

Pacific Ovarian Cancer Research Consortium Patient Advocacy Group
Bridging the Gap Between Science and Community

Minutes
January 25, 2002

The meeting started with Advocate introductions.

Nicole Urban, POCRC Principal Investigator
“Screening Study for Average Risk Women with Symptoms”

Nicole Urban, POCRC Principal Investigator, began the round table discussion by defining the 2 screening studies already under way.

The **Quest** Study, which enrolled average risk women, is almost finished. The intent was to look at quality of life issues. The study was designed to see if one kind of testing caused more stress than another. The intent was to not worry women with a positive result, which became a concern during a similar trial for breast cancer. The Quest trial was to show the importance of screening, without creating a group of women with anxiety like the breast cancer trial. Another question the researchers asked was, were women willing to come for testing? This was a flip-of-the-coin randomized trial where 50% of the women participated in the trial.

The second trial that Nicole talked about is the **High Risk** trial. Nicole explained the qualifications for a woman at high risk, two first-degree relatives with ovarian cancer or one first-degree relative with ovarian cancer and one pre-menopausal first-degree relative with breast cancer. There are 27 women enrolled in the study and 12 screened so far. The study is looking at how well CA125 works in finding ovarian cancer and how often the test is positive. If during the trial the CA125 is positive in a high-risk woman, the women goes to ultrasound screen every 3 months. If the ultrasound is positive, then she goes to surgery. Women will be screened with ultrasound or blood test every 6 months if low risk or every 3 months if high risk.

Nicole discussed **a new study** under construction with Dr. Barbara Goff and Dr. Charles Drescher taking the lead. Nicole thought that the best way for this study to be useful would be to have a screening study for women who have symptoms. The design of the new trial will be to screen women with symptoms and find a better blood test with 2 or 3 new markers added to the design of the new study. Sensitivity is a problem with CA125. CA125 only finds 50% of early stage ovarian cancer. Nicole wants to design the new study to benefit the most women. Advocates will be able to educate women about the symptoms of ovarian cancer. If a woman feels she has these symptoms she will see her physician. The physician will then have the option to refer his patient to the screening study rather than to ultrasound.

The focus will be on sonographer Dr. David Nyberg's population. One reason to focus on this population will be to see if women's self reported symptoms can be a prediction of ovarian cancer. By including the Dr. Nyberg population, the study will be able to recruit women from several sources. Physicians will be invited to participate and refer their patients to the study or women can refer themselves to the study, if they have a physician who can work with the researchers.

During the study, women would answer Dr. Goff's questionnaire on symptoms. It will be very important for the women going to ultrasound to fill out the survey and note any changes and the duration of her symptoms before her diagnosis. Women will note changes and the duration of their symptoms. then donate blood to test for new markers.

We would prefer to have a Dr. to refer you to the study. Therefore we will have a physician advisory committee, who admit patients to Swedish, meet regularly, then participate in study.

Susun Hosford asked, "Will there be open ended questions? No, only closed end questions. We would need to articulate specific questions about the symptoms. We would like to be able to say when a women comes to you with these symptoms, send her to the study. This study will give us the proof that we need to tell the world "here are the symptoms." Once the study is designed then primary care physicians will be asked to send letters of support.

There was concern that the health care providers may prevent rather than promote their patients from entering the study. In the survey by Barbara Goff, M.D., et al, patients indicated that they were misdiagnosed or initially diagnosed with no problem by their health care provider.

We need to step back and get some evidence that screening works. Once the evidence is there that shows that screening works, then we need ways to send women to screening. The screening study would be a place where a doctor could send a woman when he has no answers for her.

It will not be imperative that the woman has the symptoms, it will be more important that the Dr. does not know what to do with the women.

Two approaches

The first hurdle is convincing the primary care physicians that ovarian cancer is an important issue since it is rare. They don't see enough ovarian cancer.

How do the advocates get an audience with this group of physicians?" It will be one on one. Advocates will make an appointment with the doctor and explain the importance of this trial.

The only way to see what happens is to randomize women . either take them or not. Primary care doc refers to the trial not to another Dr. So he is not giving up the patient. He will be required to follow-up if tests are positive.

Joan McAree, POCRC Advocate Speakers' Bureau Chair ***"Public Education and Outreach Materials"***

The goal of the Speakers' Bureau.

- To recruit women to participate in research studies of the POCRC by explaining the value of ovarian cancer research through community outreach.
- To increase awareness of ovarian cancer by educating the public about the subtle signs and symptoms of the disease.

Presentation package:

The advocates reviewed the Ovarian Cancer Research Fund PowerPoint presentation "Research Kit for the Lay Public." The kit has a lot of good factual information from the American Cancer Society and the National Cancer Institute.

The POCRC advocates' presentation package is being designed to communicate to women the importance of research and will encourage women to participate in research studies. The point will be made that working together as a team the scientists, clinicians and community can make powerful strides in the fight against ovarian cancer. The presentation will also be informative on the signs and symptoms of ovarian cancer. Having knowledge of the signs and symptoms of the disease will empower women to be proactive and seek medical care if they have symptoms.

Susan Hosford will oversee creating a 15 slide, 30-minute, sample presentation for review at the advocates' annual meeting on March 22, 2002. The presentation will include:

- Power point presentation
- History of POCRC
- History of POCRC advocates & mission statement
- Research materials
- Awareness of ovarian cancer signs & symptoms
- Survivor stories
- Photos
- Handouts

All presenters will go through a series of public speaking courses. (Sheryl is going to ask Ann Kitt at OCNA about a teleconference with Betty Riser to hear her speech: "How to tell your cancer story effectively to physicians.")

It was noted that the discussion of ovarian cancer signs and symptoms might make women in the community fearful. This fear may cause a woman to deny her symptoms and avoid seeing her physician. To overcome this fear the advocates will stress the optimistic side of early detection and the fact that detected early there is more than a 90% chance of survival. To help diminish fear, the advocates will suggest that women look for changes occurring in their bodies rather than cancer when looking for symptoms.

Next meeting: Friday, Feb. 22, 2002, 11:00 AM-1:00, in the Sze Conference Room at the Fred Hutch Day Campus