Welcome to the FAPAC research study.

Please read the information provided below carefully. If you have any questions or concerns at this point or in the future, please feel free to contact:

The FAPAC project research team
Principal Investigator: T. Mike Hsieh, MD
University of California San Diego
200 West Arbor Drive, #8897
San Diego, CA  92103-8897
Telephone: (619) 534-2009 - *If you leave a voicemail, we will call you back within 24 hours.*

If you have any questions about your rights as a participant in this study, you may also contact the Human Research Protection Program Office at (858) 455-5050.

**What is the purpose of this study?**

Dr. T. Mike Hsieh is conducting a research study to learn more about the reproductive experiences of young female and male cancer survivors. You have been invited to participate because you are cancer survivor between the ages of 18 and 35 years who was diagnosed at least one year ago. The purpose of this study is to find out more about young cancer survivors’ reproductive health and their concerns and feelings toward fertility and parenthood now or in the future. There will be approximately 150 female and 150 male participants in this study. This study is sponsored by the American Cancer Society and the UCSD Academy of Clinical Scholars. Please take your time to make your decision and be sure to contact us with any questions that you may have.

**What will I need to do?**

First, you will be asked to complete an online interest screening form. This form will determine your eligibility for the study by asking a few questions. If you are eligible, you will be asked if you would like to participate in the online survey.

The survey will take about 20 minutes of your time. The survey includes the following topics: general information about demographics, your cancer diagnosis and treatment, attempted pregnancy, your experience with fertility evaluation and treatment, fertility-related information you have gotten or wanted to get, your reproductive history, your feelings toward fertility and parenthood, your knowledge and feelings toward genetic counseling and testing, your feelings about adoption, and your personal well-being.
You will not be asked for any personal contact information during the survey, including your name, email, address, or phone number. Therefore, the researchers and staff involved with this study will have no way to contact you after you complete the survey.

If you agree to participate, you will be directed to a website to complete the online survey. You may also choose not to participate at that time. If you are not eligible, we will notify you after you complete the screening form.

**What are the risks to me in taking this survey?**

The risks associated with completing the screening form and survey are minimal. A small risk to you is that some of the questions may make you feel uncomfortable because they are personal. If this occurs, you may discontinue completing the screening form or the survey at any point. Even though all your answers will be stored on a secure server with all files protected by passwords, you may also be concerned about release of your private information if a security breach were to occur.

**What are the benefits of taking this survey?**

There may not be a direct benefit to you personally for participating in this study. However, the researchers hope to develop a method of measuring fertility and parenthood concerns that would improve research in this area and possibly help healthcare providers identify and address these concerns among young cancer survivors.

**What compensation do I receive for completing the survey?**

There is no compensation for completing the online screening form. However, if you meet the eligibility criteria and complete the online survey, you will be provided a $20 gift card after calling or emailing the reimbursement coordinator to tell us you have completed the survey and to give us your contact information. If you do not call or email the study staff, we will not have a way of contacting you or sending you this gift card.

**What if I don't want to participate?**

Your participation in completing the screening form and online survey are both completely voluntary. You may choose to leave the study at any time. Your refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled.

You can discontinue the survey at any time by simply closing your browser.

**Are my answers confidential?**

Yes, your confidentiality will be maintained at all times. Research records will be kept confidential to the extent provided by law. Access to your research records will be limited to the study investigators, the study staff and the UCSD Institutional Review Board. Your data will be stored appropriately on a secure computer server in order to minimize the risk of loss of
confidentiality. All information collected for this research that is stored on our secure computer will be identified by Study ID number only. Strict security measures will be taken to insure that none of these procedures results in release of any information you provide us.

**Can I find out about results of the study?**

Upon request, the researchers will share with you available information regarding the overall results of this study. If you are interested in learning more about when and how to get the results of this research study, please contact Dr. Hsieh at (619) 543-2009.

**What other options are there?**

You don’t have to be in this study if you don’t want to. The alternative to participation in this study is not to participate.

**What are the costs?**

There will be no cost to you for participating in this study.

**What if you are injured in the study?**

If you are injured as a direct result of participation in this research, the University of California will provide any medical care you need to treat those injuries. The University of California will not provide any other form of compensation to you if you are injured. You may call the UCSD Human Research Protections Program at (858) 455-5050 for further information about this.

Please click here to view and print the Subject’s Bill of Rights

**Participant's statement of informed consent:**

By checking the box “I agree” below you are agreeing to complete the online interest screening form to determine your eligibility. If you are eligible, you will then be asked whether you would like to participate by agreeing to the following statement:

“I am at least 18 years of age, have read and understood the Consent Agreement provided to me, and voluntarily agree to participate in this survey.”

If you do not agree, simply close your browser.

I agree