



**NATIONAL
CERVICAL
CANCER
COALITION**
a non-profit organization
501 (c) 3

Extraordinary Moments

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

Alan M. Kaye
Executive Director

Medical Advisory Panel

Juan Carlos Felix, MD
*Chairman, NCCC
USC Keck School of Medicine
Women's and Children's Hospital*

Raquel D. Arias, MD
*USC Keck School of Medicine
Women's and Children's Hospital*

Leay Beardsley, NP
PPFA

Michael Fife, LCSW
Association of Oncology Social Work

George Garland Birdsong, MD
Grady Health System

Gary Gill, CT
Senior Science Advisor

Anna R. Guiliano, Ph.D
*University of Arizona
Arizona Cancer Center*

David Hoak, MD
Cytopathologist / QI Advocate

Christine H. Holschneider, MD
UCLA School of Medicine

Richard A. Levinson, MD
American Public Health Association

Fredrick J. Montz, MD
*John Hopkins Medical Institutes
School of Medicine*

James Navin, MD
Straub Clinic / Cytology

Cheryl L. Rock, Ph.D, RD, FADA
USCD - Cancer Prevention/Nutrition

Alice Spinelli, NP
*President, Society of Gynecologic
Nurse Oncologists (SGNO)*

Rosanne P. Wiedmann, R.Ph
Cervical Cancer Survivor

Thomas Wright, MD
Columbia University

**Cervical Cancer
A Story to Share**

I'm supposed to be a rock star - that's what I thought until April 18th, 2000. I had just left my day job to pursue my musical passion. Everything was great, until I went in for my yearly Pap in March. I had some significant bleeding in January, but my gyno assured me nothing was wrong. "Breakthrough bleeding is normal." Of course, I had a toilet full of blood, but hey, I'm no doctor. So when he told me everything was fine, I believed him. I went on with my band, and had a blast...for 2 months. Then I had the yearly Pap, and it came back abnormal. Then the colposcopy came and my gyno was a bit somber about it. He asked me to come back in a week for the results. He saw my face and assured me I did not have cancer. He said it 3 times, "You do not have cancer." He was wrong. I found out a week later, when I got a phone call confirming an appointment I did not have, with a doctor I did not know. Realizing I had not gotten the news yet, the woman on the other end apologized and stumbled over her words as she told me that she was confirming an appointment with a gynecological oncologist at the North Shore Cancer Center. That's how I found out I had cervical cancer. It all happened very quickly after that. A radical hysterectomy 10 days later. Stage 1B, clean margins, no spread to lymph nodes, BUT extensive lymphatic invasion on my cervix itself. Further treatment was necessary. The following month I had a laparoscopic procedure to move my ovaries out of the "frying zone," with the hopes of keeping some natural hormones and the possibility of a biological child at some point. I was 31 years old, no kids, great husband - I wanted to try if I could. Then one week later I started 5 weeks of daily pelvic radiation,



"I attacked with full force - individual therapy, group therapy, anti depressant, acupuncture, yoga, journaling, etc..."

concurrent with 4 rounds of weekly chemotherapy (cisplatin), followed by 3 sessions of brachytherapy (internal high voltage radiation). Within 4 months I was done with everything. Everything other than the deep dark depression, that is. Everyone knows that treatment is hard, and everyone sees the toll it takes on your body. But for me, I think the depression that followed was almost worse. Once my body was no longer being assaulted, my mind started to digest all that had happened, and it wasn't pretty. I even lost my passion for music. I couldn't play, sing or write. I had no desire for the thing I loved the most. I didn't know who I was anymore. I attacked with full force - individual therapy, group therapy, anti-depressant, acupuncture, yoga, journaling, etc... and eventually it started to work.

Time, absolutely, was a huge part of it. Time, and the fact that I just refused to quit. I had worked too hard to stay alive, I wanted my life back. So now, I have just celebrated my 2-year remission and all looks great for my future. I'm working and playing again. I am so thrilled to be back to me, to feel my passion for music and life. ***I'm going to be doing a cervical cancer benefit concert called "POP SMEAR" at the end of the summer (August 29, 2002). I can't wait! I use to feel like I was a very unlucky girl, now I feel like the luckiest girl around.***

Submitted By:

Christine Baze
*NCCC Member
Marbelhead, MA*

What's Inside....

Page 1.....A Story to Share
Page 2.....Stepping Stones
Page 3..... Stepping Stones continued
Page 4..... Cervical Cancer Presentation Kit
Page 4.....Resources
Page 5.....HPV (Human Papillomavirus)
Page 6.....Cervical Health Awareness Month
Page 6.....Free Pap Smear Day
Page 7...Cervical Health Awareness Month continued
Page 8...Cervical Health Awareness Month continued

National Cervical Cancer Coalition
16501 Sherman Way, Suite 110
Van Nuys, CA 91406
Hotline: (800) 685-5531
Phone: (818) 909-3849
Fax: (818) 780-8199
www.nccc-online.org

Stepping Stones

When someone you care about has cancer, you may find it hard to know what to say or do. You may be uncomfortable thinking about and talking about cancer. You want to help, but you're not sure how.

Start by saying that you care

People with cancer need to know and hear that you care – so be sure to tell them! Once they've told you they have cancer, don't try to pretend that it isn't happening. Instead, let them know that you are interested. Ask about treatment and what it's like.

Learning to live with cancer means learning many new things - about the disease, about their treatment, about changes that may happen in their lives. Most people with cancer need someone to talk to about these changes. You can help by being a good listener – by letting them say what is on their mind and accepting it.

But remember – no one wants to spend every minute thinking about cancer. When you are together, just be yourself! Talk about the things that you always talked about together.

The next thing to do is to ask how you can help

Everyday life doesn't stop just because someone gets cancer. Household chores still have to get done. Cancer means changes and new responsibilities for the whole family, including spouses, partners, or others (such as adult children) who help care for someone with cancer. Parents of young children find it especially hard to balance their fight against cancer with their family responsibilities.

Below are lists of some things that you can do to help and to show that you care. There may be many other ways to help – just ask!

Things that you can do to help someone with cancer

People with cancer often have to spend a lot of time dealing with doctors and treatment, especially while they are being treated. It can be hard to find time for the everyday things they need and want to do.

You can help by doing some chores around the house, by doing small things to show that you care, or just by spending some time together doing things that you both enjoy.

You can:

- Rent a comedy on video and watch it together
- Go to treatment together and play cards, watch a movie, or just talk
- Bring fresh flowers or vegetables from your garden
- Go for a hike or bike ride together
- Lend a copy of your favorite book or CD
- Deliver a loaf of freshly baked bread
- Send a card every other week just to say you care
- Make plans to go on a trip together to some place you've both always wanted to go
- Order a gift subscription to *Coping* (a magazine for people living with cancer) at (615) 791-3859
- Help identify a support group (for both the person with cancer and the caregiver)
- Help with a project to benefit newly diagnosed patients
- Help look up information on the Internet

Things that you can do to help caregivers (spouses, partners, or others who care for people with cancer)

People who are caring for someone with cancer can be under tremendous strain. They have to manage the concerns and emotions they feel, often while taking over more housework and doing their regular job as well.

You can help by showing that you understand what they are experiencing, by lifting a few of their burdens, and maybe by helping them find a little time for themselves.

You can:

- Clean the house (bathroom cleaning is especially appreciated)
- Babysit the kids
- Set up a family relief fund to help provide financial assistance
- Send a card to let them know it's a hard job and they're doing great
- Walk the dog
- Make meals that are frozen or easily reheated for the whole family
- Give a gift certificate for a massage (and babysit the kids during the appointment)
- Help with some yard work or shoveling snow
- Ask for a grocery list and go shopping
- Drop off and pick up dry cleaning
- Sweep/mop/vacuum the floors
- Organize a healing service at church or temple for the family

Things that you can do to help the children of someone with cancer

It's hard for children when a parent has cancer. There may be confusing changes in their lives and routines. Even if children aren't old enough to know what is happening, they will usually sense that there is something wrong that they don't understand. For the parents, there are worries about the future, changes in family responsibilities, and difficulty in finding time to be together.

You can help by spending some time with the children and letting the parents have some time to read, make phone calls, or just spend some quiet time alone.

You can:

- Take the kids to the movies
- Ask for a list of preferences, then bring over dinner
- Invite them over for a home-cooked meal and some games at your house
- Read them your favorite children's stories
- Help take the kids to regular activities, such as club meetings, music lessons, or gym classes
- Ask them how they're feeling (and listen carefully)
- Take them to church or temple with you
- Help with school projects
- Take them to play for an hour in a park
- Deliver a batch of freshly baked cookies
- Help them create artwork as a gift for their parents

You can help a lot just by being there

Remember, the most important thing is to let them know that you are there to help. Remind them that you care and that you want to lend a hand.

The support of family and friends is one of the most important parts of cancer care.

NCCC PROVIDES \$50,000 TO GCF FOR HPV/CERVICAL CANCER EDUCATION

The National Cervical Cancer Coalition (NCCC) has provided a fifty thousand dollar (\$50,000) check to the Gynecologic Cancer Foundation (GCF) to jointly work on an HPV/cervical cancer general public presentation kit. The presentation kit will be utilized by education facilitators as a presentation kit tool geared to high school students and college age adults. In addition to the NCCC and GCF, the Society of Gynecologic Oncologists (SGO), the Centers for Disease Control (CDC), the National Cancer Institute (NCI), the American Social Health Association (ASHA) and the Association of Reproductive Health Professionals (ARHP) are being represented in the development of this important educational presentation kit.



From the left: Maxine Lopez (NCCC), Juan Felix, M.D. (NCCC), Karl Podratz, M.D., Ph.D. (GCF), Alan Kaye (NCCC), J. Max Austin, Jr., M.D. (GCF) (SGO), Wesley C. Fowler, Jr., M.D. (GCF), Ronald Alvarez, M.D. (GCF), and Michael Berman, M.D. (GCF).

Attention Education Facilitators: Contact the NCCC at (818) 909-3849 or send an e-mail to info@nccc-online.org to find out how to receive your complimentary copy of this important presentation kit.

Resources

Groups with information about Cancer or HPV

American Cancer Society

1-800-ACS-2345 (1-800-227-2345)

www.cancer.org

National Coalition for Cancer Survivorship

1-301-650-8868

www.cansearch.org

National Cancer Institute

1-800-4-cancer (1-800- 422-6237)

www.nci.nih.gov

American Social Health Association

Cervical Cancer Prevention Project (HPV Info)

1-919- 361-4848

1-800- 653-4325

www.ashastd.org/programs/ccpp.html

Books

When Your Friend Has Cancer. Amy Harwell.

Wheaton, III: Harold Shaw, 1987.

Share the Care: How to Organize a Group to Care for Someone Who is Seriously Ill. Cappy Capossela

and Sheila Warnock. New York: Fireside Books (Simon & Schuster), 1995.



For More Information on Cervical Cancer and Free Pap Smear Day, call the National Cervical Cancer Coalition at **(818) 909-3849** or visit our website at www.nccc-online.org

HPV (Human Papillomavirus)

What is HPV?

There are over 70 different types of HPV, a virus most commonly known to cause warts on the hands and feet. Other types infect the genital tract. Genital HPV types are sexually transmitted and cause external genital warts or cause cell changes on the cervix that increase a woman's risk for cervical cancer. Most HPV infections do not result in genital warts or cervical disease. In most cases a healthy immune system will suppress or clear the virus.

How is HPV detected?

The Pap smear is a screening tool that looks for changes in cells on the cervix. Often these changes are caused by HPV. An abnormal Pap smear is often the first sign that a woman has HPV and might be at risk for cervical cancer. Most cell changes that occur on the cervix from HPV return to normal as the body (the immune system) rejects the virus. When this does not happen the cells usually become more abnormal only over a period of years.

What are the signs of an HPV infection?

Signs of HPV infection can appear weeks, months, or even years after initial infection, so it is possible to become infected without being aware of it. Also, women infected during their teenage years may show no cervical cell changes until their thirties or forties, or may not develop any abnormality at all. An HPV infection may cause changes in the cervical cells, which are identified in your Pap test. Left untreated, these changes can lead to cervical cancer.

Smoking, drug use and heavy drinking interfere with the body's normal defense system and may cause the virus to linger. For a few, cell changes continue, eventually becoming cancer. With regular screening, this cervical disease can be found, treated, and in most cases, completely cured.

Who can be infected by HPV?

Anyone who has ever been sexually active can get an HPV infection. Experts estimate over 20 million Americans are currently infected with HPV. Although HPV is known to be the cause of cervical cancer, most people with HPV will never develop cervical cancer.

What about HPV testing?

Most of the time, the immune system on its own is able to rid the body of abnormal cells caused by HPV, even when those cells are infected with "high-risk" types of HPV. However, when abnormal cells do not go away on their own, or keep coming back after treatment, they are most likely caused by the "high-risk" types of HPV. In certain situations, HPV tests can be used to determine whether "high-risk" HPV types are present.

The American Society for Colposcopy and Cervical Pathology has incorporated HPV testing in its management guidelines for women with cervical cytological abnormalities. The FDA has approved the Hybrid Capture® II HPV DNA test that can be done at the same time as your Pap smear test, and from the same Pap smear sample if your Pap smear is done with the Thin Prep® Pap Test™.

Can HPV infections be treated?

While there is currently not a treatment for the virus itself, treatments do exist for the problems HPV can cause, such as cervical lesions or genital warts. When treatment is needed, there are several choices. The treatment will depend on age, where the abnormality is located, and if a woman is pregnant or has other gynecological problems. After treatment, a woman should talk to her provider about follow-up Pap smears to keep checking for any new signs of abnormal cell changes. Most women never have any more problems, but some will have abnormal Pap smears again and will need more treatment.

American Social Health Association (ASHA)

For more information on HPV, please visit the National Cervical Cancer Coalition's website at:
www.nccc-online.org

January is Cervical Health Awareness Month

What is Cervical Health Awareness Month?

The United States Congress designated January as Cervical Health Awareness Month. During January, you may wish to highlight issues related to cervical cancer. Some of the issues you may wish to highlight are personal stories of women and family members/caregivers battling issues related to their precancer and/or cervical cancer. You may wish to highlight recent advances and research in the detection and treatment of cervical cancer. You can highlight the success of your local/regional early detection cervical cancer screening and treatment programs and human-interest stories on the importance of early detection, education and the emotional issues related to battling cervical cancer. You may wish to help develop and/or highlight a FREE Pap Smear Day in your community. The second Friday of January is FREE Pap Smear Day.

What is Free Pap Smear Day All About?

FREE Pap Smear Day was originally designed to offer a FREE Pap smear to women that have not had a Pap smear for three years or more. There may not be a Free Pap Smear Day set up in your area. We need your help to work with local providers in your community to help make a FREE Pap Smear Day in your area possible. There is a lot you can do to help highlight the important issues related to cervical cancer in your community. **We can't do it without you!**

What Can You Do?

As someone who is interested in educating and advocating for increased knowledge of cervical cancer, you can do a lot. Motivation is the key, that, and the willingness to make contacts with local media.

As part of a nation-wide education effort surrounding Cervical Health Awareness Month and **FREE Pap Smear Day on January 10, 2003**, we are asking that state and local supporters of the NCCC mobilize to get the word out about cervical cancer. Specifically, we ask for three things:

- ** Distribute the NCCC's cervical cancer press releases to state and local media;
- ** Enlist radio stations to announce the FREE Pap Smear Day public service announcement (PSA); and
- ** Seek placement of the NCCC's "print" public service announcement in local newspapers and magazines.

To receive the press release and "print" public service announcements, please contact the NCCC at (818) 909-3849 or send an e-mail to info@nccc-online.org.

Imagine the amount of education that could be accomplished if each state had a story and/or public service announcement placed in each of the three major media venues – radio, television and print.

To help you get started, review this easy-to-follow guide on how to work with the media at your state and local level to spread the message of Cervical Health Awareness Month and Free Pap Smear Day.

Who Should You Contact?

To help spread the message as widely as possible, you should aim to contact the health or medical editor at each of your local newspapers and magazines, and the news directors or health reporters of each of your local television and radio stations. Because their time is often limited, be sure to be quick and concise in communicating your message.

It's important to keep track of all of your media contacts and to note their interest in reporting on cervical cancer. This will help keep you organized, and will help you respond more efficiently and promptly to requests for information and interviews.

Continued on Page 7.....

January is Cervical Health Awareness Month

How Can You Gain the Media's Interest?

State and local media are firmly committed to making the news they report relevant to their readers. In other words, they like to report what's happening in the neighborhoods they serve.

Strive to introduce elements of local interest to your story "pitch." There are a number of simple ways this can be achieved, just be creative. Some examples include:

- ** Make available local cervical cancer survivors for interviews. Local human interest "angles" are always popular with reporters, and their readers or viewers.
- ** Talk about innovative research on cervical cancer that is going on at a local research university, or suggest local physicians who are willing to be interviewed.
- ** Organize a local event to raise awareness of, or money for, cervical cancer research and then invite media to attend. Be sure to send out announcements at least a week in advance to ensure the greatest amount of interest and attendance.
- ** Research local statistics on cervical cancer to provide as background to reporters. It can help to provide a local "tie-in" to a broader story about cervical cancer.

Who Can You Contact for Media Help?

We realize that many of you may have questions about how to develop a media list, where to go for reporters' addresses and phone numbers, or just need a little coaching to get started.

Please contact the National Cervical Cancer Coalition (NCCC) with any questions you may have dealing with the media at (818) 909-3849.

Media relations work can be intimidating at first, but remember that you have a strong educational message to deliver, and a newsworthy cause to promote. Before long, you'll be confident and proficient!

You can make this happen! Your active participation within your community will help educate women, family members and caregivers to issues related to cervical cancer and HPV. Help make a difference. Your action will make a difference. **Early Detection Saves Lives!**

When Should You Get Started?

January is Cervical Health Awareness Month. FREE Pap Smear Day for women that have not had a Pap smear for three (3) years is on **January 10, 2003**. That gives you plenty of time to get organized to work effectively through the media. The following is a rough timeline to help guide your activity:

November, 2002

- ** Develop your media contact list.
- ** Develop list of local experts and/or survivors who are willing to be interviewed.
- ** Begin to call magazine reporters who require a longer lead time to file their articles.
- ** Contact providers in your community to develop a FREE Pap Smear Day on January 10, 2003.

December, 2002

- ** Send copy of public service announcements to radio station managers. Follow-up with a phone call.
- ** Send press release to all print and broadcast reporters.
- ** Begin follow-up phone calls to all print and broadcast reporters to urge coverage of cervical cancer.

Continued on Page 8...

January is Cervical Health Awareness Month

January, 2003

- ** Work with local media who plan to cover cervical cancer awareness activities in your community.
- ** Re-send press releases and public service announcements to all media contacts, and follow-up with phone calls.
- ** Send any press releases announcing specific local events relating to Cervical Health Awareness Month and/or FREE Pap Smear Day.

February, 2003

- ** Collect all print articles and written transcripts of broadcast and radio mentions of cervical cancer in your local media. Forward copies to the National Cervical Cancer Coalition. (Thank you!)
- ** Send thank-you notes to those reporters you worked with to thank them for covering cervical cancer. Ensure that they have your contact information, should they cover the topic again.

Donations

The generosity of many donors enables the NCCC to address cervical health needs of women in the United States and internationally. Your donation can help support the NCCC's developing health projects.

Contributions to the NCCC are tax-deductible in the United States. The NCCC is a registered 501(c)(3) tax-exempt organization. If your employer has a matching gift program, you may be able to double your gift to the NCCC; please check with your human resources department. The NCCC also accepts gifts of stock, which may offer you significant tax advantages.



Extraordinary Moments

c/o The National Cervical Cancer Coalition
16501 Sherman Way, Suite 110
Van Nuys, CA 91406

NON-PROFIT
U.S. POSTAGE
PAID
Van Nuys, CA
#2423