

**Project Title:** The Visions of Charles Bonnet Syndrome

### Researchers:

Prof Andrew Brown, Dr Vincent Moug, Dr Michelle Douglas, Ms Victoria Hamilton  
Queensland College of Art, Griffith University

Prof Andrew Brown: Phone - (0)7 3735 6252 Email - andrew.r.brown@griffith.edu.au  
Ms Victoria Hamilton: Phone - 0408723276 Email - vicky.hamilton@griffithuni.edu.au

### Why is the research being conducted?

This research aims to investigate Charles Bonnet Syndrome (CBS) visions. It is exploring the complex pseudohallucinations that take place when a loss of sight is occurring.

It is important to note this is **not** medical research. The research will focus on how our thoughts become physical visions through design. Of particular interest to be explored in this study is the link between metaphor and images. A common example of metaphor is 'Laughter is the best form of medicine'. Metaphors are thought connections essential for both day-to-day life and night-time dreaming.

To introduce myself, I am Vicky Hamilton, and had an aneurysm pressing into my optic nerve. I had CBS complex visions for many years. The wish to be able to express these visions to friends, family and doctors has inspired this PhD research with Griffith University. The aim is to provide valuable insight into CBS and to raise awareness by expressing the inexpressible.

### What will you be asked to do?

You be invited to contribute in the following ways:

- o Participate in co-creating one of your CBS visions.

To help us to better understand the way that thoughts and visions interact, we invited you to co-create one (or more) of your complex CBS visions. If you give your consent, you may participate with the group, by email and at virtual meeting place.

## Why have you been invited to participate?

You have been asked to participate in this investigation as you are a visitor to a Charles Bonnet Syndrome website. The researchers appreciate that your time is valuable. Your participation or non-participation is entirely voluntary.

## What are the benefits of this research?

Charles Bonnet Syndrome is a little-known lived experience. Participation in this study will give you the opportunity to reflect on your visions in a small group. This group is for creative/design reasons and is not for therapeutic benefit: there is no medical content. The CBS research community may benefit from the findings of this research in terms of identifying context and content of CBS complex visions.

## Risks to you:

As this is a creative design group it is not anticipated there will be any risks to you. Although unlikely, there is a chance that you may feel discomfort. You can decline to answer any questions or cease at any time without explanation. If you experience discomfort, you can access free counselling provided through CBS Foundation Australia or Esme's Umbrella, England.

## What is Personal Information:

Your personal information can be anything that is associated to you. For example, your name, age, opinions, what you say, and audio recordings.

## How are we going to use your Personal Information?

All the data that is collected will be anonymous: we will remove all identification and replace it with a code. For example, Jane Smith may become participant 06. You can indicate if you *do* wish to be identified for the exhibition of the design. The use of your design and opinions will only be used in the research publication if you give specific consent. The research results will be reported in an academic thesis, and may also be disseminated via journal articles, conference presentations, and an art exhibition.

## Who are we going to give this Personal Information to:

After the completion of data collection, the researcher will provide a summary report of the data for participants. The thesis will also be available upon request. You will be anonymous in all publication of results. We will remind all participants of the importance of confidentiality but cannot guarantee that other participants will maintain confidentiality.

## How will this Personal Information be stored?

Surveys, copies of the focus group transcripts, and audio files, will be stored on the Griffith University secure server accessible only by the researchers. No sooner than 5 years from the publication of the PhD thesis, all transcripts and notes will be shredded, and computer files deleted. All information collected by the researchers will be treated confidentially.

## Your participation is voluntary:

If you decide to withdraw your participation at any time, you may do so without providing an explanation.

## What if I have questions about this study?

If you have any questions relating to this study, please feel free to contact one of the researchers:

Prof Andrew Brown: Phone - (0)7 3735 6252 Email - [andrew.r.brown@griffith.edu.au](mailto:andrew.r.brown@griffith.edu.au)  
Ms Victoria Hamilton: Phone - 0408723276 Email - [vicky.hamilton@griffithuni.edu.au](mailto:vicky.hamilton@griffithuni.edu.au)

Griffith University conducts research in accordance with the National Statement on Ethical Conduct in Human Research. If you have any concerns or complaints about the ethical conduct of this research project, you are encouraged to contact the Manager, Research Ethics on 07 3735 4375 or [research-ethics@griffith.edu.au](mailto:research-ethics@griffith.edu.au).

## Privacy Statement:

“The conduct of this research involves the collection, access, storage and/or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes, including publishing openly (eg. in an open access repository). However, your anonymity will at all times be safeguarded. For further information consult the University’s Privacy Plan at <http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan> or telephone (07) 3735 4375