## **Principal Investigator:**

# ADVOCACY INVOLVEMENT

# Limit is 1 page

A. Advocacy Organization/Advocate(s) Selection and Engagement to Date. (Explain why the advocacy organization and the advocate(s) are appropriate for the proposed research project. Detail your interactions with the advocate(s) and their organization in preparing this application.)

Susan G. Komen, founded in 1982, is the world's largest source of nonprofit funds dedicated to supporting breast cancer patients and curing breast cancer. The [Affiliate of Susan G. Komen is dedicated to combating breast cancer on every front, with the overall mission to save lives and end breast cancer forever by ensuring quality care for all and investing in science to find the cure. The Komen affiliate hosts educational conferences for breast cancer patients, featuring presentations and workshops given by renowned clinicians and researchers from the Cancer Center, California University.

Jane Doe and Sally Jones are breast cancer survivors and experienced research advocates who haves received extensive training, and are members of Komen's Advocates in Science program. They have served as reviewers for both Komen's national and community grant mechanisms, in addition to being a Consumer Reviewers for the DoD Breast Cancer Research Program. They are knowledgeable and engage in ongoing education to enhance their advocacy skills. As Komen advocates passionate about the urgency of finding innovative cures and treatments for metastatic breast cancer, they are especially well-suited to the scientific team in this proposed research project.

I initially contacted them in [DATE], when we began our collaboration by discussing current research in and treatment of metastatic breast cancer, and the challenges associated with ensuring the highest quality of life for patients so afflicted. The ideas generated in our collaboration have influenced this research proposal.

B. **Advocate(s) Role in Proposed Research.** (Describe the role of the advocate(s) in the project design, implementation and dissemination of results; be specific.)

The advocates, Jane Doe and Sally Jones, play an integral role in our research process by asking questions from a patient/survivor/trained advocate perspective. They have offered suggestions to improve this proposal, and together we have discussed the scientific approach of this project and its potential results and benefits to patients. The advocates are also able to share with us current patient perspectives on issues relating to clinical research, including barriers to participation and inclusion of minorities and underserved populations. As valued members of our research team, the advocates will interact regularly with the Principal Investigator, and participate in discussions regarding progress of the proposed research throughout the course of this grant. The advocates are actively involved in the advocacy community, serving in leadership roles at several breast cancer advocacy organizations, and will partake in the implementation and dissemination of results obtained from this research project.

C. **Meeting and Payment Plans.** (Note plans for when and where the advocate(s) and research team will meet and how you will communicate between meetings. Specify the basis and mechanism for paying the advocate(s) for time and effort and for reimbursing their expenses.)

The Principal Investigator and the advocates will meet 3-4 times a year, and over the course of the grant period, will participate in 5-6 in-person meetings at our lab and/or via teleconference calls. Email communication during the interim periods will facilitate up-to-date sharing of project progress and outcomes. Two percent of the project funding will be allocated to the advocates for their time, effort and reimbursement of expenses for attending the in-person meetings and for advocates to attend the CBCRP Research Symposium or other research conferences such as the annual ASCO conference, in order to support their continued advocacy training. In addition, the Principal Investigator and her research team will acknowledge the advocates by name in all progress reports, scientific conference presentations and publications.

#### **Advocates**

Jane Doe and Sally Jones Susan G. Komen Advocates in Science

# **Principal Investigator**

Mary Doctor, MD Professor, California University

This letter confirms the commitment between the Advocates and the Principal Investigator (PI), referenced above, to collaborate on the research project proposed in the PI's grant application.

The Advocates heartily supports this proposed research because they understand that it addresses a critical unmet need in the treatment of patients with metastatic breast cancer. Despite promising strides achieved in the field of breast cancer research over recent years, patients with breast cancer metastasis continue to suffer a paucity of therapeutic options on their way to poor clinical outcomes. The Advocates believe that the proposed research may have the potential to elucidate the genetic characteristics of breast cancer metastases by identifying and prospectively monitoring mutations in circulating cell-free tumor DNA. Furthermore, the Advocates acknowledge that this approach not only advances the basic understanding of breast cancer tumor biology, but also aims to define a specific biomarker(s) that can be used to develop diagnostic and therapeutic monitoring tools.

The PI and Advocates began their collaboration on [DATE], when they discussed together the scientific presentation describing the research project. The PI highly appreciated the patient perspective provided by the Advocates, and readily incorporated their feedback into her research project LOI. Together, they have agreed on terms of the Advocates' continued engagement as members of the PI's research team in this project:

### The Advocates will:

- participate in five meetings at the PI's laboratories and/or via teleconference communications with the PI and research team:
- communicate with their colleagues and disseminate results of the proposed research within their advocacy
  organizations and the broader breast cancer community in which they are active advocate members;
- attend the CBCRP Research Symposium and/or other relevant research conference(s).

# The Principal Investigator will:

- participate in five meetings at the PI's laboratories and/or via teleconference communications with the Advocate and the rest of her research team:
- solicit input from the Advocate in the course of designing, refining and implementing her research plan;
- compensate and reimburse (including research conference attendance) the Advocates in the amount of \$3,000 over the duration of the grant (1.5 years).
- acknowledge the contribution of the Advocates in all publications and presentations of this research.

As breast cancer survivors, the Advocates recognize that metastatic breast cancer patients currently undergo multiple invasive procedures, and suffer toxic effects of drugs that confer little or no benefit. The Advocates believes that the clinical implications of the research proposed in this grant may be transformative for such patients, in making possible the selective use and monitoring of therapeutic agents known to be efficacious, as well as reduction of the number of painful invasive procedures. The PI and Advocates have established a mutually valued partnership that they believe will help drive the progress of the proposed research. They look forward to collaborating in the design and development of the project, and to disseminating its relevant findings to the breast cancer patient community.

Sincerely,

Advocate: Advocate: [SIGNATURE] [SIGNATURE]

Jane Doe, Komen Advocate in Science Sally Jones, Komen Advocate in Science

Principal Investigator:

[SIGNATURE]

Mary Doctor, Professor of Medicine, California University