

“you are not alone...” **together**

THE WOMAN TO WOMAN NEWSLETTER | THE MOUNT SINAI HOSPITAL GYNECOLOGIC CANCER SUPPORT PROGRAM



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WOMAN TO WOMAN

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FROM THE EDITOR

“TO KNOW THE ROAD AHEAD, ASK THOSE COMING BACK.”*



VIVIAN PORT

WELCOME TO **together**, THE NEWSLETTER OF *Woman to Woman*. We are launching this newsletter not only to disseminate information about our innovative program, but also to increase knowledge and awareness of gynecologic cancers and their symptoms.

It is imperative that both women and their doctors, particularly primary care physicians, become more knowledgeable about symptoms that warrant further investigation.

The fact that most women with ovarian cancer report frequent symptoms of a gastrointestinal nature needs to be emphasized.

In the United States every year, 23,000 women are diagnosed with ovarian cancer, 32,000 women with uterine cancer, and 12,000 with cervical cancer. It is important for women to know how to recognize early signs and symptoms of these cancers (which will be listed in each edition of our newsletter) and to communicate frankly with their doctors.

It is our hope that the *Woman to Woman* newsletter will empower women by providing specific knowledge, peer support, and an open attitude about gynecologic cancers. Only through dialogue among themselves and with their doctors will women be able to prevent unnecessary deaths. Until there are reliable screening tests for ovarian and uterine cancer, as there are for cervical cancer/HPV disease, our best defense is early detection.

We hope to include informative articles in future editions of our newsletter, as well as activities of the dedicated gynecologic oncology staff and heartwarming stories of our work as survivor volunteers at *Woman to Woman*. ■

*Chinese Proverb

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“I longed for someone to tell me ‘I’ve been where you are’...”

a volunteer's **EXPERIENCE**

a regal woman walked out of the examining room

in the Gynecologic Oncology Clinic and sat down next to me in the waiting room. She looked shaken. I introduced myself as a volunteer survivor of ovarian cancer. She looked at me, astounded. “I was just told I have ovarian cancer,” she said. “I have never heard of this cancer. You had it too?”

M. had come from Ethiopia to visit her family in the U.S. During the visit she experienced abdominal pain, so her cousin, a nurse practitioner, recommended a sonogram. M. had had a hysterectomy a year earlier, but still experienced discomfort. Her cousin knew this shouldn't be.

M. wanted to know my story, and kept repeating her surprise that I was waiting for her. She said I was sent from God.

The doctor was quite alarmed by the extent of her disease and wanted to schedule surgery immediately. M. felt overwhelmed. She needed some time to adjust to the idea.

Thus began a relationship that has been so rewarding to me as a volunteer and, I hope, to M. as a patient. We visited after her surgery, talked on the phone, saw each other at Thursday clinic visits, went to Gilda's Club together. I got to know her devoted sister, too. She has been by her side during this illness, even though she lives with her family in Washington, DC.

M. became close to our social worker, Arden, who helped her in many ways. But the volunteer's relationship with a patient is different. There is a bond, a mutual understanding, a feeling of kinship that develops from sharing a diagnosis, even if the illness has a different course. But more than that, sometimes two people just click, and that's what happened with us... woman to woman, one from Ethiopia, one from New York. —**VIVIAN PORT**



a discussion with Dr. Dottino.

Dr. Peter Dottino is the Director of Gynecologic Oncology and Associate Professor of Obstetrics, Gynecology, and Reproductive Science at Mount Sinai. He became Director two years ago, with Dr. Rudy Segna as his Associate Director. Dr. Dottino assumed leadership about the same time that *Woman to Woman* was created. His interest and support have been critical to its establishment and so helpful to the staff, volunteers, and patients of *Woman to Woman*. I talked with Dr. Dottino about his goals and vision for the Department in addition to his thoughts about the effect *Woman to Woman* has had at the hospital.—VP

selecting a doctor

Dr. Dottino wants women to feel empowered, to make decisions about their treatment through good communication with their doctors. A woman should select a doctor with whom she feels comfortable to ask questions and feel confident that she will get answers. “It’s the small things that make the big difference,” he emphasized. Gynecologic oncologists in the New York area are all technically excellent, he explained, so women need to make a selection based on the comfort level of the doctor-patient relationship.

second opinions

He emphasized the importance of second opinions before surgery and/or before treatment. He finds that some women are helped by hearing the same thing more than once. Discussion of the illness, surgery, or treatment options with several doctors becomes a process that furthers understanding and acceptance.

talking about it

Woman to Woman has changed the way women talk about cancer. Residents have told Dr. Dottino that they find patients more open and direct about their illness after talking with volunteer survivors. There is a frankness between women that does not exist with the doctor. For example, he said, talking about what actually happens, about losing one’s hair and coping with that, finding a wig, etc., is easier with someone who has gone through it. Most important, volunteers with *Woman to Woman* give patients hope, he said.

outreach programs

There will be more outreach programs to the East Harlem community, including screening programs, particularly for cervical cancer, which is the one gynecologic cancer for which there is a reliable screening test (Pap smear).

access to clinical trials

Another of his priorities is to expand accessibility to clinical trials through the GOG (the Gynecologic Oncology Group) that has been established recently at Mount Sinai, and which will supplement the ongoing clinical trials of the Department.

integrated care

To improve a woman’s experience at the hospital, the Division is working toward creating “our own integrated floor.” That means only gynecologic cancer patients would be treated on the floor, instead of being scattered throughout the hospital and housed with patients who have other kinds of illnesses. This will improve both medical care and emotional support.

caregivers

WE WILL INCLUDE
INTERVIEWS WITH INDIVIDUALS FROM
THE GYNECOLOGIC ONCOLOGY SERVICE IN
EVERY ISSUE OF THE NEWSLETTER

35 YEARS OF CARING

An interview with Nurse Elma Barranda

BY VIVIAN PORT

Elma, her husband, and I had dinner to celebrate her 35th anniversary at Mount Sinai, and to discuss her years of service. Elma has the most longevity of any nurse working in Gynecology, so she has the honor of being interviewed for our first edition of the *Woman to Woman* newsletter. Since her first job in Toronto about 37 years ago, she has worked in the gynecology field. >

ELMA BARRANDA,
GYNECOLOGIC
ONCOLOGY
NURSE—KP4

In Toronto she was *assigned* to gynecology, but at Mount Sinai she *chose* it. She has worked the night shift since 1972—at first because she had young children to care for during the day, but later continued that shift for a number of good reasons. She gets to know the families in the evening and the doctors on their rounds in the morning. She prefers to see her role in a comprehensive way, to see the patients in their social context and to help the whole family cope with the illness. And now that there is flex time, she works a 12-hour shift three days a week and thinks it is a positive improvement. Women are able to go to school or care for children more easily. It also leaves her more free time, and since she is tireless, she consults in the public schools once a week, too!

She has loved working here and has become very knowledgeable about oncology. She received a Masters in Nursing from NYU in 1995 with assistance from the Mount Sinai tuition reimbursement program. She attends Oncology Nursing Society meetings twice a year, attends New York Nursing Association meetings as a Mount Sinai Delegate, and with Mount Sinai's help, has traveled to annual meetings of the Medical Symposia and attended their gynecologic oncology conferences as far away as Alaska and Hawaii. Mount Sinai has afforded her professional improve-



hitting the streets

Some of the *Woman to Woman* team members who walked in the 9th Annual Revlon Run/Walk for Women on May 6th, 2006, in New York. The event raises money for research into women's cancers as well as support and education programs. The Revlon Run/Walk has raised 37 million dollars in past years. Our team had 20 participants who raised \$4000 in this year's event.

ment, and the staff of KP4 has been like family. That is the main reason she has stayed so long at one institution and on one service. Volunteers at *Woman to Woman* know that patients feel that sense of family on the floor—the commitment to a single purpose that provides such excellent and compassionate care. I asked Elma what she thought motivated her to enter the nursing profession, and her reasons go back to family influence. She explained that, when she was a teenager, she took such good care of her sick grandfather that her aunt suggested she become a nurse. She felt very comfortable in this role. Her first thoughts about career had been to become a nun, but she was encouraged to go into the medical field by her family, and there were role models in her family, too. Her cousin was a baby nurse. Her brother, married to a nurse, became an MD, and her

younger sister, also a nurse, is married to a doctor. Her husband's sister was a PhD.

The Barrandas have three accomplished children (no grandchildren yet), but they have chosen other fields. Their 32-year-old married daughter works for Putnam Books as a senior publishing manager. Their 30-year-old married daughter works for Channel 5 Fox TV, and their 29-year-old son is a NYC policeman. Mr. Barranda has retired from a banking position, but likes to continue in his field, as chairman of his own consulting business. Needless to say, he is very proud of his wife.

It was a privilege to learn about Elma and appreciate above all the seriousness of her commitment to continuing education in the field of gynecologic oncology, in order to improve the care of all of us who have been patients at Mount Sinai. ■

survivors & VOLUNTEERS

POWERFUL CONNECTIONS

FROM ARDEN MOULTON
WOMAN TO WOMAN
PROGRAM COORDINATOR

When I was hired in November of 2003 as Program Coordinator for a new support program for women with gynecologic cancer, I knew few facts about gynecologic cancer and less about its effect on survivors. Two years later I am awed by the strength, dignity, and courage of the women with whom I am privileged to work.

Woman to Woman matches survivor volunteers of gynecologic cancer with women who are newly diagnosed and/or in treatment. Survivors provide many services, offering hope and knowledgeable information.



ARDEN MOULTON

“I didn’t expect to feel such a powerful connection. She understands the way only someone who has been there can.”

—SHEILA A., PATIENT

From their first meeting with a woman to the end of treatment, volunteers help women adjust to their lives as survivors. *Woman to Woman* volunteers are a critical complement to a woman’s treatment. Volunteers see women on inpatient floors, at the gynecologic clinic, and at treatment centers.

Sheila A. had just been diagnosed with ovarian cancer. She told the social worker she was not interested in meeting a survivor.

When a volunteer stopped by with the wellness basket we provide for every woman, Sheila began to talk about the shock she experienced after diagnosis, her fears, and her concerns about treatment. Sheila and her volunteer remain in close contact. When asked why she had initially turned down the visit, Sheila said, “I didn’t expect to feel such a powerful connection. She understands the way only someone who has been there can.”

One survivor volunteer met a woman from Ethiopia at the gynecologic oncology clinic, moments after her diagnosis of ovarian cancer. The survivor volunteer guided her through the often confusing and stressful treatment process. She provided her with a woolen coat when her own light-weight clothing was inadequate for a New York winter. The woman returned to Ethiopia and now she and her survivor partner communicate through e-mails and touching letters:

“I only wish we had a support group in Ethiopia who are as dedicated as you all are. You see there is no support group in my country, and it is very difficult to start one, too, because people don’t open up to you.

They hide their illness. Our support comes from immediate families who have no idea what you are going through. One has to be a cancer survivor to know and help a person who is suffering from cancer. Families smother you with love and think of you as a fragile person and won’t let you do anything.”

Other volunteers meet with women during their chemotherapy treatments, offering snacks and welcome conversation. Strong bonds are formed during the months women spend in chemotherapy.

The *Woman to Woman* volunteers have provided hope, friendship, and invaluable information and advice to over 200 women experiencing the fear and confusion that accompany a cancer diagnosis.

Please call us at 212-241-3793 to be included in the *Woman to Woman* support program. ■

THANKS TO EVERYONE WHO MAKES WOMAN TO WOMAN POSSIBLE

Message from
Dr. Michael Brodman

CHAIR, THE MOUNT SINAI DEPARTMENT OF OBSTETRICS, GYNECOLOGY, AND REPRODUCTIVE SCIENCES

It is an honor for me to help initiate this first semiannual newsletter from *Woman to Woman*, The Mount Sinai Medical Center's gynecologic oncology support program for women and their families.

We are so proud of this unique service, made possible through a collaboration of the Division of Gynecologic Oncology of the Department of Obstetrics, Gynecology and Reproductive Sciences, the Mount Sinai Department of Social Work, and the Mount Sinai Auxiliary Board. Support from Mount Sinai has been supplemented by generous funding from the Ovarian Cancer Research Fund and gifts from individual women and families.

Receiving a diagnosis of gynecologic cancer often creates fear, confusion and anxiety for patients and their families. It is for this reason that the *Woman to Woman* volunteer program was created. *Woman to Woman* has provided peer-to-peer emotional support and information to over 300 women in treatment at Mount Sinai. This program and its volunteers, in collaboration with dedicated professional staff, have added a much valued dimension to the continuous quality of care offered at Mount Sinai.

My personal thanks to everyone who makes *Woman to Woman* possible. It is programs like *Woman to Woman* that make me proud to work at Mount Sinai.

The journey for survivors is extremely difficult. We hope that this newsletter, filled with information and inspirational stories, will help make it easier for women treated at Mount Sinai. ■



at the heart of it

PORTRAIT OF OUR SURVIVOR VOLUNTEERS: (STANDING FROM LEFT) PAMELA HERMAN-ELLIOTT, SILVANA KEEGAN, VALERIE GOLDFEIN, JANE LURY, (SEATED FROM LEFT) ROBIN FINDLING, JOYCE MANHEIMER, JOAN BROWN, VIVIAN PORT, LINDA NEWSON

I'VE BEEN WHERE YOU ARE

A MESSAGE FROM OUR
FOUNDER, VALERIE GOLDFEIN



“You are not alone...” This statement which appears on the cover of our brochure defines the heartfelt promise of *Woman to Woman*.

Six years ago, when I was diagnosed with gynecologic cancer, though I had the support of family and friends, I longed for someone to tell me “I’ve been where you are,” or “Do you have any questions?” I started *Woman to Woman* so that other patients would have the kind of companionship in their illness that wasn’t available to me.

Toward the development of *Woman to Woman*, Dr. Peter Dottino gave unstintingly of his time and energy, and the Mount Sinai Auxiliary Board generously granted seed money. The heart and soul of the program, however, are the nine volunteer survivors and Arden Moulton, the *Woman to Woman* Program Coordinator. They have made my dream a reality.

Gynecologic cancers are more mysterious and personal than many other illnesses. I hope that we are able to help debunk the myths, shed some light on the darkness, and provide support to patients here at Mount Sinai. ■



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RETURN SERVICE REQUESTED

know the symptoms

ovarian cancer

- 1 | Vague but persistent and unexplained gastrointestinal complaints such as gas, nausea, and indigestion
- 2 | Pelvic and/or abdominal swelling and/or pain; bloating and/or feeling of fullness, increased abdominal size
- 3 | Unexplained changes in bowel habits
- 4 | Unexplained weight gain or loss
- 5 | Frequency and/or urgency of urination
- 6 | New and unexplained abnormal postmenopausal bleeding
- 7 | Fatigue
- 8 | Backache

uterine cancer

- 9 | New and unexplained abnormal bleeding

cervical cancer

- 10 | A **Pap test** is used to detect **cervical cancer**, *not* **ovarian** or **uterine** cancer.

Every woman should undergo an annual rectal and vaginal pelvic examination.

If an irregularity of the ovary is detected, or if some of the vague symptoms are expressed, further testing should be performed. This may include a CA-125 blood test and a transvaginal sonogram.

According to an article in the *Journal of the American Medical Association* [Goff BA, Mandel LS, Melancon CH, Muntz HG. "Frequency of symptoms of ovarian cancer in women presenting to primary care clinics." *JAMA* 2004;291:2705-2712], studies indicate that **ovarian cancer is not a silent disease; most women had symptoms in the year prior to diagnosis.** In fact, 89% of women with stage I/II disease and 97% of women with advanced disease reported symptoms.