

Pacific Ovarian Cancer Research Consortium (POCRC) Advocate Quarterly Meeting
Saturday, September 29, 2001
9:00 AM - 1:00 PM

Minutes

Introductions:

Sheryl Eisenbarth, POCRC Patient Advocacy Coordinator, started the meeting by inviting each advocate to introduce herself and share why they were part of the POCRC advocate group.

It was decided that each meeting will begin with an "Advocate in Action" story.

Ovarian Cancer National Alliance (OCNA) Advocacy Conference:

Shirley Inveen shared her experience at the OCNA Conference "Ovarian Cancer: Silent No More" held 9/19-22, 2001 in Indianapolis, IN. Shirley had to leave her Gig Harbor home at 3:00 AM in the morning to catch her flight and represent us at the conference! Free webcasts of the conference can be viewed at www.cancereducation.com. Sessions included cancer genetics, new and promising treatment therapies, prolonging remission, complementary therapies and nutrition, immunologic approach, cancer biology and imaging. Shirley offered to share additional conference details on specific topics with advocates (Shirley's email: sinveen@ups.edu). Shirley also has a video of the ovarian cancer play, "WIT," that she will loan to advocates.

Advocates as reviewers on the POCRC Developmental Research Projects Review Committee:

Cynthia Becker shared the experience she and Sandy Moon had as advocate reviewers on the POCRC Developmental Research Projects Review Committee. Committee members received the proposals about two weeks prior to the committee meeting. The advocates utilized an online medical dictionary [www.graylab.ac.uk/omd] to help understand the proposals. The committee met on 9/17/01 to review the 5 pilot studies submitted to the POCRC for 1-year funding. The two-hour lunch meeting was comprised of half clinicians, half researchers plus 2 advocates and was led by Nicole Urban, Sc.D., Principal Investigator for the POCRC. A summary sheet was presented on each proposal followed by discussion and numerical scoring (1 through 5). The advocates didn't participate in the scoring process, but were invited to comment during proposal discussions. Cynthia suggested that the advocates have a consistent group of advocate reviewers to enable them to gain experience in the review process and thereby allow participation in a more meaningful way. If advocates are interested in participating as advocate reviewers please contact Sheryl Eisenbarth at 206-667-5717 or Lisa Isozaki at (206) 667-6054.

Inviting New Advocates to join the POCRC Advocate Group:

Community members interested in participating in the advocacy group or research can call Sheryl or the Marsha Rivkin Center for Ovarian Cancer Research (MRC) at 1-800-328-1124. The MRC will send out an informational packet giving the potential new advocate the opportunity to participate in the advocate group or in the research program of the POCRC or both. Advocates should refrain from coercing a woman into a specific POCRC research study, but rather suggest that if the woman would like more

information on how to participate in studies, they can call the MRC. For confidentiality reasons, we will not pass along her name to the Center. They will need to call for themselves. Sheryl is planning an advocate meeting with Karen Hansen, representative from the Hutch IRB (Institutional Review Board), November 29th from 11:00-11:30 before the scientific discussion group meeting to learn more about the IRB. Please come.

Community Outreach - Mark Your Calendars Now for November 3, 2001, Public Speaking Training:

Once the POCRC advocacy presentation package is completed and approved, the POCRC advocates who have received community outreach training will go out into the community and inform women about the opportunity to participate in POCRC research and advocacy. The first phase of the advocate outreach training will be on Saturday, November 3, 2001, at the Hutch Day Campus Room #B1-072 from 9:00 AM - 4:00 PM. Advocates will be given the opportunity to present their story (limited to 10 minutes in length) and the presentations will be videotaped to serve as a learning tool. Additionally advocates will be asked to speak for 1 - 2 minutes on one of the following subjects: 1) Favorite childhood memory; 2) Dream vacation; 3) My favorite holiday to celebrate. Please let Sheryl know of any presentation AV requirements you may have. A goal for the POCRC advocate group is to ensure that everyone in the Puget Sound area is aware that September 2002 is Ovarian Cancer Awareness Month.

SummeRun - Women of Courage 2002:

To learn more about planning for the SummeRun and Women of Courage Tribute (ovarian cancer survivor tribute) please call Jocelyn (206-215-6202) at the Marsha Rivkin Center for Ovarian Cancer Research .

POCRC Advocate's Web Page Update:

Cynthia Becker, Sheryl Eisenbarth and Lisa Isozaki worked with the POCRC webmaster to set up an advocacy web page as part of the POCRC web site. The site will be simplified and standardized and it will be easier to find information on advocacy from the POCRC home page. Cynthia will serve as the advocates' webmaster. Email Cynthia (cbecker@adobe.com) with information you would like to post on the advocates' web page. The following categories are possible additions to the advocacy web page:

- A calendar with advocacy activities
- Advocates' newsletter and meeting minutes
- Health Resources - links to other sites
- Conference information
- Meet an advocate - highlight an advocate
- Get involved - survey form
- Symptoms
- How to contact us
- Support Groups
- Chat room

"What's in our blood and why do scientists want it?"

Presentation by researcher Patty Theiss, R.N.. Researchers are interested in the white blood cells, the immunological cells plus the proteins they make. Immunological cells (white blood cells) produce antibodies which attach to the proteins on the bacteria or virus and actively participate in their destruction. Researchers hope to find tumor markers (tumor proteins) made by the tumor that don't exist unless there is cancer present. Normal cells divide, differentiate, function and then die (apoptosis is

programmed cell death). Cancer cells that are poorly differentiated, have multiple genetic alterations (mutations), cell division proliferates and apoptosis doesn't occur. No two tumors are alike; therefore each tumor makes a different tumor marker. Email Patty at: ptheiss@vmresearch.org if you have any questions. Patty has graciously agreed to give us pre-lecture science lessons before the scientific discussions group meetings. Let's all say a big "thank you" to Patty.

Donating Blood and Tissue Specimens:

The advocates would like to learn more about the process of donating blood and tissue specimens for research.

They would also like to know what tissue samples are kept on file and for how long for ovarian cancer patients following surgery. Sheryl Eisenbarth will look into allowing advocates to attend the next specimen core meeting.

Recruiting for the Strength Study:

The advocates were asked their opinion on what timing would be best to approach a woman to ask her if she'd like to participate in the 9 weeks of strength study workshops. The majority of advocates felt that a woman should be approached as soon as possible after diagnosis for participation in the strength study with a reminder half way through treatments. The idea of instigating the "Buddy System" came up again.

Upcoming Advocate Meetings:

November

POCRC Scientific Discussion Seminar Thursday, November 29, 2001, 11:00 AM - 1:00 PM

11:00 - 11:30 AM Monthly Advocate Meeting with Karen Hansen of the Hutch IRB

11:30 - 12:00 Pre-lecture Science Lesson with Patty Theiss, RN

12:00 - 1:00 Lecture: PM David Haynor, MD, PhD (Univ. of WA)

December:

Advocates' Winter Welcome , Saturday, December 1, 2001, 1:00 - 4:00 PM

FHCRC Day Campus, Thomas Bldg., Sze Conference Room

1100 Fairview Ave. North, Seattle

See you soon,
Sheryl

If you prefer to not receive the advocacy minutes, please contact Sheryl Eisenbarth at 206-667-5717 or 1-800-328-1124 to be removed from this mailing.