



Information Statement

Project Title: Investigating the health of Pink Disease Survivors and their descendants

Investigators: Ms Kerrie Shandley and Associate Professor David Austin

What is the study about? The first mention of Pink Disease dates back to the late 1800s and was particularly prominent in Australia, North America and Central Europe. The cause of the disease was eventually revealed as mercury, primarily contained in teething powders. Our understanding of the signs and symptoms of Pink Disease comes largely from case studies or case series reported by medical practitioners from the early to mid 1950s. However since the removal of mercury-laden products the disease has all but disappeared and subsequently so too have any studies investigating it. The purpose of this study is to investigate the impact of Pink Disease on the health of the children and grand-children of Pink Disease survivors.

Who is carrying out the study? This research is being conducted by PhD candidate Ms Kerrie Shandley and Associate Professor David Austin.

Ms Shandley is a registered psychologist and Research Fellow in the Faculty of Life and Social Sciences at Swinburne University. She has authored papers in the areas of biochemistry, internet-based treatments for psychological disorders and gambling published in peer-reviewed journals.

Associate Professor Austin is a clinical psychologist and Associate Professor in the Faculty of Life and Social Sciences, Swinburne University. David has published widely in international peer-reviewed journals in the area of children's health.

Who can complete this study? Anyone who has ever had a diagnosis of Pink Disease (Acrodynia). In cases where the Pink Disease Survivor is incapacitated or has passed away the survey can be completed by a family member.

What does this study involve? This survey will take approximately 15-20 minutes of your time and is comprised of three parts:

- Part A - asks for demographic information (age, gender) of the Pink Disease Survivor
- Part B - asks about childhood behaviours and characteristics of the Pink Disease Survivor
- Part C - asks about health information of the Pink Disease Survivor's descendants

What do I have to do to participate? This survey can be completed via the internet, post or telephone. Directions to complete the survey by each method are as follows:

- Internet - complete the survey online at the following website: <http://tiny.cc/pinkdisease>
- Post - If the survey has already been received, simply complete it and return via the reply-paid envelope. If a postal survey has not already been received please contact Ms Kerrie Shandley (contact details below) to request one.
- Telephone - If you would like to complete the survey via telephone interview please contact Ms Kerrie Shandley (contact details below) to schedule an interview time.

Prize Draw: Participants who successfully complete the survey will have the option of being entered into a prize draw to win one of 10 Amazon.com or Coles/Myers vouchers valued at \$75 (Australian) each.

Can I withdraw from the study? Participation in this study is voluntary and completely at your discretion. If you decide not to participate, or choose to withdraw your participation at any stage, this will in no way impact upon your current or future relations with Swinburne University or the Pink Disease Support Group.

Will anyone else know the results? All aspects of the study will be kept strictly confidential and only researchers directly involved in the study will have access to participant data. All survey results will be entered into a database and de-identified (no names or other identifying information will be stored with your responses). All paper and electronic data will be kept for 5 years (in a locked filing cabinet or password protected computer) before being destroyed.

The results of this study will be written up for publication and the resulting publication made available upon request. The publication will also be submitted as part of Ms Kerrie Shandley's PhD and the de-identified survey data provided to the Pink Disease Support Group.

Are there any risks from participating? We do not anticipate that you will experience any risks from participating in this study. However, we understand that completing questions can sometimes cause unintended distress. If you find yourself becoming upset as a consequence of participating in this study we encourage you to either contact the researchers (details included below) or the Pink Disease Support Group (www.pinkdisease.org).

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| <p>If you would like to speak with the researchers about any aspect of this study, please contact the PhD Candidate, Kerrie Shandley:</p> | <p>This project has been approved by or on behalf of Swinburne's Human Research Ethics Committee (SUHREC) in line with the <i>National Statement on Ethical Conduct of Research Involving Humans</i>. If you have any concerns or complaints about the conduct of this project you can contact:</p> |
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