



November 17, 2003

TO: SPORE PIs
FR: Jorge Gomez and Joe Gray
RE: New InterSPORE Patient Advocate/Research Team (PART) Program

We are pleased to announce that a new InterSPORE supplement has been awarded to the Bay Area Breast Cancer SPORE to create an InterSPORE Patient Advocate/Research Team (PART) Program. This program, while managed through the Bay Area Breast SPORE is intended to a *resource* for all SPOREs. Deborah Collyar, former director of the UCSF Breast SPORE Advocacy Core, has been recruited to direct the PART Program under the guidance of Joe Gray. Sheryl Eisenbarth, Coordinator of the Fred Hutchinson Ovarian SPORE advocate program, also will be involved, as will others as the program develops. We expect that the PART program will evolve with time. However, its initial goals are to:

- Establish new PART teams and help existing patient advocates work more effectively. Proven advocate processes and 6 different SPORE models will be summarized to provide ideas that may facilitate development of effective advocate programs that meet the needs of individual SPOREs.
- Connect PART teams together so they can effectively share ideas and issues, and provide training and other resources. The Program will host PART activities at InterSPORE meetings and at the Annual SPORE Investigators' Workshop.
- Identify common barriers that SPOREs face in translating their discoveries that advocates may work to alleviate. Advocate task forces will be established (including SPORE and external expertise, plus patient advocates) to help overcome these.
- Establish patient-related information banks for SPORE clinical trial development (including IRB information, and tools for clinical trial development and implementation).

Patient advocates have helped SPOREs in many ways, from clinical trial awareness and design to tissue consents, usage and collection, to honing translational aspects of SPORE projects. The PART Program looks forward to helping you develop patient advocate involvement that will enhance the translational goals of your SPORE - and to help create better answers for people more quickly. Deborah will be contacting each of you to discuss the program and to discuss how the PART Program can facilitate your advocate activities. Information about this program and PART resources will appear on the SPORE website in late November. In thinking about how you might interact with the PART Program, please keep in mind the following:

- This is a SPORE-wide program, not a UCSF program.
- Participation in the PART Program is not mandatory.
- The PART Program is intended to enhance advocate programs. It is not intended to "manage" your patient advocate programs, either nationally or locally.

If you want information immediately, please contact Deborah Collyar at (925) 736-8155 or information@sporeadvocates.net. Thank you.