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**Consent Form – Parent/Guardian**

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| --- | --- |
| **Title** | *A single centre, 12-week, single arm trial to examine compliance, safety and efficacy of daily L-carnitine supplementation (1000mg) for the treatment of childhood Neurofibromatosis Type 1 (NF1)- associated muscle weakness and fatigue.* |
| **Short Title** | *L-carnitine supplementation for NF1 muscle weakness and fatigue* |
| **Protocol Number** | HREC/18/SCHN/288 |
| **Coordinating Principal Investigator/****Principal Investigator** | *Associate Professor Aaron Schindeler*  |
| **Associate Investigator(s)** | *Miss Emily Vasiljevski, Professor Joshua Burns, Associate Professor Kristi Jones and Professor Craig Munns* |
| **Location**  | *The Children’s Hospital at Westmead* |

**Declaration by Parent/Guardian**

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I give permission for the child’s doctors, other health professionals, hospitals or laboratories outside this hospital to release information to Kids Researchconcerning the child’s disease and treatment for the purposes of this project. I understand that such information will remain confidential.

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

I freely agree to the child participating in this research project as described and understand that I am free to withdraw them at any time during the research project without affecting their future health care.

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

* I would like a summary of the results at the end of the study by mail (tick if yes).

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|  | Name of Child (please print) |  |  |
|  |  |  |  |
|  | Name of Parent/Guardian (please print) |  |  |
|  |  |  |  |
|  | Signature of Parent/Guardian |  | Date |  |  |
|  | Signature of Participant  |  |  Date |  |  |
|  |

**Declaration by Study Doctor/Senior Researcher†**

I have given a verbal explanation of the research project, its procedures and risks and I believe that the parent/guardian has understood that explanation.

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|  | Name of Study Doctor/Senior Researcher† (please print) |  |  |
|  |  |
|  | Signature |  |  Date |  |  |
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† A senior member of the research team must provide the explanation of, and information concerning, the research project

I consent to the storage and use of blood and urine samples taken from the child for use, as described in the relevant section of the Participant Information Sheet, for this specific research project.

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|  | Name of Child (please print) |  |  |
|  |  |  |  |
|  | Name of Parent/Guardian (please print) |  |  |
|  |  |  |  |
|  | Signature of Parent/Guardian |  | Date |  |  |
|  | Signature of Participant |  | Date |  |  |
|  |

**Declaration by Study Doctor/Senior Researcher†**

I have given a verbal explanation of the research project, its procedures and risks and I believe that the parent/guardian has understood that explanation.

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|  | Name of Study Doctor/Senior Researcher† (please print) |  |  |
|  |  |
|  | Signature |  |  Date |  |  |
|  |

† A senior member of the research team must provide the explanation of, and information concerning, the research project

Note: All parties signing the consent section must date their own signature