

Pacific Ovarian Cancer Research Consortium Advocacy Group Meeting Minutes 02/22/02

Welcome and Updates: The meeting began with the reading of the mission statement. We then went around the room telling how, as advocates, we planned to meet the needs of the patient.

New Member Mentoring: Sheryl would like to start a new mentoring program where new advocates will be paired up with seasoned advocates. This will hopefully enhance the new member experience.

Lab Tour: We have been asked to tour Seattle Genetics lab. They do not currently research ovarian cancer, but would like to add it to the list of cancers they do study and feel that advocates can help.

Advocates in Action:

CRP update: Sheryl reported on her experiences on the California Review Program. 5 committees attended and she was part of the clinical committee. There were 17 researchers, physicians and surgeons as well as 3 survivors on her team. They reviewed 38 proposals for gender specific cancers, and felt that 17 were in the fundable range. 3 of the proposals were for ovarian cancer research and only one was voted fundable. Even though proposals were voted fundable, the program is in danger of extinction unless California voters write to their state representatives asking that the program continue.

OCNA Leadership Conference: Joan McAree will be attending the OCNA Leadership conference this week. We look forward to an update on the conference.

Joan's community outreach has included addressing the Breast and Cervical Health Program (a program funded by the CDC and WA State), a Women's Cancer Support Group in Tukwila and the FHCRRC Climb to Fight Breast Cancer group.

Joan and Sheryl participated in the OCNA, Cancer Care teleconference phone training session. This is a 3-part training session designed to teach us more comprehensive ways of responding to ovarian cancer survivors. Due to the importance of the initial contact after diagnosis, this training, provided by Cancer Care Inc. and OCNA, is intended to give us the skills to make each woman we talk to feel as comforted and informed as possible.

We will make the teleconference information available in written form for those advocates interested in becoming a "buddy," but unable to take part in the teleconference.

Buddy System: Joan McAree

The following resources are being used by the advocates to design their “Buddy System”:

- OCNA/Cancer Care Inc. cancer call training
- WIN (Women’s Info. Network) Survivor to Patient Peer Mentoring
- UWMC Cancer Care Binder
- NCI’s new “Community Outreach & Advocacy for Clinical Trials“ resource manuals, videos, CD’s and training (order resource guides from NCI PubsOnline at www.cancer.gov/publications).
- Randy Hale, with a background in psychosocial oncology, has offered her talents to train advocates for the Buddy System.

The Importance of Training: Randy Hale

Randy recommends training of volunteers who have had cancer prior to their volunteer experience, and ongoing support in some form because survivors need to remember to take care of themselves too.

3 areas Randy feels are essential in training:

- 1) Listening -- develop skills to really hear what people are saying and what they need.
- 2) Talking -- practice telling only what is helpful, and be brief; learn to honor the process of the other person even if it's different from your own
- 3) Knowing and caring for yourself -- discover what you are comfortable with in the service of helping others; explore your comfort level with different situations and levels of intimacy that may occur in the volunteer situation; become expert at identifying and dealing with your own feelings -- know who, what and where you can go for support

Good training should prepare you, teach you new skills, and provide ongoing Support.

Update on the Speakers’ Bureau Community Outreach Presentation Package:

Susun Hosford

Susun showed us the beginning slides of the presentation package. We were then given printed copies as homework. Our job was to look at the slides and give Susun our feedback. The presentation will begin with the speaker’s survivor story, short and simple, then a 45 minute slide presentation followed by 15 minutes of questions and answers. The sample slides will be shown at the yearly meeting, March 22. We will then have the opportunity to define and refine the presentation.

Swedish SummeRun

Jocelyn Moore provided an update for the 8th Annual Swedish SummeRun. This year's SummeRun will take place on Sunday, July 28. This date is slightly earlier than in years past and has been moved so as not to compete with the Avon 3 Day Walk. A group of volunteers from the community will be meeting to help the Swedish SummeRun grow in numbers and amounts raised for ovarian cancer research. Jocelyn extended an invitation to the advocates to help in a variety of ways. These include building teams, helping with volunteers, pledges, and most importantly, the survivor tribute, or Women of Courage tribute. During the annual advocate meeting, March 22, there will be an opportunity to help design the Women of Courage tribute and learn more about starting a team.

The first community meeting will be held on Tuesday, February 26 at 3pm. All advocates are invited to attend this meeting or those in the future.

4th Biennial Ovarian Cancer Symposium

Jocelyn announced that the 4th Biennial Ovarian Cancer Symposium: Integration of Research & Treatment, hosted by the Marsha Rivkin Center is planned for September 19-20, 2002. Speakers have been invited, and planning is underway. This two-day conference will focus on the integration of basic science research and clinical care. Topics include Targeted Therapies, Molecular Markers, Novel Therapeutics, Screening & Imaging, Ovarian Cancer Pathogenesis, High Risk & Prevention, Updates in Standard Therapy, and a special roundtable to discuss the evidence for the benefit of early detection for ovarian cancer.

Advocates are invited to attend the symposium. As the local symposium coincides with the national OCNA conference, Sheryl Eisenbarth is looking into the possibility of videoconferencing the two meetings.

“Ovarian Tumor Antigens: What are they and why are they important?”

Patty Theiss, RN, Ph.D.

What is an antigen? Molecules (proteins) that induce an immune response.

Immune Response: The response made by a host to defend itself against a foreign pathogen.

How does the immune system work? If you cut yourself, immune cells (lymphocytes) flood the area and get rid of harmful bacteria, viruses etc. Three steps occur in this process

1. Antigen presentation to immune cells

Antigens are small segments of protein that can generate an immune response. Specific immune cells known as antigen presenting cells i.e. macrophages, dendritic cells, can ingest foreign antigen. The cells have internal enzymes that chop up the antigen into little pieces known as epitopes. The epitopes are then transported to the

surface of the antigen presenting cells are displaying the epitope to other immune cells such as T-cells and B-cells.

2. The immune cells are then activated
3. Finally the immune cell destroy cells expressing FOREIGN antigen.

How does the immune system work in autoimmune diseases?

1. During development, immune cells that can recognize “self” antigens are destroyed (deleted). Some immune cells that can recognize self-antigens are not necessarily destroyed but a state of “tolerance” occur. The immune cells that recognize the self-antigen in normal tissue co-exist with no problems. They are tolerant of each other
2. For reasons not well understood, some peoples immune cells can recognize self antigens and the immune system will destroy the tissue that expresses the self antigen i.e. pancreatic cells in diabetes. An immune reaction to self-antigens is known as “breaking tolerance”.

Tumor cells express “self” antigens and research is currently aimed at inducing an autoimmune response against tumor. So immunotherapies are aimed at breaking tolerance to tumor antigens as seen in autoimmune disease.

An example of an ovarian cancer tumor antigen is the Her2 protein. Her2 is a self-protein that is normally expressed in very low amounts and is involved in cell proliferation. Approximately 30% of ovarian cancers over express the Her2 protein. Immune cells that recognize Her2 are found in women with ovarian cancer. However, the immune cells are tolerant of the cancer cells. They co-exist. Research wants to break this tolerance (as seen in the autoimmune diseases) and make the immune cells that recognize Her2 destroy the cancer cells that have large amounts of Her2.

Next meetings:

March 22, 2002 Annual Workshop 9 - 4:00 Sze conference room.

April 11, 2002 Science and general meeting. 11-1:00 Sze conference room.

Thank you,

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