

**Research study on information about experimental stem cell treatments  
for stroke**

**HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: H-2018-128**

**PRINCIPAL INVESTIGATOR: Dr Diana Dorstyn**

**STUDENT RESEARCHER: David Unsworth      DEGREE: PhD/Masters (Clinical Psychology)**

Dear Participant,

You are invited to participate in the research project described below.

**What is the project about?**

The current project is examining whether patient education booklets and videos are a clear and informative way of communicating information about the safety and effectiveness of experimental stem cell treatments (i.e. stem cell injections to the brain, spinal cord, vein, artery or stomach) offered by private clinics in China, India, Russia and South America.

**Who is undertaking the project?**

This research is being undertaken by Mr David Unsworth (PhD student), Dr Diana Dorstyn, Professor Jane Mathias and Professor Simon Koblar, at the University of Adelaide, Australia.

**Why am I being invited to participate?**

We are surveying stroke survivors who have not previously received stem cell treatment for their stroke/stroke-related symptoms (e.g. pain) or any other medical or neurological disorder. Participants must speak English and be able to complete a number of brief online surveys, either individually or with the help of a partner/friend/family member.

**What will I be asked to do?**

You will be asked to provide an email address in order to allow us to send you a survey that contains 26 questions about your background (age, marital status etc.), stroke (type, year) and general/mental health and eight questions about stem cell treatments (e.g. how safe and effective you think they are). After providing these details, you will be asked to read a 7-page booklet, or watch a video (approx. 1 min, 17 seconds in length), about stem cells. You will then be asked to complete 10 more questions about stem cell treatments and the resources you were provided. If you are not asked to read/watch the resources straight away, you will be sent them at a later date. Thirty days after completing the survey, we will email you six further questions to reconfirm your thoughts and attitudes toward stem cell treatments.

All surveys will be completed online. We would like you to complete all of the questions, if possible, however you are not obligated to do so.

Each survey will take 15 to 30 minutes to complete. Once you have completed the study you will be provided additional stem cell resources and will be given the opportunity to email a member of the research team with any questions about stem cell treatments.

**Are there any risks associated with participating in this project?**

You will be asked about your stroke, disabilities and mood, which may be upsetting. We will therefore provide you with the contact details for counselling services, in case you do feel upset and want to talk to someone.

### **What are the benefits of the research project?**

The research will not directly benefit you, but is designed to help us understand stroke survivors' beliefs and attitudes toward experimental stem cell treatments. It is hoped that the findings will be used to improve future educational materials and to assist treating doctors in their discussions with patients about the potential risks and benefits associated with these treatments.

### **Can I withdraw from the project?**

Yes, your participation is entirely voluntary and you can discontinue at any time. Withdrawal from the project will not affect any of the services you are currently receiving.

### **What will happen to my information?**

Your information will remain anonymous at all times and will be stored securely at the University of Adelaide. The results may be published in academic journals, presented at conferences and will form part of a PhD. You will not be identified at any stage. Once published, the results will be made available upon request.

### **Who do I contact if I have questions about the project?**

The research team is available to discuss any questions you have regarding the project:

Dr. Diana Dorstyn:	Ph. +61 8 8313-5266 (Principal Investigator)
Mr David Unsworth:	Ph. +61 8 8313-3452
Professor Jane Mathias:	Ph. +61 8 8313-5266
Professor Simon Koblar:	Ph. +61 8 8313-0649

### **What if I have a complaint or any concerns?**

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2018-128). This research project will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research (2007). If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. If you wish to speak with an independent person regarding concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on:

Phone: +61 8 8313 6028

Email: [hrec@adelaide.edu.au](mailto:hrec@adelaide.edu.au)

Post: Level 4, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

#### **If you would like to participate:**

Please visit the following link: <https://www.surveymonkey.com/r/Y63DJZT>

Or contact David Unsworth via [david.unsworth@adelaide.edu.au](mailto:david.unsworth@adelaide.edu.au)

Yours sincerely,

**Dr Diana Dorstyn**  
**Mr David Unsworth**  
**Professor Jane Mathias**  
**Professor Simon Koblar**