PARTICIPANT INFORMATION STATEMENT

(1) What is the study about?

The aim of the 1000 Norms Project is to investigate normal variation in the healthy human population. The study involves collecting basic physical and health-related information from 1000 participants across the lifespan aged from 3 to 100 years. In healthcare, knowledge of what is normal for a particular test is essential for clinicians to make a diagnosis and to evaluate the effect of treatments. This information will be used to create a database of reference values that will be freely accessible to clinicians and researchers around the world. The international healthcare community will benefit greatly from this resource. The study also includes analysis of DNA extracted from saliva. We are investigating a particular gene known as the gene for speed and the effect it has on physical function.

(2) Who is carrying out the study?

The study is being conducted by Physiotherapists Marnee McKay and Jennifer Baldwin and will form the basis for the PhD degree at The University of Sydney under the supervision of Associate Professor Joshua Burns. The study is an initiative of leading researchers at The University of Sydney and receives National Health and Medical Research Council of Australia (NHMRC) funding.

(3) What does the study involve?

The study involves a one-off physical assessment that will be conducted at The University of Sydney Cumberland Campus in Lidcombe. During the physical assessment, you will take part in a range of simple activities to measure your physical health and function, including strength, movement, balance, coordination, and performance in daily activities. Examples of some of the tests include measuring how strong your grip is and how much you can bend your knee. The study also involves completing six short questionnaires assessing your health and well-being. You will also be asked to provide a small saliva sample for DNA analysis. You can participate in the study and not provide a saliva sample if you wish.

(4) What will happen to my saliva sample?

Your saliva sample will be coded to protect your identity, and transported to the genetics laboratory where it will be stored. The 1000 Norms Project genetics team will extract your DNA from the saliva sample, and analyse your DNA for the ACTN-3 gene, also known as the “gene for speed”. Use of your DNA for any other genetic analysis will require your consent.

(5) What are the possible risks to participating in the study?

i. As the assessment involves physical activities, there is a small risk associated with exercise including accidental injury or mild muscle soreness. You will be able to take rests in between the tests as you wish. The researchers are trained in first aid and The University of Sydney has emergency procedures in place.
ii. All information is de-identified and stored in password protected databases. It is possible, though very unlikely, that someone could get access to this database without permission.

iii. In the unlikely event that you become upset or distressed as a result of your participation you may prefer to suspend or end your participation in the research.

iv. There is no disease risk associated with the gene being analysed, ACTN-3, which is also known as the "gene for speed".

(6) **What if new information arises?**

During the research project, new information about the risks and benefits of the project may become known to the researchers. If this occurs, you will be told about this new information and the researcher will discuss whether this new information affects you.

(7) **How much time will the study take?**

The study will take approximately 2-3 hours, including the assessments, questionnaires and short breaks.

(8) **Can I withdraw from the study?**

Taking part in this study is completely voluntary. You are not under any obligation to consent and - if you do consent - you can withdraw at any time without affecting your relationship with The University of Sydney. You may withdraw your physical or genetic data at any time.

(9) **Will anyone else know the results?**

All aspects of the study, including results, will be strictly confidential and only the researchers will have access to information on participants. A report of the study will be submitted for publication, but individual participants will not be identifiable in such a report. The database that will be generated from results gathered during the study will be accessible via a University of Sydney online portal and will not contain any personal (or identifiable) information or genetic information.

(10) **Will the study benefit me?**

We cannot and do not guarantee or promise that you will receive any benefits from the study.

(11) **Can I tell other people about the study?**

Yes. You may also invite members of your family to contact the researchers if they are interested.

(12) **What if I require further information about the study or my involvement in it?**

When you have read this information, Marnee McKay or Jennifer Baldwin will discuss it with you further and answer any questions you may have. Marnee and Jennifer can also be contacted on (02) 9036 7435 or via email: marnee.mckay@sydney.edu.au and jbal2575@uni.sydney.edu.au

(13) **What if I have a complaint or any concerns?**

Any person with concerns or complaints about the conduct of a research study can contact The Manager, Human Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email).

_-This information sheet is for you to keep-_