



UNIVERSITY of
DENVER

ARTS, HUMANITIES
& SOCIAL SCIENCES

Department of
Communication Studies

DU IRB Approval Date: August 4, 2015

Expiration Date: July 15, 2017

**University of Denver
Consent form for Participation in Research**

Study Title: The Scraps of the Heart Project: Storying Babies(' Deaths) and Healing Parents Through Creative Arts

Principal Investigator: Erin K. Willer, Ph.D.

You are being asked to be in a co-researcher in a research study. This form provides you with information about the study. Please read the information below and ask questions about anything you do not understand before deciding whether or not to take part.

Invitation to participate in a research study

You are invited to participate as a co-researcher in a research study about how participating in The Scraps of the Heart Project Creative HeARTs workshops function to facilitate the grieving and healing process for parents who have experienced the death of a baby. This research constitutes participatory action research, which involves academic researchers working *with* co-researchers or stakeholders. Stakeholders in this study include parents and health-care or support providers who have a stake, investment, or commitment to the baby loss community. Working together as co-researchers on this project, we as parents, health-care or support providers, and academic researchers will work to identify important questions and key observations of creative arts workshops and their impact. Through this joint effort our hope is to empower families experiencing the death of a baby and to educate communities about baby loss.

The project is funded by the University of Denver's Center for Community Engagement and Service Learning's Public Good Fund Grant.

You are being asked to be in this research study because you provide support services to families who have experienced the death of a baby due to miscarriage, stillbirth, early infant death, or any other kind of baby loss.

Description of co-researcher involvement

If you agree to be part of the research study, you will be asked to participate as a co-researcher. This includes attending Scraps of the Heart Project Creative HeARTs workshops where bereaved parents will participate in creative arts activities. We will ask you to provide the type of support that is typical for you when working with bereaved families. In other words, as parents are making art you may provide support or insight regarding child loss based on your expertise, experiences, or niche in the baby loss community. You also are welcome to participate in the creative arts activities. Your role in the workshops additionally will include acting as a co-researcher along with parents and the primary investigators of this study. Having experienced the loss of our own children and babies close to us, we believe that artmaking is a powerful means of processing grief. As researchers, we are extending this interest by working with parents and those who provide bereavement services to understand more fully how artmaking helps families grieve and heal. As co-researchers we all will enact multiple roles during the workshops; we will make observations about the artmaking process, ask one another questions, and talk about our observations. Each workshop will last approximately two hours. If possible we will ask you to commit to attending all six workshops occurring over the 12-week session.

We also may ask you in informal conversations to provide feedback regarding your observations of the workshops.

Possible risks and discomforts

There are minimal risks associated with participating in this study beyond what you normally encounter when supporting bereaved families. However, given that participating as a co-researcher in the study will involve you spending additional time with bereaved families, there is a potential risk for burnout and compassion fatigue. If you experience distress, please contact one of the following child loss specialists who provide support to those working with bereaved families:

Stacey Bromberg, Ph.D.

950 S. Cherry St., Suite 1240

Denver, CO 80246

Phone: 720-505-3772

<http://www.drstacey.net/bio.html>

dr.bromberg@yahoo.com

Jennifer Harned Adams, Ph.D.

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Denver, CO 80246

Phone: 303-325-1633

<http://www.bloomhealthdenver.com/AboutMe.en.html>

jen@bloomhealthdenver.com

Possible benefits of the study

You may benefit from participating in the study as a result of feeling rewarded in helping parents process their grief in a new way. You may also identify new tools that may be useful for supporting families in your own organization. This study is designed for us to learn more about how artmaking functions to facilitate the grieving and healing process for parents who have experienced the death of a baby. Creating art will allow them to memorialize their babies in a lasting way. Artmaking is also community building. Parents experiencing the death of a baby often report feelings of loneliness and a lack of understanding from those close to them. Coming together with others who share their experiences is a powerful means of connection. Our research will provide not only a detailed look at the experiences of those who have gone through the death of a child, but also the ways in which artmaking allows parents to shape meaning about their loss, construct an identity for themselves and their babies, and empower themselves through memory making. This information is essential for educating communities who lack understanding about the significance of child loss and ways to support bereaved parents.

Study compensation

You will not receive any payment for being in the study.

Study cost

You will be expected to pay for your own transportation or parking if needed.

Confidentiality, Storage and future use of data

Generally, anything you say or do during the workshops, in email exchanges between workshop participants, and on the group's private Facebook page may be included in our research reports. If there is something you prefer we not include in our reports, you will need to let us know. We will ask your permission before using a direct quotation from you in our reports.

Reports about our research may be shared at professional research conferences and published in articles. Your individual name will be changed to a pseudonym if you choose. We will ask you to indicate this preference on the information sheet you will complete at the start of the study.

You are encouraged to maintain workshop participants' confidentiality. We, however, are not able to guarantee that participants keep information you may share to themselves.

We will take great care to keep our fieldnote books (notebooks including details about our observations) and typed fieldnotes in locked spaces in our homes and offices when we are able. There is a chance for a breach in confidentiality if our notebooks were to be stolen. We will keep our typed fieldnotes on our password-protected laptops. We will delete our fieldnotes and destroy our fieldnote books at the conclusion of the full Scraps of the Heart Project study and after completion of our write-ups (approximately 5 years).

Who will see my research information?

Although we will do everything we can to keep your information a secret, confidentiality cannot be guaranteed. Others may look at both the records that identify you and the consent form you sign. These include federal agencies that monitor human subject research and the Human Subject Research Committee. All of these people are required to keep your identity confidential. Otherwise, as described above, records that identify you will be available only to people working on the study, unless you give permission for other people to see the records.

Also, if you tell us something that makes us believe that you or others have been or may be physically harmed, we may report that information to the appropriate agencies. For example, if you give us any information about child abuse or neglect or if you tell us you are going to physically harm yourself or someone else, we have to report the information to the appropriate agencies. Also, if we get a court order to turn over your study records, we will have to do so.

Voluntary Nature of the Study

Participating as a co-researcher in this study is completely voluntary. Even if you decide to participate now, you may change your mind and stop at any time. If you withdraw early, we will ask you if we may use any of the information you provided during the study.

Contact Information

If you have any questions about this project or your participation, please feel free to ask questions now or contact Erin Willer at 303-871-4308 at any time.

If you have any questions or concerns about your research participation or rights as a participant, you may contact the DU Human Research Protections Program by emailing IRBAdmin@du.edu or calling (303) 871-2121 to speak to someone other than the researchers.

Please take all the time you need to read through this document and decide whether you would like to participate in this research study.

If you agree to participate in this research study, please sign below. You will be given a copy of this form for your records.

Participant Signature

Date