

## ADVOCACY INVOLVEMENT

- A. **Advocacy Organization/Advocate(s) Selection and Engagement to Date.** Patient Advocates In Research (PAIR) and its leader, Deborah Collyar, are extremely well suited to guide this innovative IDEA project. Ms. Collyar has been involved in many aspects of cancer research during the last 20 years, including service on the Department of Defense Breast Cancer Research Program's Integration Panel, leadership in the initiation of the NCI SPORE and Patient Advocate Research Team (PART) Programs, implementation of biospecimen projects at UCSF, creation of plain-language result summaries in an NCI cooperative group, membership on many NCI committees (such as the Investigational Drug Steering Committee), and recipient of CBCRP awards through the UCSF Tlsty lab and CTSA Community Engagement grants through the Sentinel Network. Her multiple publications on patient advocacy and research have informed generations of scientists and patient advocates on how to work effectively together. Ms. Collyar responded to our request for her participation with great enthusiasm and has been instrumental in the development of this grant. In a series of calls and emails, we have worked iteratively on the design and construction of our LOI and full application. In addition to providing critical review of our documents, she has generated a number of insightful ideas for applying our model to unmet clinical needs, and creating an interface with the breast cancer community that will enrich the design and path of our research.
- Advocate(s) Role in Proposed Research.** Deborah Collyar is our lead patient advocate, and will contribute to the ongoing scientific development and clinical relevance of this grant, including design discussions, strategies, and issue resolution. For instance, her suggestion to stratify bone and tissue samples by age, menopausal status, healing abilities, and race in future studies may help us elucidate and connect key biologic factors with diverse patient issues. Our bone culture model is very new, and Ms. Collyar will work to help us build an interface with the breast cancer community to enrich its design, find new applications, and help us move this proof-of-principle research in the most relevant and useful ways for patients. To ensure up-to-date input, she will communicate directly with breast cancer patients and related groups on a regular basis to bring their critical input and feedback into our project as we learn how our bone model emulates human metastasis. She will lead the creation of annual presentations about our work (including research results) that can be given online and face-to-face, while including specific questions to elicit feedback on real-life issues that patients face with bone metastasis, such as Osteonecrosis of the Jaw. Groups and programs from the Metastatic Breast Cancer Network, Breast Cancer Connections, Terminally Pink, Bay Area Young Survivors (BAYS), Anna's Program, UCSF Health Disparities Outreach, Breast Cancer Action, and support groups at Kaiser, John Muir and Stanford, in addition to online resources (e.g. Association of Cancer Online Resources/Smart Patients, After Breast Cancer Diagnosis, Breastcancer.org, and other forums) will all be contacted for feedback. In addition, Ms. Collyar will connect us with relevant researchers, pathologists and clinicians through her many academic contacts, to help source tissue (if needed), focus the design of our studies, and interpret results.
- B. **Meeting and Payment Plans.** We will communicate regularly by phone, email and direct interactions, beginning with a daylong on site visit with Ms. Collyar at our Stanford lab for an introduction to our experimental approaches, and where she can observe our process for working with human bone tissue specimens. Deborah will also attend internal seminars here at Stanford relating to this research. To create an interface between the research and breast cancer community, she will organize annual presentations at breast cancer organizations and programs throughout the Bay Area as well as online for those who cannot participate face-to-face. The annual request budget for these meetings is \$1000 to help cover transportation, refreshments, and materials. Conference calls with visual aids will also be incorporated 2-4 times/year, as will surveymonkey.com, with an annual budget of \$500. Ms. Collyar's travel to two breast cancer-related conferences (e.g. Metastatic Breast Cancer Network or San Antonio Breast Cancer Symposium, plus the CBCRP meeting) will also be budgeted for a total annual travel and registration allowance of \$2,400. Ms. Collyar will receive a stipend of \$12,600 to cover her time to develop and implement presentations, contact breast cancer patients through forums and groups, create plain-language result summaries, disseminate research results, and give critical input into our ongoing efforts over the duration of this research project.

## Letter of Commitment

December 5, 2013

### **Advocate(s)**

Deborah Collyar  
Patient Advocates in Research (PAIR)  
Danville, CA 94506

### **Principle Investigator**

Christopher Contag, PhD  
Stanford University School of  
Medicine Department of Pediatrics  
Stanford, CA 94305-5427

We are writing this letter in support of our grant application titled: “Targeting the Breast Cancer Metastatic Niche.” This project will develop a unique high throughput platform for testing therapeutic strategies targeted at breast cancer cells within the metastatic niche with the goal of finding more effective ways to prevent and treat breast cancer metastasis.

While working together on the NCI Experimental Therapeutics (NExT) Program’s Special Emphasis Panel, we discovered many common interests and decided to work together on this grant. It supports new approaches to old problems, incorporating new technologies and open mindsets about how cancer cells develop into metastatic time bombs. It is refreshing to get away from “a recurrently narrow focus that often keeps researchers from seeing the ‘big picture,’ and therefore can hinder meaningful breakthroughs for patients<sup>1</sup>.”

PAIR is supporting this project because it challenges existing approaches to adjuvant therapies, and incorporates a suite of new technologies and approaches that will evaluate and target breast cancer cells within the critical **human** metastatic microenvironment. The new ROCK technique that separates and categorizes breast cancer cells from the fresh primary breast tumor tissue of breast cancer patients constitute a unique and effective way to generate many individual cell colonies. Use of the new SmartFlare RNA probes is an innovative way to immediately categorize colonies and transfer them into an extremely novel culture system that uses human bone tissue fragments from hip replacement surgeries. Testing new therapeutic interventions in this setting is desperately needed and offers the opportunity to attack these errant cancer cells before they gain a metastatic foothold in breast cancer patients.

Since PAIR is a communication network of patient advocates who work with research communities (primarily cancer), advocacy organizations, and patients, we can quickly mobilize to gather critical patient input that will inform this project. PAIR’s comprehensive network spans many groups, including some in the Bay Area breast cancer community. Ms. Collyar is perfectly suited to create this interface, and will reach out to national and local breast cancer groups, including the Metastatic Breast Cancer Network, After Breast Cancer Diagnosis, Breast Cancer Connections, Terminally Pink, Bay Area Young Survivors (BAYS), Anna’s Program, UCSF Health Disparities Outreach, and Breast Cancer Action.

In a series of calls and emails, we have worked iteratively on the design and construction of our LOI and full application. In addition to providing critical review of our documents, Ms. Collyar has generated a number of insightful ideas for applying our model to unmet clinical needs and creating an interface with the breast cancer community that will help enrich the design and path of our research. Here are the agreements we have made:

Deborah Collyar will:

- Participate in quarterly meetings, phone calls and emails as needed with Chris Contag and/or Bonnie King
- Jointly develop annual presentations and a series of questions to use during communications with the above cited advocacy organizations and community groups
- Disseminate results with these groups
- Attend CBCRP Research Symposium or other research conference(s) (e.g. MBCN, San Antonio) to present a patient advocate perspective and update on the project
- Participate in publications from this project

Chris Contag will:

- Participate in quarterly meetings, phone calls and emails as needed with Deborah Collyar
- Review presentations and questions that will be posed to advocacy organizations and community groups, and participate in them whenever possible
- Compensate and reimburse Deborah Collyar for grant-approved costs associated with organizing and implementing meetings and presentations, and for travel to scientific meetings.
- Acknowledge Deborah Collyar's contributions in presentations and manuscripts.

We really look forward to working together on this innovative project to learn how to stop breast cancer cells that colonize in bone. This would be a huge advance that could help eliminate metastatic situations for many patients. The synergy of novel research methods and direct contact with many different breast cancer groups will help ensure that our efforts truly meet the needs of breast cancer patients.

Sincerely,

Deborah Collyar  
PAIR Founder and Leader

Christopher Contag, PhD  
Professor of Pediatrics

1. Collyar, D. How have patient advocates in the United States benefited cancer research? Nature Reviews Cancer (5): 73-78, 2005.