



EXTRAORDINARY MOMENTS

A newsletter for women, family members, caregivers and healthcare professionals battling issues related to cervical cancer

www.nccc-online.org

National
Cervical
Cancer
Coalition

a non-profit organization
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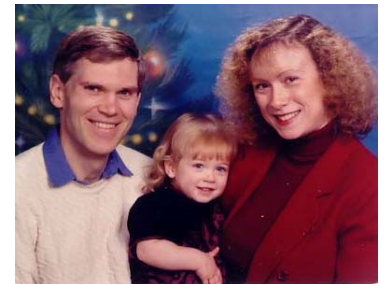
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Cervical Cancer My Personal Experience

I was diagnosed with cervical cancer in March, 1994. I began having symptoms (irregular bleeding) August, 1993. During the time between noting my initial symptoms and receiving my diagnosis, I had three Pap smears, two of which were negative. I was persistent because I knew that while many women have "breakthrough bleeding", it was not normal for me. When I finally received the diagnosis, it was obviously devastating. In a strange way, it was also a relief because, subconsciously, I believe that I already knew, and now we could finally take action. At the same time I was terribly frightened because I knew it had been there for several months, and I am very aware of the importance of early detection in improving chances of survival. My gynecologist referred me to a gynecologic oncologist. The gynecologic oncologist took the time to patiently explain to me my condition and my options. I learned more about the type of cancer that I had (adenocarcinoma), which is less likely to be detected by a Pap smear, and the details of my treatment options. My family and I had enough information to feel comfortable with immediately moving ahead with my treatment, which was to start with a radical hysterectomy. Thankfully, I did not require further treatment. The impact of dealing with cancer was compounded for me with the fact that my husband and I had only been married a year and a half at that time, and we had not yet started our family. Fertility was definitely an issue with this type

of cancer, as it is with many. One of the helpful issues that my oncologist had discussed with us at our first meeting was that he knew of a gestational carrier program that would be possible for us since the surgery did not require removal of my ovaries. My support system was crucial to my survival and to my recovery. My husband Rich and I were put through this test relatively early in our marriage, and it made our relationship incredibly strong. He has been there for me through all of the physical and emotional challenges that I've encountered through my illness and through the aftermath. The gift we have received after facing all of these challenges is our beautiful daughter Jamie who we were able to have through the gestational carrier program. My mom, Anna, has also been an incredible source of comfort to me from the beginning. She is a very strong person, and I feel that I learned from her how to stay strong while going through that period. My extended family and friends all showed great support, also. In addition, I heard from people who I had lost touch with over the years. I truly say the best side of people during this time, and I try to keep that with me every day. The key for me to staying strong through this ordeal

was to remain hopeful. I know that the hope that motivated me through that difficult time was derived through my own personal beliefs and faith. I am so grateful that I had this to turn to. I don't know if it was my strong sense of faith, or an incredible case of de-



*The Weidmann Family
Rich, Jamie & Rosanne*

nial, but as soon as I was diagnosed, I wanted to move ahead with treatment so I could beat this. I have unfortunately heard stories of women delaying treatment because they did not feel hopeful of their outcome. If I can give anyone going through this any advice, it would be to remain hopeful. It will motivate you to make the right decisions to get treatment, and to appreciate the time that we have.

*Submitted By:
Rosanne P. Wiedmann*

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Questions & Answers

Q What is a clinical trial?

A In medical research, a clinical trial is a study conducted with cancer patients, usually to evaluate a new treatment. Each study is designed to answer scientific questions, and to find new and better ways to help cancer patients.

The search for good cancer treatments begins with basic research in laboratory and animal studies. The best results of that research are tried in patient studies, hopefully leading to findings that may help many people.

Before a new treatment is tried with patients, it is carefully studied in the laboratory. This research points out the new methods most likely to succeed, and, as much as possible, shows how to use them safely and effectively. However, this early research cannot predict exactly how a new treatment will work with patients.

With any new treatment there may be risks as well as possible benefits. There may also be some risks that are not yet known. Clinical trials help us find out if a promising new treatment is safe and effective for patients. During a trial, more and more information is gained about a new treatment, its risks, and how well it may or may not work.

Standard treatments, the ones now being used, are often the base for building new, hopefully better treatments. Many new treatments are designed on the basis of what has worked in the past, in efforts to improve on this.

Only patients who wish to, take part in a clinical trial. You may be interested in, or asked to enter a trial. Learn as much as you can about the trial before you make up your mind.

Q What kinds of clinical trials are there?

A There are many kinds of clinical trials. They range from studies of ways to prevent, detect and diagnose, control and treat cancer, to studies of the psychological impact of the disease and ways to improve the patient's comfort and quality of life (including pain control).

Most cancer clinical trials deal with new treatments. These treatments often involve surgery, radiation therapy (the use of X-rays, neutrons or other types of cell-destroying radiation), and chemotherapy (the use of

anticancer drugs). Alone, or in combination, these types of treatments can cure many cancer patients and prolong the lives of many others. A fairly new area of cancer treatment is biological therapy - the use of biologicals (substances produced by the body's own cells) and biological response modifiers (substances that affect the body's natural defense systems against disease).

Clinical trials are carried out in phases, each designed to find out certain information. Patients may be eligible for studies in different phases depending on their general condition and the type and stage of their cancer. More patients take part in the later phases of studies than in the earlier ones.

In a Phase I study, a new research treatment is given to a small number of patients. The researchers must find the best way to give a new treatment and how much of it can be given safely. They watch carefully for any harmful side effects. The research treatment has been well tested in laboratory and animal studies, but no one knows how patients will react. Phase I studies may involve significant risks for this reason. They are offered only to patients whose cancer has spread and who would not be helped by other known treatments. Phase I treatments may produce anticancer effects, and some patients have been helped by these treatments.

Phase II studies determine the effect of a research treatment on various types of cancer. Each new phase of a clinical trial depends on, and builds on, information from an earlier phase. If a treatment has shown activity against cancer in Phase II, it moves to Phase III. Here it is compared with standard treatment to see which is more effective. Often researchers use standard therapy as the base to design new, hopefully better, treatments. Then in Phase III, the new treatment is directly compared to the old one. In Phase IV studies, the new research treatment becomes part of standard treatment in patient care. For example, a new drug that has been found effective in a clinical trial may then be used together with other effective drugs, or with surgery and/or radiation therapy.

*Reprinted from the National Cancer Institute's booklet **What Are Clinical Trials All About? A Booklet for Patients with Cancer**. For more information on clinical trials, please contact NCCC at 800-685-5531, the National Cancer Institute, at 800-4-CANCER, or visit the NCI's Cancer Trials Web site on the Internet at <http://cancertials.nci.nih.gov>.*

The Cervical Cancer Quilt Project

Initiated and Managed By:
The National Cervical Cancer Coalition



The Cervical Cancer Quilt Project is a key component of the National Cervical Cancer Coalition (NCCC) public education initiative to raise awareness about cervical cancer. The quilts are composed of squares made by, or in memory of, women who have battled cervical cancer and precancerous lesions. Like the famous AIDS and ovarian cancer quilts, they are magnificent works of art. They give a human face to cervical cancer, create a compelling sense of urgency about this terrible disease, and serve as a dramatic way of expanding awareness about cervical cancer and the importance of early detection. They also reach women, their family members and caregivers in an affirmative way - allowing a cancer message to be absorbed in a comforting environment.

The quilts are exhibited in hospitals, cancer centers, clinics, and at professional and women's health conferences across the country. Beautiful standing alone, they also serve as focal points and powerful visual aids for education programs about cervical cancer and the importance of early detection. With the quilts as a backdrop, physicians, oncology nurses, advocates, family members, women who have battled precancerous lesions and survivors speak about cervical cancer to their colleagues, women in the community, family members, caregivers and others. The message on how cervical cancer impacts various population groups at higher rates will be personalized to everyone with the quilt as a backdrop.

The cervical cancer education programs provide an opportunity to raise awareness about cervical cancer's risk factors, HPV, early detection screening programs, and prevention strategies as well as to educate survivors, caregivers and families about treatments, new research and management of the disease. Survivors, social workers, NCCC local chapters and supporters are taking responsibility for scheduling the quilts, organizing the accompanying education program, and doing the local outreach to ensure an audience. The National Cervical Cancer Coalition (NCCC) is creating a booklet, "Creating a Special Event with the Cervical Cancer Quilts" in multiple languages, to assist with this effort.

NCCC Medical Advisory Panel members are available to speak at programs held in connection with exhibits of the Cervical Cancer Survivors' Quilts. Materials highlighting cervical cancer risk, symptoms, early detection programs, The Quilt Project, fact sheets, newsletters and CD-ROMs are being developed in multiple languages and will be disseminated with these programs.

We did not invent this idea. The quilts began from seeing the important face the quilts have placed on issues related to AIDS and ovarian cancer. Women, family members and caregivers who have battled cervical cancer and precancerous lesions and abnormal Pap smears helped begin this quilt project. Mrs. Randi Kaye, a DES daughter, had battled issues related to persistent ASCUS Pap smears, begun The Quilt Project. Randi was diagnosed with an advanced Stage IIIB lung cancer June, 1998. Prior to Randi's lung cancer diagnosis, she and her husband, Alan Kaye, the Executive Director of the National Cervical Cancer Coalition (NCCC), had been advocates of cervical cancer issues through the NCCC.

For more information or to arrange to help in the development of quilts and bringing them into your community, please contact the NCCC at ncccak@nccc-online.org or call (818) 909-3849.

TAKING TIME TO TALK WITH A CHILD WHOSE PARENT HAS CANCER

Children usually have trouble coping with cancer in a parent. But it is important not to try to keep your illness hidden. Even young children are able to sense when something is wrong. They realize that you are not spending as much time with them as usual and that you do not feel well. You may look different than you did before treatment. There may be more visitors and phone calls than usual. You may need to be away from them for periods of time for treatment.

The reason for telling your children that you have cancer is to give them a chance to ask questions about the disease and to express their feeling about it. It's okay to tell them that you do not know all the answers. Telling them the truth is better than letting their imaginations suggest the worst. Simple misunderstandings can be very frightening to them. Use terms they can understand and make them feel that they are an important part of the support your family provides to you. Use reading material appropriate for their age to help them learn about cancer.

Your young children are likely to feel confused, scared, and lonely. Children often feel guilty thinking something they did caused your illness. They need reassurance that you did not get sick because they were naughty. They may feel angry because they are asked by others to behave all the time, to play quietly, or to do more chores around the house. Children may resent the absence of attention that they once enjoyed. Some regress to earlier behaviors. They may start to have discipline problems at school. Once independent children may now even be anxious about leaving home.

It's important for other adults in your child's life to know about your illness. Teachers, neighbors, coaches, and extended family can provide needed companionship and help maintain scheduled activities. They can also listen to your child's concerns and feelings and provide reassurance. Ask your doctors or nurses if they have time to meet with your children and answer their questions.

For additional information on talking to children about cancer, contact the National Institutes of Health (NIH), National Cancer Institute (NCI) and request the booklet, Taking Time (NIH Publication No. 98-2059). You may also receive this free booklet by contacting the National Cervical Cancer Coalition (NCCC) at 800-685-5531 or send your request via e-mail to plazear@nccc-online.org.

But What Does It Mean?

...Some Useful Definitions with the Letter "C"

Cancer: A term for a disease in which abnormal cells divide without control. Cancer cells can invade nearby tissues and can spread through the bloodstream and lymphatic system to other parts of the body.

Carcinoma (kar-si-NO-ma): Cancer that begins in the lining or covering of an organ.

Carcinoma in situ (kar-si-NO-ma in SY-too): Cancer that involves only the cells in which it began and that has not spread to other tissues.

Cervical intraepithelial neoplasia (SER-vi-kul in-trae-pi-THEEL-ee-ul NEE-o-play-zha): A general term for the growth of abnormal cells (precancerous) on the surface of the cervix. Numbers from 1 to 3 may be used to describe how much of the cervix contains abnormal cells. Also called CIN.

Colposcopy (kul-POSS-ko-pee): A procedure in which a lighted magnifying instrument (called a colposcope) is used to examine the vagina and cervix.

Condylomata acuminata (kon-di-LOW-ma-ta a-kyoo-mi-NA-ta): Genital warts caused by certain human papillomaviruses.

Conization (ko-ni-ZAY-shun): Surgery to remove a cone-shaped piece of tissue from the cervix and cervical canal. Conization may be used to diagnose or treat a cervical condition. Also called cone biopsy.

Cryosurgery (RY-o-SER-jeer-ee): Treatment performed with an instrument that freezes and destroys abnormal tissue.

Cervix (SER-viks): the lower, narrow end of the uterus that forms a canal between the uterus and the vagina.

NINE COMPONENTS OF OPTIMAL CERVICAL CARE

The NCCC believes the following nine components of optimal care are essential for people who are at risk of being or have been diagnosed with cervical cancer:



Education, access, and early detection!



Careful monitoring for those at risk



Referral at diagnosis to gynecologic oncology professionals



Supportive care from the day of diagnosis



Information about clinical trials and encouragement to participate



Information about the potentially curative and/or the palliative role of treatment



Assistance in making informed decisions



Effective, patient-friendly treatment



Education about living with cervical cancer

RELEVANT RESOURCES

Internet Resources

The Internet is an extremely useful tool for those searching for information on cancer. Listed below are several Internet resources on cancer. If you do not have access to the Internet at your home or office, many local libraries offer free Internet access.

If you are searching scientific literature: <http://cnetdb.nci.nih.gov/cancerlist.html> will take you to the National Cancer Institute's CancerLit database. Another search engine for published materials can be found at the National Library of Medicine at <http://www.ncbi.nlm.nih.gov/PubMed/>.

OncoLink, a service offered by the University of Pennsylvania, offers general cancer information including information on locating financial assistance from pharmaceutical companies. OncoLink can be reached at <http://www.oncolink.upenn.edu/>.

For useful information about the rights of people affected by cancer and other diseases, check out the Americans with Disabilities Act Document Center at <http://janweb.icdi.wvu.edu/kinder>.

Remember that the Internet is a valuable tool, but please use care when gathering information. Not all sources are reputable. Take any medical advice and/or information you may receive to your physician or another member of your healthcare team for discussion and confirmation.



Print Resources

For those interested in clinical trials, speaking to your doctor or other members of your healthcare team is encouraged. If you would like printed materials on clinical trials, the National Institutes of Health (NIH) offers two valuable booklets: *What Are Clinical Trials All About? A Booklet for Patients with Cancer* (NIH Publication No.98-2706) and *Taking Part in Clinical Trials: What Cancer Patients Need to Know* (NIH Publication NO. 98-2450). Both are available free of charge. Call the Cancer Information Service, a program of the National Cancer Institute, at **800-4-CANCER** to order the booklets. For excerpts, please see this issue's *Question and Answer* column.



PHONE PALS MAKING A DIFFERENCE

The NCCC is forever grateful to all of the volunteers who will help to make our new Phone Pals program a big success. We continue to look for Pals, and would welcome your participation in the program. Whether you are a patient or survivor, family member or friend, we can use your help! We also receive requests for Pals who are willing and able to talk via electronic mail (e-mail). If you are interested in participating in this wonderful program, [please call the NCCC at 800-685-5531](tel:800-685-5531).



NATIONAL CERVICAL CANCER COALITION (NCCC)

Despite all that is being done to prevent cervical cancer, including potential HPV vaccines, it will remain a major health problem for many years. Cervical cancer survivors like all other cancer survivors, deserve the best in treatment, care support, access, technology and education. To that end, the **National Cervical Cancer Coalition (NCCC)** was founded to help people living with cervical cancer improve the quality of their lives by increasing awareness about issues surrounding early detection, diagnosis, treatment, and living with cervical cancer. The NCCC provides a method through which survivors and family members can receive psychosocial support; and provides education about the disease, access options, and how best to live with it. Please visit our web site at www.nccc-online.org



January is... Cervical Health Awareness Month

Could I have cancer of the cervix and not know it?

Yes - often there is no pain. And this kind of cancer kills many women every year.

What does that mean for me?

It means get a pap test. A Pap test can find cancer early. If it's found early, it's easier to cure.

How often should I get a Pap test?

Get a Pap test every year.

How is the Pap test done?

The nurse or doctor wipes a small brush on the cervix in your vagina. This takes only a few seconds.

Where do I get a Pap test

Family doctor
OB/GYN
Medical Clinic / Family Planning Clinic
Local Health Department

Who needs to have a Pap test?

You do if:
You are over 18; or
You are 18 or under and have sex
There is no upper age limit for the Pap test. Even women who have gone through the change of life (menopause) need a one every year.

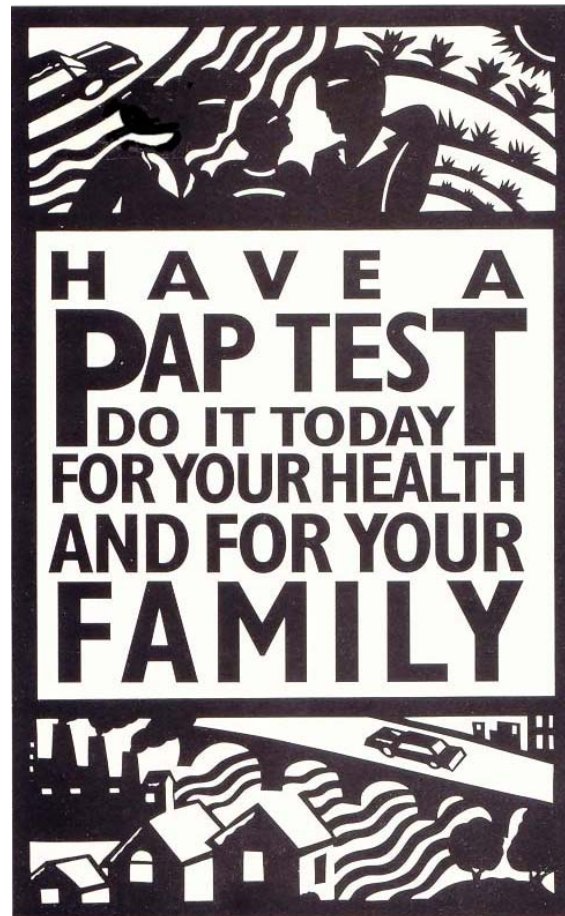
Why is a Pap test important to me?

Because it can tell if you have cancer of the cervix early - while it's still easier to cure.

It can save your life!

For more information on the pap test, call the National Cancer Institute's toll-free Cancer Information Service at 1-800-422-6237. Persons with TTY equipment, dial 1-800-332-8615.

Call your family doctor or local medical clinic today for your Pap test appointment.



Join a NCCC Circle—and Help Others!

Giving Level

Donors' Circle	\$1 to 249
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Directors' Circle	\$500 to 999
Founders' Circle	\$1000 to 2499
Benefactors' Circle	\$2500 to 9999
Leadership Circle	\$10,000 and up



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