Testimony

Ву

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Tο

New York City Committee on Health Resolution 380 Recognizing September As Ovarian Cancer Awareness Month in New York City

September 18, 2014

GOOD MORNING. MY NAME IS DR. NADEEM ABU-RUSTUM, AND I AM A GYNECOLOGIC ONCOLOGIST AND CHIEF OF THE GYNECOLOGY SERVICE AT MEMORIAL SLOAN KETTERING. THANK YOU FOR CONSIDERING THIS IMPORTANT RESOLUTION TO RAISE AWARENESS OF OVARIAN CANCER. I APPRECIATE THE OPPORTUNTY TO SHARE MY PERSPECTIVE.

AS SOMEONE WHO TREATS WOMEN WITH OVARIAN CANCER, I AM ALL-TOO FAMILIAR WITH THE DEVASTATING EFFECT OF THIS DISEASE.

OVARIAN CANCER IS THE NINTH MOST COMMON CANCER FOR WOMEN IN THE U.S., BUT IT IS ALSO ONE OF THE DEADLIEST. THE AMERICAN CANCER SOCIETY ESTIMATES THAT NEARLY 22 THOUSAND NEW CASES OF OVARIAN CANCER WILL BE DIAGNOSED THIS YEAR. MORE THAN 14 THOUSAND WOMEN WILL DIE FROM THIS DISEASE.

OVARIAN CANCER IS DEADLY BECAUSE IT IS A
"SILENT KILLER." IT DOES NOT CAUSE NOTICEABLE
SYMPTOMS IN ITS EARLY STAGES. BY THE TIME A WOMAN
NOTICES ANY OF SYMPTOMS AND GOES TO SEE HER
DOCTOR; IT IS TOO LATE TO SUCCESSFULLY TREAT HER.

SOME SYMPTOMS ARE SO COMMON THAT WOMEN MAY NOT PAY ATTENTION TO THEM. THESE INCLUDE BLOATING, WEIGHT LOSS, FEELING FULL, CONSTIPATION, FREQUENT URINATION, FATIGUE AND LOWER BACK PAIN.

MOST PEOPLE WOULD WRITE OFF THESE SYMPTOMS AS THE USUAL ACHES AND PAINS OF LIFE. BUT IT'S IMPORTANT FOR WOMEN TO KNOW WHAT IF SUCH SYMPTOMS PERSIST, IT'S CRITICAL THAT THEY SEE THEIR PHYSICIAN.

UNFORTUNATELY, WE CANNOT SCREEN ADEQUATELY FOR OVARIAN CANCER OR PREDICT FRM THE GENERAL POPULATION WHO MAY DEVELOP THIS DISEASE. SOME GENETIC TESTS AND FAMILY HISTORY MAY HELP DETERMINE WHETHER A WOMAN IS AT HIGHER THAN NORMAL RISK FOR OVARIAN CANCER, BUT THERE IS NO GUARANTEE.

OVARIAN CANCER AWARENESS MONTH OFFERS THE GYNECOLOGIC ONCOLOGY COMMUNITY THE OPPORTUNITY TO RAISE AWARENESS OF SYMPTOMS, AND TO HELP WOMEN KNOW THEIR RISK FACTORS. WOMEN WHO ARE AT INCREASED RISK INCLUDE THOSE WITH A FAMILY HISTORY OF BREAST OR OVARIAN CANCER OR A PERSONAL HISTORY OF BREAST CANCER. OBESITY, ENDOMETRIOSIS AND LATE PREGANCY ALSO MAY PUT WOMEN AT RISK. AND A WOMAN'S RISK INCREASES SIMPLY AS SHE GETS OLDER.

MANY WOMEN ARE NOT AWARE THAT THERE ARE SPECIALISTS WHO TREAT GYNECOLOGIC CANCERS SUCH AS OVARIAN CANCER. IT IS IMPORTANT FOR WOMEN TO SEEK A REFERRAL TO A GYNECOLOGIC ONCOLOGIST WHO IS FAMILIAR WITH THIS DISEASE AND TREATS THESE CANCERS ON A REGULAR BASIS. THIS IS THE PHYSICIAN

WHO WILL PERFORM SURGERY, PRESCRIBE
CHEMOTHERAPY, AND LEAD THE MULTIDISCIPLINARY
CANCER CARE TEAM.

AWARENESS EFFORTS IN NEW YORK CITY MAY LEAD TO EARLIER DIAGNOSES, APPROPRIATE REFERRAL AND MORE POSITIVE OUTCOMES FOR WOMEN WITH OVARIAN CANCER.

ON BEHALF OF MY PATIENTS, THEIR FAMILIES AND FRIENDS, AND THE GYENCOLOGIC CANCER CARE COMMUNITY, I URGE YOUR APPROVAL OF THE RESOLUTION AND AGAIN THANK YOU FOR YOUR CONSIDERATION.



THE HONORABLE TINA BROZMAN FOUNDATION FOR OVARIAN CANCER RESEARCH

Prepared remarks before the New York City Council in support of Res. 380 Resolution recognizing September as Ovarian Cancer Awareness Month in New York City

September 18, 2014

Contact information: Andrew Brozman, Tina's Wish Board Member andrew.brozman@cliffordchance.com info@tinabrozmanfoundation.org

212.878.8134

Good morning and thank you to the members of the Council for the opportunity to appear before you today in support of Resolution No. 380. My name is Andrew Brozman and I address you in my capacity as a member of the board of directors of the Honorable Tina Brozman Foundation for Ovarian Cancer Research, known as "Tina's Wish." Tina's Wish is focused on one thing – to fund research to promote the early detection and prevention of ovarian cancer.

Our mission was undertaken at the request of my wife shortly before she died of this insidious disease. We have served that mission for just six years but have grown to the third largest independent source of funding for ovarian cancer research in the country. Her charitable foundation has created the Tina Brozman Ovarian Cancer Research Consortium embracing five of the leading research institutions in the country – Memorial Sloan Kettering, Dana Farber, Penn, Yale and Johns Hopkins. MSK currently is acting as the coordinating center for a groundbreaking, collaborative, consortium-wide project of potentially great importance to our mission.

For the last forty years, government funding for ovarian cancer research has declined in real dollars. But the pace of deaths from late detection has not.

Unfortunately, with so few survivors of ovarian cancer, the cause has not been broadly championed. That is one of the reasons this Resolution is so appropriate.

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Tina's life and work were inextricably bound to the City of New York. She served as the Chief Judge of the United States Bankruptcy Court for the Southern District of New York with a view of the Statue of Liberty from her chambers. She practiced law here for almost thirty years, a career sadly interrupted. She raised and educated our children in this great metropolitan area. Finally, this is where she died of a disease that took hold with no warning and no means to beat back its unerring assault.

Without greater and more widespread knowledge about this stealthy killer, women will continue to die owing to late detection. It is fundamental to the protection of the women of the City of New York and elsewhere that a heightened level of knowledge and scrutiny is spread among the general public and the medical community.

It is unfortunate, even unacceptable, that a large portion of our physicians in New York and nationally know too little about, and fail to diagnose, this disease. It is essential that the doctors who treat the citizens of our city at publicly funded or managed medical facilities are equipped with both the knowledge, and, eventually, the means to seek out this hidden illness. They should be fluent in the symptomatology, understand the importance of intra-uterine ultrasounds and, until there is a better test, selectively monitor CA-125 levels, however imperfect the results might be. The women of our city should be counseled to be aware of and take charge of their bodies, to recognize the rather unremarkable symptoms of this disease, at least to the point of asking their physicians to consider the possibility of ovarian cancer.

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We and medical science have made great progress in fulfilling Tina's Wish – to save women from her own fate. But, we have much work ahead of us. That work requires the support of the broader citizenry of our city. The adoption by the Council of Resolution 380 will help serve that salutary purpose.



September 18, 2014

Tell Every Amazing Lady About Ovarian Cancer Louisa M. McGregor Ovarian Cancer Foundation also known as T.E.A.L. is proud to be here today to support the resolution recognizing September as Ovarian Cancer Awareness Month in New York City.

My sister Louisa and I started our 501C3 not for profit back in 2009, soon after she was diagnosed with Ovarian Cancer. Louisa lost her battle with the disease in 2011. Our foundation emerged from the urgency we felt to educate others about this disease and to fund the critical need for research.

Ovarian Cancer is extremely difficult to diagnose and most women are not informed about the disease. A lot of the general public believes that they are being tested for Ovarian Cancer during their annual exams, but the truth is that there's NO perfect screening test for Ovarian Cancer. The Pap test doesn't test for Ovarian Cancer and doctors lack the tools in order to find the disease early.

Ovarian Cancer does have signs and symptoms. These symptoms are sometimes vague like back pain or gastrointestinal problems, also making it difficult to diagnose. Ovarian Cancer has some risk factors including family or personal history of breast, colon or Ovarian Cancer. Until we have better early detection tools, all women should be educated about the disease so they might achieve early diagnosis and a more successful treatment.

Tell Every Amazing Lady's mission is to promote public awareness and education of the signs, symptoms and risk factors of Ovarian Cancer, while providing support to survivors and raising funds for research in order to find the cure for Ovarian Cancer. Teal is the color that symbolizes Ovarian Cancer hence our name Tell Every Amazing Lady or T.E.A.L.

Tell Every Amazing Lady is busy around New York City and beyond all year long promoting awareness and raising funds for research. We've turned Citi Field T.E.A.L. by helping to establish Ovarian Cancer Awareness Day at Citi Field, which is now an annual event. We've lit up Brooklyn Borough Hall the color Teal and created many public health awareness campaigns. You'll find us all across the city in schools, at health fairs, symposiums, and hospitals. We make our way through the medical community trying to reach out to Ovarian Cancer survivors to connect with them by providing them with resources and support.

We're also known for our annual T.E.A.L. Walk/Run, which takes place in Brooklyn's Prospect Park every September. The T.E.A.L. Walk has grown to include other cities including Highland Mills, NY, Litchfield, Connecticut and Fairfield, PA.

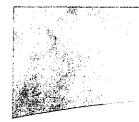
We've accomplished a lot but still function as a grassroots foundation working out of a home office with the help of volunteers and interns. We continue to have supporters who realize the need for what we are trying to achieve for this important women's health issue. We survive solely on public donations and community support. We are thrilled to have New York City recognizing the importance of Ovarian Cancer awareness.

Ovarian Cancer can happen at any age. It's the leading cause of death from Gynecological Cancers in the United States and is the fifth leading cause of cancer death among U.S. women. In the United States alone there will be 22,000 new cases of Ovarian Cancer this year and about 15,500 deaths. There are about 200,000 women currently battling Ovarian Cancer in the United States today. In New York City alone there are 589 new cases of Ovarian Cancer a year and 339 deaths a year. 41 women die a day in the United States from Ovarian Cancer. That's almost 2 deaths an hour.

With this resolution we hope to create a culture of awareness that has the potential to save women's lives ad start to change these statistics while creating hope for survivors of this deadly disease.

Sincerely,

Pamela Esposito-Amery Co Founder & CEO







TESTIMONY FROM KITTY SILVERMAN REGIONAL CHAPTER MANAGER, NEW YORK CITY NATIONAL OVARIAN CANCER COALITION

I wanted to thank the City Council's Committee on Health for inviting me to join you at this important hearing and for allowing me the opportunity to testify. The New York City Chapter of The National Ovarian Cancer Coalition is proud to lend its support to Resolution 380 recognizing September as Ovarian Cancer Awareness Month in New York City.

Ovarian cancer continues to be the deadliest of all gynecologic cancers and ranks fifth as the cause of cancer deaths in women. There is no test that detects ovarian cancer -- a pap test does **not** detect the disease. The symptoms of the disease are often subtle and can mimic unrelated conditions. For these reasons, ovarian cancer has been termed 'the silent killer' with most cases being diagnosed in later stages when the prognosis is poor.

According to the American Cancer Society, a woman's risk of getting ovarian cancer in her lifetime is approximately 1 in 71. This year, it is estimated that 21,980 women will receive a new diagnosis of ovarian cancer, and 14,270 will die. According to the National Cancer Institute, only 44% of women survive 5 years or more after being diagnosed with ovarian cancer. However when ovarian cancer is localized and diagnosed at an early stage, the five-year relative survival rate goes up to 92%. Unfortunately, only 15% of all ovarian cancers are diagnosed at this early stage.

Because there is no one test to detect ovarian cancer and because the disease is often diagnosed in later stages, raising awareness about the signs and symptoms of the disease is crucially important and can lead to improved survival rates.

The National Ovarian Cancer Coalition, a designated 501(c)(3) organization, was founded nearly 25 years ago. Through our more than 20 chapter offices nationwide, we have been

working hard in our communities to promote research, raise awareness, and provide education about ovarian cancer, and to improve the quality of life for survivors. The NOCC opened the doors of a new Regional New York City Office in March of this year, and we look forward to working with the City Council and all the other advocates here today in the fight against this insidious disease.

In his presidential proclamation issued this year for Ovarian Cancer Awareness Month,
President Obama called upon "citizens, government agencies, organizations, health care
providers, and research institutions to raise ovarian cancer awareness and continue helping
Americans live longer, healthier lives." New York City can play an important part in these
nationwide efforts and this resolution is a great step in helping to raise awareness and save
lives.



Testimony of Jacqueline Reinhard, Executive Director of SHARE

New York City Council Health Committee

September 18th, 2014

Good morning. My name is Jacqueline Reinhard and I am executive director of SHARE, a New York City-based non-profit organization that has been a lifeline for women diagnosed with cancer for 38 years.

We thank the Health Committee and sponsors of this resolution recognizing September as Ovarian Cancer Awareness Month in New York City.

We are energized to join you and our fellow ovarian cancer advocates in our sustained, important and unified mission – to promote awareness of the symptoms of ovarian cancer... to let all women know they are at risk and what they can do if ovarian cancer is suspected... and to educate and support women diagnosed with ovarian cancer... many of whom will thrive and go on to become powerful advocates to steer and fund the research we need to detect this deadly disease earlier and with better outcomes.

At SHARE we live this mission every day. And we couldn't do it without the ovarian cancer survivors who are the backbone of our free programs. Ovarian cancer survivors answer our toll-free ovarian helpline. Ovarian cancer survivors participate in workplace seminars to share their experiences and the latest evidence-based information. Ovarian cancer survivors facilitate our support groups, serve as patient advocates on research review panels and raise money for critical research.

It is now my pleasure to introduce one of our newest and busiest volunteers.

From the day she first called our helpline, it was clear that she would be a tremendous asset to our outreach efforts, notably our Ambassador Program, an

initiative created to take our message of symptom awareness and informed medical decision-making to the African American communities in the five boroughs.

Lisa....

FACT- 1:72 Women will be diagnosed with Ovarian Cancer in her lifetime FACT- Every 24 minutes marks another diagnosis of ovarian cancer in the United States

FACT- Ovarian Cancer is the 11th most common cancer in women

Ovarian Cancer devastates the lives of families to the tune of 21,980 yearly and this is one woman's story.

A vibrant otherwise healthy woman in her 40's begins to feel small "annoying" yet pervasive feelings of indigestion, loud gurgling from her stomach, and a general feeling of queasiness daily. Thinking she has a virus, she goes to the doctor and is tested for ulcers, acid reflux, and parasites. All tests come back negative. That was in March 2012.

Fast forward to August 2013...

Same otherwise healthy woman's stomach begins to swell as if she's several months pregnant. She goes to the emergency room and is diagnosed with Stage IV Ovarian Cancer, after several visits to both her gynecologist and primary care physician during this year-long period when she complained of the same symptoms from 2012.

Women get this news because the public lacks knowledge and education about ovarian cancer, the cancer that "whispers." Well, today we are here to make noise about this form of cancer. Ovarian cancer is no longer a whisper in part because of organizations like SHARE, who serve as a lifeline for women and their families throughout their "cancer journey."

In closing, against the odds, this same woman has lived to tell her story and advocate for women in underserved neighborhoods such as Jamaica, Queens. And, she decided to join the mighty force of SHARE as an Ambassador to educate, advocate, and champion the cause of ovarian cancer: THE #1 CAUSE OF GYNECOLOGIC CANCER DEATHS.

FACT: MY NAME IS LISA P. FRANKLIN and I am that woman. I am an Ovarian Cancer Survivor.

SHAREAM DOSSOLOT Program



Tree of Life by Keith Mallett

a SHARE initiative

providing outreach & information about breast & ovarian cancers for the African-American Community

SHARE

A NON-PROFIT ORGANIZATION FOR OVER 35 YEARS THAT HELPS
PEOPLE THROUGH THE BREAST AND OVARIAN CANCER JOURNEY
WITH THE UNIQUE SUPPORT OF SURVIVORS WHO'VE BEEN THERE

SHARE AMBASSADOR PROGRAM

Responding to the research on health disparities in communities of color in New York City, SHARE is expanding its mission of providing informed peer support, empowerment, and education to help more people affected by breast or ovarian cancer through an innovative Ambassador program.

This program is a grassroots strategy to reach medically under-served general populations in the African-American and Latino/Hispanic communities, especially in the boroughs of New York City.

The Ambassadors are breast and ovarian cancer survivors trained by SHARE. They build public awareness and health empowerment through educational presentations. These presentations encourage earlier detection, provide resources and information to promote access to diagnostic treatment and, if needed, cancer treatment for these diseases.

Crucial help comes through various services ...

- Breast, Ovarian, and Caregiver Helplines
- Support Groups
- Educational Programs
- Caregiver Circle for Family and Friends

- Advocacy Initiatives
- Survivor Patient Navigator
- LatinaSHARE
- Pink & Teal Seminars
 In The Corporate Workplace

If you would like a SHARE Ambassador to make a presentation in your community, PLEASE CALL 212-937-5586.

BREAST CANCER MYTHS

"I've heard that cancer only afflicts people whose family members have or have had cancer."

FACT: Breast cancer is not always hereditary. Most breast cancer cases occur in people who have no family history with breast cancer.

"If I have cancer I'll know it because it will hurt. That's why I only have to be tested for cancer if I have pain. Right?"

FACT: Only in very rare cases does breast cancer cause pain. That's why you need to become familiar with how your breasts look and feel. If you notice any change, you should notify your doctor right away.

"Are there herbs that can cure cancer?"

FACT: Some cancer patients take herbs hoping they will help cure cancer but scientific studies have not found any evidence to support this.

DID YOU KNOW?

- Breast cancer is the most commonly diagnosed cancer among African-American women.
- Breast cancer mortality is 41% higher in African-American women than in white women.
- In African-American women under 40, breast cancer is more common than in white women.

BREAST CANCER SYMPTOMS

- A lump in the breast or underarm (armpit)
- Thickening or swelling of any part of the breast
- Irritation or dimpling

 (i.e. like the skin of an orange)
 or puckering of breast skin
- > Redness or flaky skin in the nipple area (areala) or on the breast
- Breast is warm, red and swollenInflammatory Breast Cancer
- Any change in the size or the shape of the breast
- Nipple turned inward (i.e. into the breast) or pain in the nipple area that wasn't there before
- Nipple discharge other than breast milk, including blood
- Pain in any part of the breast

SHAREAmbassac

WHAT IS BREAST CANCER?

🕽 reast cancer is an abnormal growth of cells that originates in breast tissue. There are several types of breast cancer. The most $oldsymbol{ extstyle}$ common kinds of breast cancer form in the milk ducts or lobules, which are the glands that make milk. Although it's rare, men can get breast cancer, too.

WHAT IS OVARIAN CANCER?

varian cancer is a disease that forms in tissues of the ovary or fallopian tubes. It is unclear what causes it. The American Cancer Society estimates that in 2014, about 22,000 new cases of ovarian cancer will be diagnosed and more than 14,000 women will die of ovarian cancer in the United States. Approximately 75% of ovarian cases are diagnosed at an advanced stage when the cancer has spread beyond the ovaries. For this reason, it is necessary to know the symptoms of ovarian cancer to detect it at an early stage.

RISK FACTORS

Anything that increases your chance of getting a disease is called a risk factor. People who think they may be at risk should discuss this with their doctor. Risk factors for breast and ovarian cancers include the following:

AGE λ

Cancer risks increases with age.

FAMILY HISTORY & &

Having a first degree relative li.e., mother, father, sister, brother, or daughter) can double a woman's risk.

GENETICS 👗 🔏

Presence of abnormalities in certain genes called BRCA1 or BRCA2 increase the risk of breast and ovarian cancer.

NUTRITION & DIET 🔏 🔏

Diets high in fats, especially hydrogenated fats and trans fatty acids increase one's risk.

OBESITY & &



Has been found to increase breast cancer risk, especially for women after menopause.

MENSTRUAL HISTORY 🔏 🧸



Women who begin menstruating at an early age (before 12), and women who reach menopause after age 55 are at greater risk.

DRINKING ALCOHOL 🔏



A few drinks a week is linked to an increased risk of breast cancer.

DELAYED CHILDBIRTH 🔏 🧸



Having a child after 30, or never having a child, increases a woman's risk.

PERSONAL CANCER HISTORY 🔏



Having had breast cancer increases your risk of developing a new cancer. Having breast cancer before 45 increases your risk of ovarian cancer.

REPRODUCTIVE HISTORY 🐰

Your risk is higher if you have never had children or have a history of difficulty getting pregnant.



HORMONE & ESTROGEN THERAPY Studies suggest women using estrogen after menopause may have an increased risk of developing ovarian cancer.

- Bloating
- Pelvic or abdominal pain
- feeling full quickly
- Ultiniois/symiptions: (brgeney or frequency)

- Additional symptoms may include fatigue, indigestion, back pain, constipation, pain with intercourse, or menstrual irregularities
- Vague but persistent aastrointestinal upsets such as aas or nousea. or unexplained weight loss or weight gain, particularly weight gain in the abdominal region, may also indicate ovarian cancer
- see a gynecoloalst







"I wanted to acknowledge the two speakers that shared their personal stories. I am touched by their passion, knowledge, and commitment in educating others. They are wonderfull"

- Audience member at a SHARE Ambassador presentation

HELPFUL RESOURCES

African American Breast Cancer Alliance

www.aabcainc.org

National Breast Cancer Coalition

www.breastcancerdeadline2020.org 800.622.2838

National Cancer Institute's Cancer Information Service

800.4.CANCER

Department of Health & Human Services

Public assistance & food stamps www.os,dhhs.gov

Patient Access Network Foundation

www.panfoundation.org 866.316.PANF [7263]

MealsOnWheels

www.mowaa.org 703.548.8024

Patient Advocate Foundation

www.patientadvocate.org 757.837.6668

SHARE

Supporting those facing breast and ovarian cancers, including family caregivers

www.sharecancersupport.org 844-ASK-SHARE

Patient Advocate Foundation Co-Pay Relief

www.copays.org 757.952.0118

Social Security

www.ssa.gov 800.772.1213

Medicare and Medicaid

www.cms.hhs.gov 877.267.2323

Healthwell Foundation

www.healthwellfoundation.org 800.675.8416

Look Good Feel Better

www.lookgoodfeelbetter.org 1-800-395-LOOK U.S. Administration on Aging Benefits for Older Adults

www.eldercare.gov 800.677.1116

CancerCare

www.cancercare.org 800.813.HOPE

American Cancer Society

www.cancer.org 1.800.ACS.2345

CancerCare Co-Payment Assistance Foundation

www.cancercarecopay.org 866.55.COPAY

Partnership for Prescription Assistance (PPA)

www.pparx.org 888-4-PPA-NOW [888-477-2669]

Ovarian Cancer National Alliance

www.ovariancancer.org 1-866-399-6262

CALL SHARE FOR MORE INFORMATION AND RESOURCES: 844-ASK-SHARE (844-275-7427)

DEDICATED EXPERIENCED SUPPORT

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SHARE
1501 Broadway, Suite 704A
New York, NY 10036
212.719.0364
844-ASK-SHARE
info@sharecancersupport.org
www.sharecancersupport.org

HELPLINES

Breast Cancer: 866.891.2392 Ovarian Cancer: 866.537.4273 Caregiver: 855.498.5523

FOLLOW US twitter.com/SHAREing facebook.com/SHARECancerSupport

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