



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 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 scrapbooking workshops and their impact, and plan future studies. 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 identify as having experienced the death of a baby due to miscarriage, stillbirth, early infant death, or any other kind of baby loss at some time in your life.

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 creative arts workshops where you will participate in creative activities. We will invite you to provide input regarding what type of creative activities you would like to do in the workshops. Together we will design activities. Your participation in workshops may include sharing your experience of baby loss, talking about challenges you face, and talking to the group about your art and your process of artmaking. As co-researchers we also will make observations about the artmaking process, ask one another questions, and talk about our observations. Each session will include six workshops that occur every other week over the course of 12 weeks. Each workshop will last approximately two hours. We encourage you to commit to attending all six workshops during the 12-week session.

As participants in the study, we will also ask if we can take pictures of your artwork, journals, and artmaking during the workshops and possibly afterward at the interview if necessary. We also will be observing participants' group emails and Facebook group interactions.

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Acting as a co-researcher also will involve completing a five- to ten-minute survey before and after you attend your first and last workshop of the session in order to assess the impact the scrapbooking workshops had on you.

We also will offer you the opportunity to participate in a 60- to 90-minute follow-up interview where you will meet with one of the researchers to talk about your experience in the workshops. At this interview we will request that you bring your artwork with you so that we can ask you questions about it.

Possible risks and discomforts

There are risks associated with participating in this study. You may become upset when thinking about and talking about your baby who has died or when doing artwork, completing the surveys, or participating in the interview. In most cases grief support staff will be on-site during the workshops. If they are not in attendance or if you become upset when you are not at a workshop site, please contact one of the following child loss resources for support:

Dorotha Graham Cicchinelli, BASW, MNM, LCCE, CLC
 Executive Director
 Colorado Pregnancy & Newborn Loss Services
 7355 S. Peoria
 Englewood, Colorado 80110 (not a mailing address)
 Mail: P.O. Box 476, Parker, CO 80134
<http://www.coloradopregnancyloss.org>
dorothacicch@yahoo.com
 Office: 720-946-2828
 Cell: 303-514-9603

Stacey Bromberg, Ph.D.
 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.
 950 S. Cherry St., Suite 1240
 Denver, CO 80246
 Phone: 303-325-1633
<http://www.bloomhealthdenver.com/AboutMe.en.html>
jen@bloomhealthdenver.com

Possible benefits of the study

This study is designed for us to learn more about how creative arts function to facilitate the grieving and healing process for parents who have experienced the death of a baby. Engaging in creative activities may allow you to process your grief in a way that you cannot otherwise do. 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 creative arts allow 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

The first 20 parents who work on their scrapbooks for five total hours and/or complete their scrapbooks will receive \$100 Target Gift Cards.

Study cost

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

Confidentiality, Storage and Future Use of Data

Generally, anything you say or do during the workshops, in group emails or interactions on the private Facebook group, during the interview, as well as details about your babies and your artwork 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. If we use a direct quotation or picture of your artwork in our reports, we will request your permission to use it. Reports about our research may be shared at professional research conferences and published in articles. Your individual names and those of your babies will be changed to pseudonyms if you choose. We will ask you to indicate this preference on the information sheet you will complete at the start of the workshop session.

You are encouraged to maintain other participants' confidentiality. We, however, are not able to guarantee that participants keep information to themselves.

We will take great care to keep our fieldnote books (notebooks including details about our observations), fieldnotes, your interview recordings, and interview transcripts in locked spaces in our homes and offices and password protected on our computers when we are able. There is a chance for a breach in confidentiality if our notebooks were to be stolen. We will delete our fieldnotes, interview audio and transcripts, 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).

When completing the online surveys at the start and finish of the study, you will identify yourself with a code number. This will allow us to match your surveys for analysis purposes, while keeping your identity private. You will complete the online questionnaire via Qualtrics, a secure site that encrypts information should a third part intercept it. Your computer IP addresses will not be collected.

Who will see my research information?

Although we will do everything we can to keep your records a secret, confidentiality cannot be guaranteed. A transcriptionist will transcribe your interview. 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.

Options for Participation

In addition to agreeing to allow the researchers to observe your interactions during the workshops and in group emails and Facebook group interactions and completing the survey before and after the workshop session, you may choose to agree or disagree to the following participation options. Please **initial** the lines below to indicate your agreement or disagreement.

Please initial your choice for the options below:

The researchers may photograph my artwork, journals, and artmaking
 The researchers may not photograph my artwork, journals, and artmaking

The researchers may interview me following the workshop session.
 The researchers may not interview me following the workshop session.
 (Even if you agree to participate now, you can choose not to do so later.)

The researchers may audio record my interview.
 The researchers may not audio record my interview.
 (Even if you agree to be recorded now, you can choose not to do so later.)

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