ADVOCACY INVOLVEMENT

A. Advocacy Organization/Advocate(s) Selection and Engagement to Date: The investigators are partnered with the Young Survival Coalition (YSC) and the [redacted] affiliate of Susan G. Komen for the Cure (Komen) for this proposal. The goal of the proposed reproductive health survivorship intervention directly supports the missions of both advocacy organizations. The YSC is dedicated to supporting educational and clinical care interventions that empower young breast cancer survivors. The Komen affiliate in our community is deeply committed to supporting the continuum of care in the transition from treatment to survivorship. The partnership between these groups and the PI is also a natural extension of ongoing interactions. Because of her research and clinical care focus on young breast cancer patients, the PI has worked with the YSC over the past year through speaking at the annual C4YW conference for young survivors and participating in the Research Think Tank. When the YSC Research Think Tank convened in 2013, discussion focused on the immediate and late effects of treatment including infertility and sexual dysfunction and the urgency for increased understanding by young survivors and their healthcare providers. The PI's interactions with the local Komen affiliate began one year ago and have focused on raising awareness about fertility preservation in the community; with this support, [redacted] (Komen patient advocate) were recently co-featured in a televised interview on fertility in young survivors prior to the Susan G. Komen 3-Day Walk.

The PI has worked closely with both organizations in the formative stages of this grant application. [redacted] (Science and Public Policy Liaison at [redacted] Komen), [redacted] (Program Manager of Advocacy and Research for YSC), and [redacted] (young breast cancer survivor and research advocate for YSC) reviewed and gave invaluable feedback on the LOI. Both Komen and YSC connected the PI with advocates interested in the project. The interactions with [redacted] and [redacted] have been in person, while [redacted] who is located in the national YSC office in New York has communicated via email. <u>The primary feedback from our advocacy partners focused on the high relevance of a reproductive health survivorship care plan to the community of young survivors</u>. Feedback also resulted in intervening on healthcare providers in addition to survivors. [redacted], [redacted], and [redacted] (young breast cancer survivor and patient advocate for Komen) have reviewed and advised on the full application. Through these and prior experiences in partnering with advocacy groups, we believe that the proposed research will be improved in relevance, recruitment and retention, and dissemination of results in the young breast cancer survivor community.

B. Advocate(s) Role in Proposed Research: [redacted] have and will continue to contribute to project design, implementation and dissemination of results. In the first year, they will participate in expert panel sessions every 6 weeks to generate the web-based Reproductive Health Survivorship Care Plan (rhSCP). Both [redacted] have significant scientific research and patient advocacy background that will be key to shaping the clinically relevant reproductive survivorship tool. In Years 2 and 3, they will meet with [redacted] and the research team in person on a quarterly basis to discuss and advise on progress of the randomized controlled clinical trial. They will be invited to co-author manuscripts that arise from the project. Through [redacted] and their respective advocacy organizations, the investigators have additional resources for participant recruitment. Finally, [redacted], YSC and [redacted] Komen will support dissemination of study findings and the rhSCP in the young breast cancer survivor community.

C. Meeting and Payment Plans: [redacted] and [redacted] will meet with the research team every 6 weeks for the expert panel sessions in Year 1. While most sessions will be by conference call, they will attend the meeting at [redacted] in person at least quarterly. During Years 2 and 3, [redacted] will meet with [redacted] and the research team in person at [redacted] quarterly to discuss and advise on the clinical trial. For consulting on the project, they will be compensated [redacted] in Year 1 and [redacted]/year in Years 2 and 3. They will also be reimbursed for mileage-based travel costs. They will submit quarterly invoices for their consultation services.

December 5, 2013

Advocate **Principle Investigator**

[redacted]

I'm writing to express my support of Dr. Su's proposal, "Intervening on Reproductive Health in Young Survivors" and to describe my participation on this project.

As a survivor of early onset breast cancer I can attest to the dearth of information for young breast cancer survivors on the effective treatment of estrogen deprivation symptoms, fertility concerns and sexual function, as well as the need to fully implement survivorship care plans that cover these areas, in addition to all other crucial health areas. A breast cancer diagnosis isn't only about survival; it is about living the remainder of one's life, however long, with quality and with effective management of the collateral damage of cancer treatment.

It is tremendously exciting that Dr. Su seeks to intervene on this shortcoming in care with this research study, introducing specialty care into the management of cancer patients. This research study has great appeal in its inclusion of both young breast cancer survivors and the health care providers who care for them.

It is with great delight that I agree to serve on the expert panel for this project. I serve in this role at the invitation of the Young Survival Coalition for which this research area is a high priority. The Young Survival Coalition has the ability to disseminate information about this study and the study's eventual findings to its constituency. In addition my longstanding affiliation with the breast cancer oncologists at the [redacted] will prove helpful, especially as they develop their Adolescent and Young Adult Cancer Program which will include young breast cancer patients. I'm anxious to disseminate these findings.

Over the past four months [redacted] have met in person and have exchanged emails regarding this grant application and survivorship care planning. We have agreed upon the following:

I, [redacted], will**:**

- Participate in expert panel conference calls every 6 weeks in Year 1 to develop and refine the web-based rhSCP intervention.
- Review and provide feedback of iterations of the web-based rhSCP intervention in Years 1-2.
- Meet with [redacted] and the research team quarterly to discuss and advise on clinical trial progress and results in Years 2 and 3.

- Provide help with recruitment as needed.
- Communicate findings with the Young Survival Coalition community.

I, Irene Su, will:

- Participate in expert panel conference calls in Year 1 to develop and refine the web-based rhSCP.
- Solicit input from [redacted] on the web-based rhSCP intervention in Years 1-3.
- Compensate [redacted] for Year 1 and [redacted] each year for Years 2 and 3.
- Acknowledge [redacted] and the Young Survival Coalition's contribution to the research study. [redacted] will be invited to co-author publications that result from this research study.

This research study holds great promise for the care of young women with breast cancer in the future. As a longterm survivor of early onset breast cancer, it is an honor to represent them and to be part of this process.

Sincerely,

[redacted]

Patient advocate Principal Investigator

[redacted]

Advocate **Principle Investigator**

[redacted]

I, [redacted], am writing this letter in full support of [redacted] application for the CBCRP Translational Research Award. “Intervening on Reproductive Health in Young Survivors” aims to develop and test the efficacy of a tailored reproductive health survivorship care plan (rhSCP) in young breast cancer patients and their health care providers.

As a young breast cancer survivor and patient advocate for Susan G. Komen for the Cure, I am happy to provide my unequivocal support for [redacted] research on reproductive health in young cancer survivors. The Komen Foundation is committed to empowering survivors and improving quality of care. I believe that the proposed rhSCP has significant potential to improve management of reproductive health issues and empower young survivors.

Continuum of care is central to cancer survivorship. In the two years that I have known [redacted], she has played an important role in my breast cancer journey from diagnosis to survivorship in supporting my reproductive health needs. I am well aware that many young patients do not have access to reproductive health specialists during their cancer continuum of care. This proposed web-based rhSCP is needed to support young survivors who lack or have limited access to reproductive health information and management strategies. In talking with other survivors, it is difficult enough to get proper care and diagnosis being a young cancer patient because we are dismissed as “too young” so it is not surprising that healthcare providers are ignorant about reproductive concerns. Yet, these concerns must be addressed. Transitioning from cancer treatment to survivorship is challenging for various reasons and only compounded by reproductive concerns. Young survivors just want to feel normal and healthy again.

[redacted] have discussed this grant application. We have agreed upon the following:

I, [redacted] will**:**

- Participate in expert panel conference calls every 6 weeks in Year 1 to develop and refine the web-based rhSCP intervention.
- Review and provide feedback of iterations of the web-based rhSCP intervention in Years 1-2.
- Meet with [redacted] and the research team regularly to discuss and advise on clinical trial progress and results in Years 2 and 3.
- Provide help with recruitment as needed.

- Communicate findings with the Komen community.

I, [redacted] will:

- Participate in expert panel conference calls in Year 1 to develop and refine the web-based rhSCP.
- Solicit input from [redacted] on the web-based rhSCP intervention in Years 1-3.
- Compensate [redacted] for Year 1 and $[redacted] year for Years 2 and 3.
- Acknowledge [redacted] and Komen's contribution to the research study. Dr. Ehren will be invited to co-author publications that result from this research study.

Over the past two years, I have interacted with [redacted] as a patient, a clinical research participant in her studies and now as Komen breast cancer advocate. As cancer patients, we want to be reassured that everything will be OK and that is facilitated by having a competent health care provider working with us to manage our individual health needs. I have been inspired by her passion for young breast cancer survivors and their reproductive health outcomes after cancer. I am excited to support [redacted] research and play an integral role in the development of the proposed rhSCP intervention. I am confident that the outcomes of this proposed study will greatly improve the reproductive health of young breast cancer survivors.

Sincerely,

[redacted]

Patient Advocate Principal Investigator

[redacted]