yes, what is the main reason you would be interested in contributing to a biobank? Select the main reason:

- ☐ I believe I/my family may benefit from this type of research
☐ I would like to help researchers understand the genetics of cerebral palsy
☐ I think it is important to contribute to future research efforts
☐ Other

Please clarify

If not, what is the main reason you would not be interested in contributing to a biobank? Select the main reason:

- ☐ I have concerns regarding security and privacy
☐ I would want to know the results from all experiments in which my sample was used
☐ I do not want my sample used in future research studies without my consent
☐ I do not feel comfortable with someone having access to a sample of my DNA
☐ I do not want someone making commercial products from my sample
☐ Other

Please clarify

BIOBANKING (continued)**What additional information would help you decide to take part in a CP BIOBANK?**

| | Not important | | | | Very important | Would not donate |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| What the biobank's objectives were | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| How the biobank would protect my confidentiality and data | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| What kind of sample I would have to provide | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| What research projects my sample was being used for specifically | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| The possible risks and benefits of contributing a sample to a biobank | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| The commercial profits that could be made from the biobank | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| How researchers may benefit from accessing my sample | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Which researchers have access to my sample | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Who has control over access to my sample (i.e. gatekeeper) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| How I could opt out of having my sample accessed by other researchers | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| How I could withdraw my sample in the future, should I wish to change my mind) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| If my results would be returned when my samples are used in a study | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Other, please clarify

BIOBANKING (continued)

If you were invited to take part in a CP genomics study, where you donated your de-identified sample to the CP BIOBANK:

Who would you want to have access to your sample:

- ☐ The international CP research community
- ☐ The CP research community in my home country
- ☐ A single CP research institution in my home country
- ☐ I need more information / unsure
- ☐ No one

Is there anyone you would not want to be allowed access to your sample?

Would you like to be informed/contacted every time a new research project wishes to access your sample in a biobank?

- ☐ Yes
- ☐ No
- ☐ I need more information / unsure
- ☐ I would not donate my sample to a biobank

Would you be happy to agree to a committee (such as an accredited ethics committee) or a custodian of the biobank to decide on your behalf who should have access to your sample?

- ☐ Yes
- ☐ No
- ☐ I need more information / unsure
- ☐ I would not donate my sample to a biobank

GENOMICS

These next questions are focused on genomic research. If you would like additional information about genomics, please read the attached file.

[Attachment: "genomics.pdf"]

Are you familiar with the term DNA?

- ☐ Yes
☐ No
☐ Unsure

Are you familiar with the term genetics?

- ☐ Yes
☐ No
☐ Unsure

Are you familiar with the term genomics?

- ☐ Yes
☐ No
☐ Unsure

Have you ever had any type of genetic testing done, including being involved in a genetic study?

- ☐ Yes
☐ No
☐ Unsure

If yes, what was the main reason you did this? Tick all that apply:

- ☐ I am interested in family history, heritage or genealogy
☐ I am interested in contributing to scientific research
☐ I am concerned about the health of future children in my family
☐ I am concerned about my health
☐ Other

Please clarify

GENOMICS (continued)

This section will ask you questions about how you feel about genetic results being returned to you and your family. If you were invited to take part in a CP GENOMICS STUDY:

Would you be interested in being offered your results?

- ☐ Yes
☐ No
☐ Unsure

Would being offered your results influence your decision to donate?

- ☐ Yes
☐ No
☐ Unsure

Are you aware that genetic results may have implications for your extended family?

- ☐ Yes
☐ No
☐ Unsure

In genetic research projects, there are different types of genetic results that participants may be offered. Some of the genetic variants may be directly related to CP; however, there may be variants that are unrelated to CP and associated with risk for other diseases (i.e. cancer). What kind of results would you like to receive?

- ☐ I would like to be offered all my genetic results
☐ I would like to be offered my genetic results that are associated with CP only
☐ I would like to be offered my genetic results that are associated with my risk for other health ailments only
☐ I would not like to receive any results

How regularly would you like to be contacted about the general study's findings / outcomes?

- ☐ Monthly
☐ Quarterly
☐ Biannually
☐ Annually
☐ Upon the completion of the project
☐ Never

GENOMICS (continued)**What additional information would help you decide to take part in a CP GENOMICS STUDY:**

| | Not important | | | | Very important | Would not donate |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| The research study's objective | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| How my confidentiality would be protected | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| What research projects my genomic data was being used for specifically | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| The possible risks and benefits of genetic testing | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Where my sample will be processed / sequenced | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Whether or not I might be acknowledged for my contribution | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Other, please clarify

DATABASE STORAGE AND PRIVACY

You may have heard recent buzz words like big data being used more commonly. As the scientific and genomics industry evolves, the way we store data changes, particularly due to the global approach of genomic research. At present, genetic researchers in cerebral palsy have recognised the benefits of having a cerebral palsy genetic database, whereby de-identified DNA / clinical data are integrated into one large database that authorised CP researchers can access. For additional information, please refer to the attached file.

[Attachment: "data storage.pdf"]

Would you be interested in contributing your
de-identified data to a CP genomics database?

- ☐ Yes
☐ No
☐ Unsure

DATABASE STORAGE AND PRIVACY (continued)

If you were invited to take part in a CP genetic study, in which you were asked to donate your de-identified DNA/clinical data to a database, how would you feel about your de-identified data being stored:

| | Very unhappy | | Neutral | | Very Happy | | Would not donate |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| In a database on a local storage system (i.e. personal laptop) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| In a database on a network-attached storage system (i.e. most workplace computer networks) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| In a database in the cloud (i.e. iCloud, Google Cloud) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Other, please clarify

DATABASE STORAGE AND PRIVACY (continued)

What additional information would help you to agree to donate your de-identified clinical/DNA data to a database:

| | Not important | | | | Very important | Would not donate |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| How the data will be stored securely (i.e. encryption, logs, audits, firewalls etc) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| What research projects my clinical / DNA data will be used in | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| How researchers can gain access to the database | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| How to opt out of having your data accessed by other researchers | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| How to withdraw my DNA / clinical data in the future, should I change my mind | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| What will happen in the event of a data breach | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| How my personal identifier information will be hidden or removed from the health data | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Other, please clarify

DATA SHARING AND ACCESS

The sharing of health-related data for scientific research is of key importance in ensuring continued progress in our understanding of cerebral palsy. Researchers from around the world that are investigating the genetics of CP recognise the strength of international collaboration and are interested in collating de-identified clinical / DNA data into one large CP genomic database that researchers can collectively use to investigate the role of genomics in CP.

[Attachment: "data sharing.pdf"]

Are you concerned about who may have access to your de-identified clinical data (i.e. medical records)?

- ☐ Yes
☐ No
☐ Unsure

Are you concerned about who may have access to your de-identified DNA data?

- ☐ Yes
☐ No
☐ Unsure

DATA SHARING AND ACCESS (continued)

If you were invited to take part in a CP genetic study, where you are asked to provide your de-identified clinical / DNA data to be incorporated into a CP genomic database:

Who do you think should have access to your de-identified clinical / DNA data in the database

- ☐ The international CP research community
- ☐ The CP research community in my home country
- ☐ A single research institute in my home country
- ☐ I need more information / unsure
- ☐ No one

Is there anyone that you would not want to have access to your de-identified clinical / DNA data in the database?

Would you like to be informed every time a new research project wished to access your de-identified clinical / DNA data in the CP genomic database

- ☐ Yes
- ☐ No
- ☐ Unsure
- ☐ I would not participate

Would you be happy to agree to a committee (such as an accredited ethics committee) or a custodian of the data to decide on your behalf which researchers are allowed access to your de-identified clinical / DNA data

- ☐ Yes
- ☐ No
- ☐ Unsure
- ☐ I would not participate

DATA SHARING AND ACCESS (continued)**How do you feel about researchers securely storing and accessing your de-identified data in a database?**

| | Very unhappy | | Neutral | | Very happy | | Would not donate |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Medical doctors from your HOME country | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Medical doctors from ANOTHER country | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Non-profit researchers from your HOME country | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Non-profit researchers from ANOTHER country | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| For-profit researchers from your HOME country | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| For-profit researchers from ANOTHER country | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Feel free to expand:

FINAL SAY

Finally, if you have any other views, thoughts or comments regarding genomic research, biobanking and the management of genomic and clinical data in cerebral palsy research, please feel free to leave a comment:
