

JOHANNA'S LAW

HEARING
BEFORE A
SUBCOMMITTEE OF THE
COMMITTEE ON APPROPRIATIONS
UNITED STATES SENATE
ONE HUNDRED NINTH CONGRESS
FIRST SESSION

SPECIAL HEARING
MAY 11, 2005—WASHINGTON, DC

Printed for the use of the Committee on Appropriations



Available via the World Wide Web: <http://www.gpoaccess.gov/congress/index.html>

U.S. GOVERNMENT PRINTING OFFICE

22-776 PDF

WASHINGTON : 2006

For sale by the Superintendent of Documents, U.S. Government Printing Office
Internet: bookstore.gpo.gov Phone: toll free (866) 512-1800; DC area (202) 512-1800
Fax: (202) 512-2250 Mail: Stop SSOP, Washington, DC 20402-0001

COMMITTEE ON APPROPRIATIONS

THAD COCHRAN, Mississippi, *Chairman*

TED STEVENS, Alaska	ROBERT C. BYRD, West Virginia
ARLEN SPECTER, Pennsylvania	DANIEL K. INOUE, Hawaii
PETE V. DOMENICI, New Mexico	PATRICK J. LEAHY, Vermont
CHRISTOPHER S. BOND, Missouri	TOM HARKIN, Iowa
MITCH McCONNELL, Kentucky	BARBARA A. MIKULSKI, Maryland
CONRAD BURNS, Montana	HARRY REID, Nevada
RICHARD C. SHELBY, Alabama	HERB KOHL, Wisconsin
JUDD GREGG, New Hampshire	PATTY MURRAY, Washington
ROBERT F. BENNETT, Utah	BYRON L. DORGAN, North Dakota
LARRY CRAIG, Idaho	DIANNE FEINSTEIN, California
KAY BAILEY HUTCHISON, Texas	RICHARD J. DURBIN, Illinois
MIKE DEWINE, Ohio	TIM JOHNSON, South Dakota
SAM BROWNBACK, Kansas	MARY L. LANDRIEU, Louisiana
WAYNE ALLARD, Colorado	

J. KEITH KENNEDY, *Staff Director*
TERRENCE E. SAUVAIN, *Minority Staff Director*

SUBCOMMITTEE ON DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND
EDUCATION, AND RELATED AGENCIES

ARLEN SPECTER, Pennsylvania, *Chairman*

THAD COCHRAN, Mississippi	TOM HARKIN, Iowa
JUDD GREGG, New Hampshire	DANIEL K. INOUE, Hawaii
LARRY CRAIG, Idaho	HARRY REID, Nevada
KAY BAILEY HUTCHISON, Texas	HERB KOHL, Wisconsin
TED STEVENS, Alaska	PATTY MURRAY, Washington
MIKE DEWINE, Ohio	MARY L. LANDRIEU, Louisiana
RICHARD C. SHELBY, Alabama	RICHARD J. DURBIN, Illinois
	ROBERT C. BYRD, West Virginia (Ex officio)

Professional Staff

BETILOU TAYLOR
JIM SOURWINE
MARK LAISCH
SUDIP SHRIKANT PARIKH
CANDICE ROGERS
ELLEN MURRAY (*Minority*)
ERIK FATEMI (*Minority*)
ADRIENNE HALLETT (*Minority*)

Administrative Support
RACHEL JONES

CONTENTS

	Page
Opening statement of Senator Arlen Specter	1
Statement of Dr. Andrew C. von Eschenbach, Director, National Cancer Institute, National Institutes of Health, Department of Health and Human Services	2
Prepared statement	3
Statement of Fran Drescher	7
Prepared statement	9
Statement of Sheryl Silver	11
Prepared statement	13

JOHANNA'S LAW

WEDNESDAY, MAY 11, 2005

U.S. SENATE,
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN
SERVICES, EDUCATION, AND RELATED AGENCIES,
COMMITTEE ON APPROPRIATIONS,
Washington, DC.

The subcommittee met at 9 a.m., in room SDG-50, Dirksen Senate Office Building, Hon. Arlen Specter (chairman) presiding.
Present: Senators Specter, Shelby, Harkin, and Murray.

OPENING STATEMENT OF SENATOR ARLEN SPECTER

Senator SPECTER. Good morning, ladies and gentlemen. The Appropriations Subcommittee on Labor, Health, Human Services, and Education will now proceed.

This morning, we will be hearing testimony on proposed legislation known as Johanna's Law which will provide for gynecological cancer education and awareness in order to focus on this very, very serious medical problem.

We have this morning with us Dr. von Eschenbach who is the head of the National Cancer Institute, Ms. Fran Drescher, an actress, a star, who has focused very significant public attention on this issue because of her own personal involvement.

She is the author of a very important book called "Cancer Schmancer," which is her way effectively of focusing attention on the issue. And she has some words of wisdom on how patients have to be their own advocates.

We also have Ms. Sheryl Silver who is the sister of Johanna Silver Gordon after whom Johanna's Law is named.

The issue of cancer research is one which has attracted tremendous attention by this subcommittee where Senator Harkin and I on a bipartisan basis have joined together to take the lead in increasing funding for the National Institutes of Health from \$12 to \$28 billion. And so far, it is not enough.

The funding for cancer is in the \$5 billion range and that is not enough. For a country which has a Federal budget of \$2.6 trillion and a gross national product of \$11 trillion, if we made up our minds to lick cancer, we could do it.

President Nixon declared war on cancer in 1970. And we could have won this war long ago. This is an issue which has been on my mind long before I had a personal involvement.

My new hair styling is not voluntary. It is a result of a temporary bout with Hodgkin's. And I am advised that it will come in

fuller and curlier and darker. I'm glad to see Dr. von Eschenbach nodding in the affirmative to confirm that as an expert in the field.

Later today, a number of us will join together to again emphasize the need for legislation on stem cell research. Legislation is pending in the House sponsored by Congressman Mike Castle and in the Senate sponsored by Senator Tom Harkin, Senator Diane Feinstein, Senator Orrin Hatch, Senator Ted Kennedy, and myself.

So we have a real fight on our hands here and I am glad to see so many television cameras who did not come for me. I think they must have come from you, Dr. von Eschenbach.

So our generalized rule is 5 minutes. This is a crowded morning as almost every day is here. I am committed to be at a Judiciary Committee meeting which I Chair at 9:30 on the Asbestos bill and this room will be filled at 10 o'clock on a hearing on Amyotrophic Lateral Sclerosis.

STATEMENT OF DR. ANDREW C. VON ESCHENBACH, DIRECTOR, NATIONAL CANCER INSTITUTE, NATIONAL INSTITUTES OF HEALTH, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Senator SPECTER. Welcome again to the witness table, Dr. von Eschenbach. Thank you for all you have done and we look forward to your testimony.

Dr. VON ESCHENBACH. Thank you, Mr. Chairman.

Let me express at the very outset my gratitude to you, to Senator Harkin, and the other members of the committee for welcoming us here today and giving us the opportunity to talk to you and testify on a topic of extreme importance to this nation, namely gynecologic cancers.

I am going to keep my remarks very brief and I have testimony for the record because we do have two other witnesses that have important stories to tell. And I would like to leave as much time for them as possible.

At the outset, I would like to add on a personal note, first of all, as the Director of the National Cancer Institute, to express our gratitude specifically to you as I have witnessed over a long period of time your commitment to furthering research in cancer and specifically, more importantly, to further the progress that is essential to affect people's lives. And I know that your record in that regard has been exemplary and we are all grateful for that.

As a fellow cancer survivor, though, I also want to express my personal admiration to you. The courage that you have demonstrated over these recent months as you have continued to exercise all of your responsibilities as a leader of this country has been for all the rest of us a great example in courage and a model for all the rest of us—

Senator SPECTER. Thank you very much.

Dr. VON ESCHENBACH [continuing]. Who are cancer survivors to follow.

The National Cancer Institute, as you know, has set a goal that by the year 2015, we will eliminate not cancer, but we will eliminate the suffering and death due to cancer. Therefore, it is very appropriate that we focus on gynecologic malignancies, cancers that affect the cervix and the body of a woman's uterus, as well as affect the ovary.

Those three sites of cancer account for over 75,000 women in this country each year hearing the words you have cancer. And 28,000 of those women will die as a result of those diseases.

Each of those cancers, ovarian, uterine, and cervix present important challenges, but also important opportunities.

In cervical cancer, we have seen progress because of the opportunities to detect the disease very early by virtue of the availability of a PAP smear. However, that diagnostic test has not been applied as widely and as completely as is necessary and there are still areas in this country and around the world where cervical cancer is not detected until it is advanced and in a lethal or a form that takes someone's life.

So the National Cancer Institute is committed to enhancing our ability to more widely disseminate early detection of cervical cancer and at the same time is working on more sophisticated methods to predict and detect the presence of cervical cancer, especially the use of detection studies for the human papilloma virus which is responsible for the development of cancer of the cervix.

With regard to ovarian cancer, again, it is a cancer that results in death because we too often do not detect it at a time when it is much more easily eradicated and, if you will, curable. And the opportunity is there for us to continue to pursue strategies in early detection of ovarian cancer using new and modern technologies that can look at proteins, proteins that are created and developed by the presence of the tumor cell.

Those proteins can be detected in the blood stream and we are working on methodologies to identify those proteins so that we could be able to detect and predict ovarian cancer at very early stages when it is much more easily curable.

We are already seeing progress and we have seen even as late as this week reports of specific proteins that have been identified that may serve to help in early detection of ovarian cancer.

PREPARED STATEMENT

With regard to endometrial cancer, it is important for us to understand the biology of this disease. And so our research into understanding the disease in a way that will enable us to affect it and treat it earlier is one of our highest priorities.

I will be happy to answer any specific questions in the areas of early diagnosis, more effective treatment for each of these specific malignancies, and greatly appreciate the opportunity to be here today.

[The statement follows:]

PREPARED STATEMENT OF ANDREW C. VON ESCHENBACH

Senator Specter and members of the Subcommittee, thank you for the opportunity to testify on the topic of gynecological cancer on behalf of the National Cancer Institute (NCI). Ovarian, cervical, and endometrial (also known as uterine) cancers are grouped as gynecological cancers. One hundred years ago, gynecological cancer, specifically cervical cancer, was the leading cause of cancer deaths among women in the United States. Over the past century, we have made major progress toward the defeat of this dreaded disease in our Nation. Today, I would like to talk to you about some of the exciting work NCI is doing to eliminate the suffering and death due to gynecological cancers in the United States and around the world.

Cervical cancer is the most common of cancers among women worldwide. Over 400,000 new cases are diagnosed each year, resulting in about 200,000 deaths. With

the continuing education and application of early detection through pelvic examinations and Pap smears, the frequency of advanced or recurrent cervical cancer has diminished in the United States. However, advanced cervical cancer is still observed and has a poor prognosis. We recognized that a better preventive strategy against cervical cancer is needed, and NCI investigators have developed a new vaccine approach to prevent the transmission of the human papillomavirus, the virus responsible for most cases of cervical cancer. We have licensed this technology to two large pharmaceutical companies, Merck and Glaxo Smith Kline, who have recently reported that results of clinical trials indicate that the vaccines were almost 100 percent effective in preventing the acquisition of the virus types 16 and 18, which together account for nearly 70 percent of cervical cancer worldwide.

We have also been working to make screening for cervical cancer less expensive, more reliable, and more available. Even with the arrival of potential vaccines, we will need to continue screening for many years to come. An effective vaccine in combination with cervical cancer screening is expected to reduce cervical cancer rates by 90 percent in the United States.

NCI is working to bring state-of-the-art cervical screening to geographic regions of excess mortality. In one of our most exciting projects, NCI is collaborating with the Centers for Disease Control and Prevention (CDC), the Department of Agriculture, and State health departments to improve screening for cervical cancer among poor, rural women in the Mississippi Delta, who have had some of the highest rates of cervical cancer in the United States for the last 50 years. We know that cervical cancer disproportionately affects members of particular racial and ethnic minority subgroups and other underserved women.

If successful in Mississippi, we hope to promote region-specific programs with collaborators in other underserved regions like Appalachia, the Mexican-U.S. border, urban clinic populations, and centers serving migrant workers. This initiative also falls within the Health and Human Services Secretary Leavitt's 500-day plan to support community-based approaches to close the health care gap, particularly among racial and ethnic minority populations. Later this month, the NCI Center to Reduce Cancer Health Disparities will publish a report titled, "Excess Cervical Cancer Mortality: A Marker for Low Access to Health Care in Poor Communities." This report will explore the components of the problem of excess cervical cancer mortality and identify critical needs.

Ovarian cancer remains the most deadly of the gynecologic cancers. Reasons for this continuing poor outcome include the nonspecific and late clinical presentation of ovarian cancer and the lack of reliable and cost efficient methods of early detection. Through the Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial, the NCI is carrying out a major evaluation of CA125 blood tests and transvaginal ultrasounds as screening procedures for early ovarian cancer detection. Currently, 70,000 women are receiving these screening methods through this trial. When we are able to validate a screening method for ovarian cancer, the early detection alone—even without changes in current standards of treatment—will have a substantial impact on public health.

Through the NCI Director's Challenge project, we have undertaken major studies into the molecular classification of ovarian cancer. This research, being conducted at the University of Pennsylvania, the University of Michigan, Memorial Sloan-Kettering Cancer Center, and the intramural Center for Cancer Research at NCI, has helped us begin to understand the biology of ovarian cancer. In addition, we have established five Specialized Programs of Research Excellence, also known as SPORÉs, to foster translational research in ovarian cancer, at the Fox-Chase Cancer Center in Philadelphia, the University of Texas MD Anderson Cancer Center in Houston, the University of Alabama at Birmingham, Harvard University (Brigham and Women's Hospital, Boston), and the Fred Hutchinson Cancer Research Center in Seattle. One of the standard drugs used to treat ovarian cancer worldwide, Taxol®, was discovered and developed by NCI in collaboration with investigators across the United States and five other international partner countries.

NCI has also begun the Proteomics Ovarian Cancer Recurrence Monitoring Prospective Trial. Among the outcomes of this trial will be a repository of tissue samples for proteomic and other biomarker validation mechanisms for the determination of ovarian cancer recurrence and will begin accrual of patients this June. This is a multi-institutional partnership led by NCI's intramural Center for Cancer Research in collaboration with the SPORÉs. This trial will explore the opportunities of the emerging field of proteomics as a way to detect early stages of ovarian cancer. Other collaborative ovarian cancer trials supported by NCI are studying the molecular characterization of newly diagnosed patients, prophylactic surgery for women at high risk for ovarian cancer, monitoring of breast cancer patients for BRCA1 and BRCA2 gene mutations, as well as several trials that are looking for specific diag-

nostic signatures for malignancy versus benign or unaffected samples. In addition, NCI is currently sponsoring a national clinical trial aimed at evaluating a novel approach to ovarian cancer screening in women at increased genetic risk of ovarian cancer. While we recognize that more women diagnosed with this disease today are living longer, with a higher quality of life than they were twenty years ago, we also acknowledge that more work is needed to end the suffering and death that too many women still face. For women who have a high risk of ovarian cancer, which includes a family history of breast, ovarian, endometrial, or colon cancer and a known BRCA1 or BRCA2 mutation, we recommend that they receive two yearly exams plus CA125 monitoring as well as a yearly trans-vaginal ultrasound.

Endometrial cancer is the most common gynecologic cancer in the United States, though not the most lethal. Around 90 percent of endometrial cancers are diagnosed in the early stages of cancer with an overall 85 percent survival rate. Population studies indicate that endometrial cancer is one where incidence and mortality are most affected by being overweight or obese, as measured by having a high body mass index (BMI). These data suggest that maintaining a normal body weight could prevent about one-half of endometrial cancers. However, the alarming trends of increasing BMI in the United States suggest that endometrial cancer may become more common.

NCI is able to utilize the latest technology to examine the genetic differences in endometrial cancers from women of normal and high BMI. The ability to monitor gene expression is at the heart of many research projects. This allows scientists to better understand the biology of risk, the knowledge of which will enable them to design and implement personalized preventive and therapeutic strategies. Through NCI's Clinical Trials Cooperative Groups, specifically the Gynecology Oncology Group (GOG), NCI has sponsored major anatomic and molecular staging studies of endometrial cancer. Additionally, the GOG has conducted landmark studies evaluating the roles of radiation, hormone therapy, and chemotherapy in women with endometrial cancer.

The NCI budget for gynecological cancers in fiscal year 2004 was \$212,527,000. This funding supports NCI's ongoing multi-pronged, multi-disciplinary effort in molecular biology, epidemiology, prevention, treatment, and survivorship issues of gynecologic cancers. Substantial advances have been made intramurally in the NCI Center for Cancer Research and the Division of Epidemiology and Genetics, and through collaborations with extramural colleagues who participate in the SPORes network, the Cancer Genetic Network (CGN), and GOG clinical trials cooperative groups. Research advances made at NCI are also complemented by collaborations with private industry. In addition to the clinical trials done through the cooperative groups, NCI also sponsors Phase I and II trials in gynecologic cancer through the NCI-designated Comprehensive Cancer Centers and a consortium of Canadian hospitals organized by the Princess Margaret Hospital in Toronto. NCI also co-sponsors the Gynecologic Cancer Intergroup (GCIG), which brings together investigators from all the clinical trials cooperative groups conducting trials for women with gynecologic cancers from around the world. The GCIG meets twice a year and under its umbrella, member groups have joined together to develop joint protocols and develop strategies for future research.

Eliminating the suffering and death from gynecologic cancer is a priority for the NCI. We are working to implement the recommendations of the Gynecological Cancer Progress Review Group, which will further strengthen our research in this area. We have also undertaken, in partnership with the American Cancer Society, the International Agency for Research on Cancer, the International Gynecologic Cancer Society, the International Union against Cancer, and the World Health Organization, a Global Initiative on Women's Cancer (GLOW) so that we can lift the burden of gynecologic cancer from around the world. This international partnership will focus on reducing the global burden of gynecological cancer, breast cancer, and tobacco use among women. GLOW will include public and professional education, the development of a needs-assessment database, and technical assistance to countries in the developed and developing world as they work to strengthen cancer control efforts, including prevention, screening, diagnosis, treatment, palliation, and end of life care.

NCI is also collaborating with the CDC on education and outreach efforts regarding gynecological cancers. Earlier this year we printed a new publication, "Understanding Cervical Changes," which is intended to assist women and their clinicians to understand the treatment decisions involved with abnormal Pap tests. The same brochures in both Vietnamese and Spanish are currently under development.

There is no single approach, organization, or act that will bring about an end to each of these diseases. It will require a collaborative effort between Federal agencies, private industry, States, health professionals and patients. Efforts to increase

healthy life potential through interdisciplinary and interagency collaboration are well underway. Public outreach efforts, comprehensive and novel prevention and early detection strategies, and scientific pursuits to improve the standard of practice will yield the end of suffering and death due to gynecological cancers.

Thank you, Mr. Chairman, for giving me the opportunity to present this information to the Subcommittee. I will be happy to answer any questions you may have.

Senator SPECTER. Thank you very much, Dr. von Eschenbach, for your testimony.

When you cite the year of 2015, what will occur by then at least according to your current projections?

Dr. VON ESCHENBACH. As we sit here today, Senator, two out of three patients who hear the words you have cancer can look forward to being a cancer survivor.

We intend to close that gap. We will close that gap across the continuum of discovering more about cancers' mechanisms—

Senator SPECTER. What is going to happen by 2015 as you project it?

Dr. VON ESCHENBACH. No one who hears the words you have cancer will suffer or die from the disease. We will prevent and eliminate the outcome—

Senator SPECTER. So you will move from two out of three survivors to all three?

Dr. VON ESCHENBACH. Yes, sir.

Senator SPECTER. What is the total budget now of the National Cancer Institute?

Dr. VON ESCHENBACH. \$4.8 billion.

Senator SPECTER. When you appeared here last, just a few weeks ago—

Dr. VON ESCHENBACH. Yes, sir.

Senator SPECTER [continuing]. I asked you what it would take to move that date up to 2010.

Dr. VON ESCHENBACH. Yes, sir.

Senator SPECTER. You have had several weeks to prepare your answer.

Dr. VON ESCHENBACH. Yes, sir.

Senator SPECTER. What is your answer?

Dr. VON ESCHENBACH. The answer has been submitted to you, sir, for the record and it is going through process through NIH and the Department as it is being submitted officially to the Congress and to you specifically.

Senator SPECTER. Okay. So tell me what the answer is.

Dr. VON ESCHENBACH. There are three parts to the answer. One is to embrace the national advanced technology initiative for cancer. The second was to expand our cancer center's program network by the addition of 15 more cancer centers. And the third part of the equation was the expansion and integration of our clinical research infrastructure.

Senator SPECTER. Now, let's say if I were to recollect my question is what will it take to do that? What will it cost?

Dr. VON ESCHENBACH. Those estimates would require—we have a proposed budget that would support those initiatives that would amount to approximately \$600 million a year.

Senator SPECTER. \$600 million a year?

Dr. VON ESCHENBACH. Yes, sir.

Senator SPECTER. Extra?

Dr. VON ESCHENBACH. Yes, sir.

Senator SPECTER. You can move the date from 2015 to 2010?

Dr. VON ESCHENBACH. We would be able to accelerate the pace of progress and close that gap in my opinion.

Senator SPECTER. Okay. Well, that is the kind of specificity we like to have. Thank you very much, Dr. von Eschenbach.

Dr. VON ESCHENBACH. You are welcome, sir.

Senator SPECTER. Now we will call both Ms. Fran Drescher and Ms. Sheryl Silver. If you ladies will step forward and flank Dr. von Eschenbach.

Ms. Drescher is a star, an actress best known for her twice emmy nominated role in "The Nanny." She is a successful author and philanthropist. She herself is a cancer survivor and has just launched a new series, "Living With Fran."

Now, the question, Dr. von Eschenbach, is what will I have to increase the budget of this subcommittee to get all this technical work done before I arrive.

Ms. Drescher, congratulations again on your outstanding contribution to this very important subject.

Johanna, Ms. Silver are the inspirations for legislation which has been introduced in the House and which Senator Harkin and I are committed to introduce in the Senate.

Thank you for joining us and we look forward to your testimony.

STATEMENT OF FRAN DRESCHER

Ms. DRESCHER. Thank you. I'm honored to be here. I appreciate it.

Is it my turn?

Senator SPECTER. You are on.

Ms. DRESCHER. Oh, okay. Yes, thank you.

Senator SPECTER. The cameras are on. The lights are on.

Ms. DRESCHER. A doctor tells his patient he has good news and bad news. The good news is you have 48 hours to live. The patient says if that is the good news, then what is the bad news. The doctor says I was supposed to tell you yesterday.

Unfortunately, too many patients are being told today that they have cancer when they should have been told yesterday. Early detection is what equals survival. Yet, we are all victimized by a medical community that is bludgeoned by big business health insurance companies to go the least expensive route of diagnostic testing.

The result being a generation of doctors who subscribe to the philosophy if you hear hooves galloping, do not look for zebra. It is probably a horse.

The danger with this thinking is that with most gynecologic cancers, earliest warnings signs, when it is at its most curable, mimics symptoms of far more benign illnesses.

This June 21, I will be 5 years well from uterine cancer. But for 2 years and eight doctors, I was misdiagnosed and mistreated for a perimenopausal condition that I did not have. And even though uterine cancer is a very slow-growing and noninvasive cancer, it remains the only female cancer with a mortality rate that is on the rise.

Women with ovarian cancer who often are misdiagnosed and mistreated for irritable bowel syndrome waste precious time because ovarian cancer is far more aggressive and fast growing. Eighty percent of all women with ovarian cancer will be diagnosed in the late stages and 70 percent of them will die.

How many women go for a second opinion when the doctor is telling them they are essentially fine? I did. I went for seven second opinions as a matter of fact. I got in the stirrups more times than Roy Rogers always telling the doctors my symptoms. But each time, I slipped through the cracks.

Initially I experienced staining between periods and cramping after sex. But eventually my stool changed. I had tenderness under my arms and leg pains. One doctor told me to stop eating so much spinach. Another said I have the breasts of an 18-year-old which I do.

Senator SPECTER. How was that relevant?

Ms. DRESCHER. A third one told me to try gin and tonics before going to bed. So there I was with perky breasts in need of roughage, going to bed sloshed in some vain attempt to cure myself.

Finally, after a 2-year and eight-doctor odyssey, I was diagnosed with uterine cancer from a simple in-office endometrial biopsy. The cure being a radical hysterectomy, a difficult operation for any women. But for one who has never had children like myself, it is a particularly bitter pill to swallow.

If only I knew what to ask for. Doctor number one said I was too young for a D&C, but I did not question her because, well, frankly, I was just so thrilled to be too young for anything.

It is time that we the patients take control of our bodies by learning the early warning symptoms for gynecologic cancers and the tests that are available because it may not even be on the menu at the doctor's office during your exam. It is our lives after all. When the doctor calls and tells you you have cancer, at the end of the day, he goes home and eats dinner with his family. You go home and eat your heart out with yours.

I do not give anyone power of attorney over my money, so why should I give it over my body? I should not. And with the education I received from Johanna's Law, I will not have to. Knowledge is power and early detection equals survival.

Please support this bill through funding so more women can have the tools to help themselves navigate through a medical system designed to placate the patient when they know in their hearts something is wrong.

After my 2-year, eight-doctor odyssey, I wrote the "New York Times" best seller "Cancer Schmancer" so what happened to me would not happen to other women. But when I went on my book tour, I realized what happened to me had happened to thousands of women all over the country and it was then that I found my purpose in life.

I am begging you to help raise the awareness of both woman and their physicians about the early warning signs of gynecologic cancers and the tests that are available. A user-friendly check list one can follow and reference in an easy-to-read and reference pamphlet so that Johanna, a woman who lost her battle with ovarian cancer due to misdiagnosis and late detection, will not have died in vain.

I am not glad I had cancer and I do not wish it on anybody. But because of my advocacy work, I am better for it. Sometimes the best gifts come in the ugliest packages.

A pilot of a 747 tells his passengers to brace themselves, they are about to crash. One man stands up and says wait a minute, my doctor told me I was going to die from cancer. Where there is life, there is hope and nobody can tell you when your number is up.

PREPARED STATEMENT

Thank you for hearing me and for considering the importance of Johanna's Law which will help women to help themselves. May God bless you all with good health and long life.

[The statement follows:]

PREPARED STATEMENT OF FRAN DRESCHER

Thank you Senators for giving me this opportunity to be heard.

A doctor tells his patient I have good news and I have bad news. The good news is you have 24 hrs. to live. The patient said "if that's the good news what's the bad news?" the doctor replies "I was supposed to tell you yesterday." Too many people are being told today they have cancer when they should have been told yesterday.

I am a five year uterine cancer survivor. Unfortunately it took me 2 years and eight doctors to get a proper diagnosis. And I, of course, went to the best doctors as you can well imagine. So why should it have taken so long? Because I didn't know what the early warning signs of gynecologic cancers were, nor did I know what tests to ask for. Which is why Johanna's Law, an education based bill targeted at women with information about the earliest warning signs of gynecologic cancers and the tests that are available, is so very important to fund.

But why didn't my doctor recognize the symptoms and offer the tests that are available?

All roads lead to big business health insurance companies who bludgeon doctors to go the least expensive route of diagnostic testing. The result being a medical community who subscribes to the philosophy "if you hear hooves galloping, don't look for zebra, when it's probably a horse."

Unfortunately for the woman with gynecologic cancer, that logic could be fatal because in it's very nature it inhibits the diagnostician's ability to cast a wide enough net to cover all bases. This situation for the woman is further inflamed by the fact that the very early warning signs of many female cancers (when it is at it's most curable stage) mimic far more benign illnesses.

So, now take a physician who has been brainwashed into believing it's prudent to, at least initially, treat the obvious and combine that doctor with the woman whose stage 1 ovarian cancer looks identical to irritable bowel syndrome, and you've got yourself a woman with one foot in the grave.

Everyone agrees that early detection equals survival and yet the paradox is 80 percent of all women with ovarian cancer find out in the late stages and 70 percent of them will die. Likewise in my case and for many women with uterine cancer, I was, for two years and eight doctors misdiagnosed and mistreated with a perimenopausal condition I did not have and all the while I had cancer.

Now how many of you would go for a second opinion when the doctor is telling you that you're essentially fine? I did. I went for seven second opinions as a matter of fact. All I can say is thank god uterine cancer (in contrast to the far more aggressive ovarian cancer) is slowing growing. Yet uterine cancer, (in spite of it's less invasive nature) due to it's habitual misdiagnosis, remains the only female cancer with a mortality rate on the rise.

When a woman is dying in the home, the tentacles of devastation is so far reaching. The tragic effects on her family, friends and community is profound.

If only I had known what the early warning signs were for uterine cancer, perhaps I wouldn't have slipped through the cracks for two painfully long and frustrating years. When doctor number one said I was too young for a D&C, I wish I knew enough to say "Not so fast Doc. A D&C can diagnose uterine cancer and since my symptoms are quite similar, why not rule out the cancer BEFORE putting me on hormone replacement therapy." I was misdiagnosed and mistreated. The HRT Estrogen that was prescribed for a peri-menopausal condition I did not have had actually exacerbated my cancer. Estrogen is like taking poison when one has uterine cancer. But I didn't know enough to challenge my physicians. In fact few women

do and it is for this reason so many of us die. Oh the regret I have felt for my ignorance. If only I had known then what I know now perhaps I could have avoided a radical hysterectomy as my only cure. That is a most difficult operation for any woman, but for one who had never had children like myself, it is a particularly bitter pill to swallow.

Most of us put more research and energy into the buying, selling and repairing of our automobiles than we do into our own bodies! This is a travesty that must end. As medical consumers we must become better informed in order to insure better healthcare. We must understand our bodies, know the early warning signs of gynecologic cancers and demand the tests available. Incidentally, this problem is not just exclusive to women. Most men don't know that they should be asking for a Tran rectal ultra sound to most efficiently determine prostate cancer over and above the usual blood test offered during an exam. We are all victimized by a lack of information.

When the business of healthcare supercedes the care of health and the value of ones life comes with a price tag, we are all that much closer to a toe tag in the morgue.

Doctors are under a lot of pressure from big business health insurance companies to keep costs down or risk being dropped from the program. Those days when a patient would go into their family practitioner, list their symptoms expecting to be given every test necessary for a proper diagnosis are over! The test you very well may need might not even be on the menu as was the case with me or poor Johanna, the namesake of Johanna's Law who, because of late stage diagnosis is dead today. We need to be given the tools to be better informed so that we can be better partners with our physicians in the quest for an accurate diagnosis.

It's our bodies and our lives so shouldn't we be participants in the decision making process after-all? Because when the doctor tells you, that you have cancer, at the end of the day he goes home and eats dinner with his family while you go home and eat your heart out with yours.

And the level of ignorance about the testing and treatment of cancers among Americans is positively staggering. Most women don't even realize that when they go for their annual checkup, the only cancer screening test they receive is a pap test which only is for detecting cervical cancer. Nothing north of the cervix is tested.

We are not even offered a transvaginal ultrasound as part of our basic gynecologic health-care. This diagnostic tool would be like putting a pair of eyes on the finger tips of the doctor to see with far greater accuracy what is abnormal looking in and around the uterus and ovaries.

Presently nothing more than the primitive manual pelvic is given during a basic gynecologic exam. But we are living in a time when obesity is epidemic rendering the manual pelvic almost completely ineffective. And there in lies the rub. If doctors provided a trans-vaginal ultrasound as part of our regular exam, the fear for big business health insurance companies is that doctors will be opening, if you'll pardon the pun, a Pandora's box. Because the ultrasound is not a cancer screening test but rather a far more efficient diagnostic tool than the manual pelvic for discovering a whole range of both cancerous and non-cancerous maladies, observation and subsequent testing would be required for a more specific diagnosis. Which is where the almighty dollar plays it's insidious role. It's so wrong that women are getting the shaft from a medical community fueled by penny pinching profit mongers in the health insurance industry.

When the doctor tells a woman, her pap came back normal, she has in most cases no awareness that her doctor is clueless as to the condition of her uterus and ovaries. That is the equivalent of the dentist looking at one-third of your mouth and telling you your teeth are fine. Anyone's response to that would be "what are you kidding me? You only checked one-third of my mouth!" And yet such is the fate of women and their gynecologic healthcare in this country. 60 percent of a woman's plumbing goes virtually unchecked and cancers that begin to grow within those areas are continually misdiagnosed for far more benign illness often resulting in a late diagnosis of cancer, at an advanced stage and a much lower survival rate.

Can anyone see how unjust, and uncaring this is for women? Shame on us all for not making research for the discovery of women's gynecologic cancer screening tests a priority. And for not providing in the mean time a more thorough in-depth pelvic exams so that more women will have more of a fighting chance for survival through early detection no matter how far it digs into health insurance profit margins.

Now I understand that tackling this late cancer detection problem from the health insurance company side is kind of like David slaying Goliath, but as Frederic Douglas , a great American once said, "Power concedes nothing without demand, it never has and it never will."

So on behalf of the mothers, sisters, wives and daughters in all of our lives, please understand as legislators the unfortunate house of cards that presently exists in women's healthcare. And at the very least, provide women with the information necessary to know exactly what the most subtle warning signs of gynecologic cancers may be and the tests that are available so that they may, as individuals, make informed decisions and take control of their own bodies.

A simple brochure that would be handed to every woman in America paid for by a benevolent federal government who can appreciate the woes of a woman kept in the dark of her own options for early detection. Kept in the dark by a medical community who remains controlled by big business health insurance companies reticent to do the right thing in spite of what it costs each of us when we suffer the loss of a woman in our lives.

Please as a representative of all my fellow sisters, I'm begging you to support and fund Johanna's Law so that what happened to me won't continue to happen to other women. Through Johanna's Law this could be made possible and is truly the first key in opening the gateway towards increased gynecologic cancer survivorship.

I'm not glad I had uterine cancer and I don't wish it on anyone but I am better for it because I have a purpose to my life that I didn't have before. And that purpose is to improve the quality of healthcare for all of us so that the business of healthcare will no longer supercede the care of our health. I have learned the valuable lesson of taking control of my body and challenging my physician. Sometimes the best gifts come in the ugliest packages!

Thank you and bless you for your time and giving me audience. I hope with all my heart you help save women's lives by supporting Johanna's Law.

Senator SPECTER. Thank you very much, Ms. Drescher.

We now turn to Ms. Sheryl Silver who is the sister of Johanna Silver Gordon who was a 58-year-old Michigan school teacher who died of ovarian cancer 5 years ago. She was not aware that the symptoms she was experiencing were related to cancer and did not have the kind of early detection which could have saved her life.

Following Johanna's death, Sheryl Silver has developed a bill and a movement to create more public awareness in this issue and has been a significant factor leading to these hearings today.

Thank you for your work, Ms. Silver, and we look forward to your testimony.

STATEMENT OF SHERYL SILVER

Ms. SILVER. Thank you so much, Senator. I am honored to be here and truly grateful to you and Senator Harkin for your decision to sponsor Johanna's Law in the Senate and to you for holding this hearing today to discuss funding this terribly important and urgently needed program.

We have heard a few statistics. I will not add too many more, but just a few that are so startling. Every 6.5 minutes, a woman in this country is newly diagnosed with some form of gynecologic cancer. And in the last 10 years alone, we have lost over 250,000 of our mothers, sisters, daughters, and other loved ones and friends, 250,000. We stand to lose another 29,000 this year.

What magnifies the tragedy of these deaths is the fact that these cancers are survivable. As Dr. von Eschenbach mentioned, when diagnosed in the earliest stage, ovarian, uterine, and cervical, the three most common cancers which account for over 90 percent of all new diagnoses, these cancers all have 5-year survival rates of 90 percent, greater than 90 percent, with many women diagnosed early going on to live long, healthy lives.

Sadly, as Fran said, thousands of women every year across this country are diagnosed after their cancers have advanced. And in the case of ovarian cancer, which killed my beloved sister and kills more women in this country every year than all other gynecologic

cancers combined, over 80 percent of women are diagnosed after the cancer has progressed beyond its earliest and most survivable stage.

We were stunned when my sister, Johanna, was diagnosed and we are a doctor's family. But we had no family history of ovarian cancer. Moreover, she was an incredibly robustly healthy woman who was disciplined about her health care. She saw her gynecologist regularly for recommended pelvic exams and PAP smears. She exercised regularly, ate nutritiously. She did everything she knew of to live a long and healthy life.

Sadly the one thing she did not know was that the symptoms that she experienced in 1996, the persistent bloating, heartburn and constipation, that those are common symptoms of ovarian cancer. She assumed they were due to a minor gastric problem. She first took antacids, then made an appointment to see a gastroenterologist.

By the time she saw a gynecologist and was correctly diagnosed, the appropriate diagnostic tools were administered, he scheduled her for surgery, major surgery the next week, the surgery that confirmed she had advanced ovarian cancer, stage 3C, and there are only four stages.

Despite very aggressive treatment after that that included four surgeries, innumerable rounds of chemotherapy, different drugs, participation in clinical trials, she died 3½ years later, tethered to an IV pole the last 9 months of her life for her basic hydration and nutrition. This was an excruciating and horrible way for a wonderful and health-conscious woman to lose her life.

But we are not here because my sister was one unlucky, uninformed woman. We are here and I proposed this bill over 2 years ago because in the days and weeks following her diagnosis, it became obvious this was a pervasive, tragically common story.

Woman after woman that I met at her ovarian cancer support groups, at Gilda's Club had the identical story. The same is true of women I met here in D.C. at the first national conference I attended on ovarian cancer given by the Ovarian Cancer National Alliance. Everyone, health-conscious women diagnosed in the advanced stages and learning only then, only after they were diagnosed that their symptoms, symptoms that they might have experienced for several months or over a year were common symptoms of this disease, but they had not known it. Moreover, they had not dismissed the symptoms like my sister. They too sought medical attention. Many began with gastroenterologists for symptoms that seemed gastric in nature. Others went to internists, even gynecologists.

No matter what type of doctor they saw, all too often, the symptoms were initially attributed to the most benign possible causes of those types of symptoms, perimenopause, menopause, irritable bowel syndrome, or the unexplained weight gain of a woman over 40 and a slowing metabolism that comes with aging.

Because these women did not know that their symptoms could be related to this cancer, they were not in a position to even ask their doctors, well, should not we rule out the most lethal possibility first, a gynecologic cancer, before we assume it is something more

benign. And they could not even ask for the appropriate tests to be performed if they were not automatically done so.

I could not believe what I was hearing over and over and it had gone on for a long time. Women I met, family members of women who had died 10 or 20 years before Johanna was diagnosed had a very similar story. The knowledge gap was pervasive. Women——

Senator SPECTER. Ms. Silver——

Ms. SILVER. I'm sorry.

Senator SPECTER [continuing]. What do you think is the answer? How can we——

Ms. SILVER. How can we do this?

Senator SPECTER [continuing]. Inform women about the symptoms which could lead to early detection?

PREPARED STATEMENT

Ms. SILVER. Thank you. The answer is for us to quickly pass and adequately fund Johanna's Law.

I am here on behalf of millions of grieving families——

[The statement follows:]

PREPARED STATEMENT OF SHERYL SILVER

Thank you Chairman Specter. As Johanna's sister and the person who first proposed Johanna's Law, I'd like to thank you for your decision to sponsor Johanna's Law in the Senate and for scheduling this hearing to discuss the urgent need to adequately fund Johanna's Law and the federal campaign of gynecologic cancer education it will create.

Let me begin with a few startling statistics. Every 6.5 minutes, a woman in the United States is newly diagnosed with some form of gynecologic cancer such as ovarian, uterine or cervical cancer. This year, approximately 29,000 American women are expected to lose their lives to these cancers. In the last 10 years alone, we have lost 250,000 of our mothers, sisters, daughters, and other loved ones and dear friends to these diseases.

What magnifies the tragedy of these deaths is the fact that these cancers are highly survivable when diagnosed in the earliest stage. The three most common gynecologic cancers—ovarian, uterine, and cervical cancer—all have 5-year survival rates greater than 90 percent when diagnosed early, with many women diagnosed in the earliest stages of these cancers going on to live healthy, normal lives.

Sadly, all too often, these cancers are not detected at the earliest stage. Thousands of women every year are detected after their cancers have progressed to less survivable stages. In the case of ovarian cancer, which killed my sister Johanna—and which kills more women in the United States every year than all other gynecologic cancers combined—over 80 percent of women newly diagnosed each year are diagnosed AFTER the cancer has progressed beyond its earliest stage. My sister Johanna was among those women diagnosed at an advanced stage.

I wish you had known my sister. She was a dynamic and loving woman who loved her family and her friends. Hundreds of people came to her funeral. And what was almost as stunning as losing her was the fact that she was diagnosed with this cancer in the first place.

Everyone who knew Johanna was shocked by her diagnosis. We had no family history of ovarian cancer—or any other cancer that we knew of. What's more, she was a robustly healthy and health conscious woman who exercised regularly, ate nutritiously and visited the gynecologist regularly for recommended pelvic exams and Pap smears. My sister did everything she knew of to be healthy and live a long life. Unfortunately the one thing she didn't know—the symptoms of ovarian cancer—contributed to a delay in her diagnosis and ultimately, to her death 3½ years later.

What are the symptoms of ovarian cancer? There are several including severe fatigue and unexplained weight gain. Among the most common symptoms are persistent bloating, heartburn and constipation—all of which Johanna experienced in the fall of 1996. Johanna initially took antacids for the symptoms, then, when the symptoms persisted, she made an appointment to see a gastroenterologist. It seemed logical. The symptoms appeared to be gastric in origin.

Sadly, by the time she saw her gynecologist and the correct diagnostic tests were performed, evidence of advanced ovarian cancer was found and she was scheduled for major surgery the following week. The day of her surgery, her gynecologist told us she might live 12–18 months. The gynecologic oncologist present offered a slightly more optimistic timetable. Ultimately, Johanna’s determination coupled with aggressive treatment that included four surgeries, numerous cycles of various chemotherapy drugs, and participation in a clinical trial—enabled her to survive 3½ years. She was, however, in treatment most of that time with the last 9 months of her life spent tethered to an IV pole at least 12 hours a day for her hydration and daily nutrition. It was a horrible way for a wonderful loving, dynamic, and health conscious woman to lose her life.

But we’re not here today because Johanna was one unlucky, uninformed woman who lost her life to cancer. No, we’re here today—and I proposed Johanna’s Law over two years ago—because my sister’s story is tragically common. In the days and weeks that followed her diagnosis, I became aware of a pervasive lack of knowledge about the symptoms and risk factors of ovarian and other gynecologic cancers—a lack of knowledge that was contributing to delayed diagnoses of ovarian cancer for thousands of women in the United States each year.

The week of Johanna’s diagnosis, every woman friend and family member we told about her situation was stunned not only to learn that their vigorously healthy friend had been diagnosed with advanced ovarian cancer. They were equally shocked to learn that symptoms like persistent bloating, heartburn, constipation and unexplained weight gain were common symptoms of this cancer. They hadn’t known it—or ever remembered their doctors mentioning these facts.

The same was true of every survivor I met at Johanna’s ovarian cancer support group meetings at Gilda’s Club and at the first national conference on ovarian cancer I attended in Washington, D.C. Over and over and over again, the stories were nearly identical to Johanna’s. These were health conscious women diagnosed at the advanced stages of ovarian cancer who learned only then, **ONLY AFTER THEY WERE DIAGNOSED**, that the symptoms they had been experiencing for months, sometimes for over a year, were common symptoms of deadly disease.

It’s not that these women ignored their symptoms for months. To the contrary. Like my sister, they sought medical attention for the symptoms. Many began with gastroenterologists for what seemed to be symptoms of a gastric origin. Others sought help from their internists, family physicians, or gynecologists. Sadly, no matter what type of physician they saw, all too often their symptoms were initially attributed to benign causes—perimenopause, menopause, irritable bowel syndrome or the weight gain that comes with aging and a slowing metabolism. Typically, their cancers were correctly diagnosed only during subsequent visits—either to the same or to other doctors for second or third opinions—after their symptoms had worsened and prior treatments they’d been given had proven ineffective.

Unfortunately, because these women were not familiar with the symptoms of ovarian cancer, they weren’t even in a position to ask their doctors to consider it as a possible cause of their symptoms early in the assessment process, during a first or second or even third visit, if their doctors didn’t automatically do so.

Frankly, I couldn’t believe how pervasive these circumstances were. The stories weren’t taking place in just one state or one region of the country. They were occurring nationwide. And they had been going on for years. I met family members of women diagnosed 10 and 20 years before Johanna whose loved ones had died—and whose original stories of delayed diagnosis were much like my sister’s.

It was obvious that something had to be done to eliminate the “knowledge gap” that had led to so much suffering and death for so many years. That’s why I proposed Johanna’s Law and have worked tirelessly for its passage the last two years in collaboration with a coalition of organizations representing cancer survivors, family members, physicians, nurses, and women.

As a compassionate nation known for valuing the lives of every citizen, we must act quickly to improve early detection and spare other American families the needless suffering and grief so many of our families have already endured. When natural disasters occur in this country or in others, as happened with the recent tsunami, we respond with a sense of urgency. We reach out with rescue and military personnel, with funds—we do whatever we can as quickly as we can to spare needless suffering and death.

And yet, for decades, this nation has allowed a tragic status quo that has caused so much immeasurable suffering to American women and their families to persist. Remember, we’ve lost 250,000 American women to these cancers in just the last 10 years. Those deaths left millions of grieving family members in their wake—and that’s just in the last ten years. And believe me, this situation has gone on for more than a single decade.

And the death toll is not declining. In just the last year, the annual death toll from gynecologic cancers has increased from 26,000 to 29,000. Part of that increase is due to a rise in the number of women dying from ovarian cancer. And since being over 50 years of age is a risk factor for both ovarian and uterine cancer, America's aging population may be in for an even higher death toll unless we do more to improve early detection of these cancers.

So, Senators, I am here today—on behalf of millions of grieving family members in this country—including my mother, brother, and Johanna's daughter who are here with me. I am here on behalf of tens of thousands of families whose loved ones are still courageously struggling to survive their diagnoses, trying desperately to beat the odds that were stacked against them from the moment they were diagnosed with an advanced stage of ovarian or other gynecologic cancers. I am here on their behalf asking—pleading really—with the members of the Subcommittee to help us. Help us adequately fund Johanna's Law so we can warn and educate America's 100+ million women at risk about the symptoms of gynecologic cancers before it's too late to save their lives.

We must act quickly. For every year we delay, nearly 30,000 more American women will die. Thousands more will be diagnosed at advanced stages and spend their next years struggling to survive. All of us who have heard the words "I'm sorry, it's cancer—and it's advanced"—and who have lived through the nightmare that followed those words, helplessly watching our loved ones endure surgery after surgery, round after round of chemotherapy and/or radiation—and then eventually run out of treatment options and die. All of us who have been devastated by these cancers are doing everything we can to spare other women and their families the same excruciating nightmare.

But we can't do it alone. We need your help and the help of all your colleagues in the Senate—to co-sponsor and pass Johanna's Law and to fund this long overdue legislation at the level requested.

We can't delay any longer. For every season we delay, for every 12 weeks—more than 7,000 American mothers, sisters, daughters, and other loved ones and dear friends, are forecast to die. More than 7,000. That's twice the number we lost on 9/11—every 12 weeks.

These deaths are not inevitable. Early detection can—and does save lives. And by passing and funding Johanna's Law adequately, we can begin to improve early detection by educating America's 100+ million women at risk for gynecologic cancers. Through the federal campaign of education it creates, Johanna's Law can provide the facts that help women recognize their symptoms as potentially cancer-related—so they can seek appropriate medical help quickly. We need women to be empowered with knowledge so they can ask their doctors' the right questions and make sure the most lethal cause of their symptoms—a gynecologic cancer—is considered first, not months later, after the cancer has progressed and the potential for long-term survival is grim.

Although many of us casually use the phrase "Ignorance is bliss," I assure you ignorance is NOT bliss when it comes to gynecologic cancers. Ignorance of the symptoms can be deadly. And for every year we leave America's 100 million women at risk uninformed about these cancers, we stand to lose another 30,000 of our precious family members and friends.

So please Senators, while we wait for much-needed research breakthroughs, like the one announced early this week, breakthroughs that we hope will provide vaccines or even better tools for early detection on asymptomatic women, please help us save more American families the needless anguish and grief so many of us have already endured. Please help us pass and fund Johanna's Law.

Senator Specter, let me close by thanking you again for your decision to sponsor Johanna's Law in the Senate and for holding this hearing today. God bless you for providing us this chance to share our experiences and to convey how urgently this legislation is needed.

SUPPORTING ORGANIZATIONS—JOHANNA'S LAW THE GYNECOLOGIC CANCER EDUCATION & AWARENESS ACT

American College of Obstetricians and Gynecologists; American Nurses Association; Association of Professors of Gynecology and Obstetrics Council; Association of Women's Health, Obstetric and Neonatal Nurses; CONVERSATIONS! The International Ovarian Cancer Connection; FORCE: Facing Our Risk of Cancer Empowered; Gilda's Club Worldwide; Gynecologic Cancer Foundation; National Cervical Cancer Coalition; National Council of Jewish Women; National Ovarian Cancer Coalition; Oncology Nursing Society; Ovarian Cancer National Alliance; SHARE: Self Help for Women with Breast and Ovarian Cancer; Society of Gynecologic Nurse

Oncologists; Society of Gynecologic Oncologists; Society of Gynecologic Surgeons; and Susan G. Komen Breast Cancer Foundation.

Senator SPECTER. Specifically how is it done?

Ms. Drescher, you have been an outspoken advocate for taking charge of your own health situation. You raise a good point that the doctor goes home to eat dinner with his family and you go home to eat your heart out.

What advice would you give people? Does everybody have to see seven doctors to get a second opinion?

Ms. DRESCHER. No. I think that, you know, there are many reasons why women do not get a first-stage diagnosis as a general rule. A manual pelvic exam is incomplete and really archaic and ineffective. And we are not offered even a simple transvaginal ultrasound to see what is going on in the uterus and the ovaries. I think that this is an insurance problem more than anything.

However, what we can do is arm women with knowledge. Through Johanna's Law, if we can make it a law that the doctor has to hand his patient, every woman in America a brochure that lists the earliest warning symptoms when the cancers are at their most curable and the tests that are available, then what happened to me and what happened to her sister might not happen because when doctor number one said, well, you are too young for a D&C, I would be able to say, well, wait a minute, whoa, Doc. You know what? It says here that I have classic symptoms for uterine cancer and why do not we do the D&C and rule out the uterine cancer before you start putting me on four different hormone replacement therapies, exacerbating my cancer with each new prescription over a 2-year period.

I was not in a position to do that. And I think that a very clear user-friendly check list that explains what the earliest symptoms are and the tests that you must demand to receive, then let women take control of their own bodies. Let them go to their employers and say I want these tests included in my basic health care plan. Let them go to their doctors and say, well, wait a minute. Why are you not giving me this test.

We put more energy into the buying, selling, and repairing of our automobiles than we do with our own bodies. Way back in the old days in the 20th century when we would go to our doctors and treat them like Gods and be like scared infants, list our symptoms and expect them to do everything on our behalf is over.

The business of health care has superseded the care of health. And if we do not all take control of our bodies and become partners with our doctors and learn that we need to be medical consumers out there, then we go walk around with one foot in the grave because we are completely victimized.

I say that Johanna's Law is a very relatively inexpensive way to reach women without having to go through all of the hassles of changing, making mandates and reaching out to deep-pocketed health insurance lobbyists. Just empower women with knowledge, give them a check list, a list, and start teaching them young, when they are in high school.

Senator SPECTER. Dr. von Eschenbach, I am going to have to excuse myself in 3 minutes, so could you give me a very short description as to what the National Cancer Institute could do to pro-

mote the objectives which Ms. Drescher and Ms. Silver are talking about, make information available to women at an early stage.

Dr. VON ESCHENBACH. Yes, Senator. We are actively engaged in communication strategies to do just that, but we are also trying to meet them, that as the awareness increases, we have the tools, more sophisticated tools to more accurately and precisely diagnose the cancers.

The problem we have today is that the tools that we have are still crude and not as specific as they need to be. So we have to go beyond PAP smears. We have to go beyond transvaginal ultrasound and CA125 for ovarian cancer, et cetera, and get to tests that are going to find these cancers much earlier at the molecular level.

That is within our grasp and that is what we are attempting to do so that we can complement what these two great women are trying to do in terms of getting the awareness and understanding out there. And the combination of both of those will save lives.

Senator SPECTER. Well, our subcommittee is going to be focusing on this issue beyond the introduction of the bill. Sometimes legislation takes a long time to move through the halls of Congress.

But we have an appropriations bill every year and later this year, we will structure an appropriations bill and that bill will focus on the issue of how to give women notice.

We may even be able to persuade Dr. von Eschenbach on his \$4.8 billion to make a little bigger allocation for this particular issue. That is not easy because he has got a lot of tugs in a lot of directions, but I think a very strong case has been made here.

It may be that a portion of the funding at NIH generally can go to education. The issue of early detection is not unique for this particular ailment.

I was talking to somebody with colon—whose husband died of colon cancer and while it is indelicate, a thought was raised about putting inside each toilet stall starting in Federal buildings a little notice if your stool has blood, do not think it is necessarily a hemorrhoid or I have some ideas about earlier detection of Hodgkin's lymphoma.

But early detection is the critical aspect and I think a very strong case has been made here today. And we will pursue it. Thank you all.

Ms. DRESCHER. Thank you.

Ms. SILVER. Thank you.

Dr. VON ESCHENBACH. Thank you, Senator.

CONCLUSION OF HEARING

Senator SPECTER. Thank you all very much for being here. That concludes our hearing.

[Whereupon, at 9:30 a.m., Wednesday, May 11, the hearing was concluded, and the subcommittee was recessed, to reconvene subject to the call of the Chair.]