Survivors Teaching Students: Saving Women’s Lives®
Presenter Training
Training Objectives

1. Understand your role as presenter
2. Know and understand the key messages of a presentation and how your story fits into the presentation
3. Understand the flow of a presentation
4. Apply program guidelines in develop your story
The goal of the program is to enhance health professional students’ understanding of ovarian cancer symptoms and risk factors in order to facilitate earlier diagnosis and detection.

We achieve this goal by bringing ovarian cancer survivors and caregivers into the classrooms of health professional students.
The STS Team®

Vice President, Scientific Affairs and Programs
Ovarian Cancer Research Fund Alliance

National Program Director
Regional Coordinators
Area Facilitators

Manager, Grants and Programs
OCRFA

International Programs

On-Site Facilitators/ Presenters
The backbone of the program

OCRFA
Ovarian Cancer Research Fund Alliance
Presentation Format

Each presentation lasts about an hour:

- Introduction by facilitator – 5 minutes
- Administer pre-evaluations – 5 minutes
- Presenter #1 – 5 to 7 minutes
- Presenter #2 – 5 to 7 minutes
- Presenter #3 – 5 to 7 minutes
- Note: Facilitator ties stories together with fact-based presentation
- Questions and answers – 15 to 20 minutes
- Closing and post-evaluations – 5 minutes
KEY MESSAGES

- Ovarian cancer is the most lethal gynecologic cancer
- The majority of women are diagnosed at advanced stages
- When detected in early stage, the survival rates greatly improve
- There is no screening test for ovarian cancer
- Risk factors
- Symptoms
- Referral to a gynecologic oncologist

Each presenter tells her story, emphasizing only the key messages (if any) that apply to her situation
Risk Factors

**Increased Risk**
- Family/personal history of breast, ovarian, colon or uterine cancer
- Certain genetic mutations
- Hormone replacement
- More menstrual cycles
- Increased age
- Obesity

**Decreased Risk**
- Removal of ovaries/fallopian tubes
- Childbearing
- Breastfeeding
- Oral contraceptive use
- Tubal ligation/salpingectomy
Symptoms

- Bloating
- Urinary frequency or urgency
- Pelvic or abdominal pain
- Difficulty eating or feeling full quickly

Ovarian cancer should be considered when the symptoms:

- Occur frequently, approximately 12 times in a month
- Are persistent over the course of 2 or more weeks
- Are unusual for her and are unexplained by other causes
When Ovarian Cancer is Suspected

The following should be performed:

- Pelvic and rectal examination
- Transvaginal or pelvic ultrasound
- CA-125 blood test if an irregularity is found on the above exams or if the patient is symptomatic
- Refer patient to a gynecologic oncologist - Studies have shown that women diagnosed with ovarian cancer generally have a better likelihood of prolonged survival if treated by a gynecologic oncologist
Visit the Survivors Teaching Students Toolkit at [https://ocrfa.org/get-involved/survivors-teaching-students/sts-toolkit/](https://ocrfa.org/get-involved/survivors-teaching-students/sts-toolkit/)

- Password  @stsocna
- Facilitator
- Regional Coordinator
- National Program Director
Preparing to Share Your Story

- Utilize “Preparing to Share Your Story” Worksheet found in the STS Toolkit to organize your thoughts
- You should be able to tell your story in 5 to 7 minutes (approximately 1000 words)
- It is YOUR story – try to involve your audience by including a little personal information
- Remember the program messages and guidelines
A note for Caregivers

Caregivers may share the story of a woman in their life who is affected by ovarian cancer

- A woman in treatment who wants to share her story but does not feel well enough (written permission required)
- A family member who has died of the disease provided the caregiver knows the accurate medical history. This story is told from the perspective of the caregiver.
A presenter

- May share medical information related to your story but may **not** provide medical advice
- Should not recommend a particular type of surgery or other treatment
- Should not suggest where a patient should go for medical care or recommend a specific doctor or facility
- Should never use the name of a physician or other health professional or medical facility
Start with your name and pertinent facts about where you were in your life when diagnosed – Susan Leighton, husband newly retired from the military, daughter graduating from high school.

How old you were when diagnosed – 48 years

A little about your family, work, activities, hobbies – worked from home, husband started second career, genealogy, crafts, traveling

The state of your general health at the time you were diagnosed – good health although overweight
Did you have symptoms. If so, what were they (mention any and all symptoms you had) and how long did you have them? **Bloating, noticed in May 1997, diarrhea and indigestion**

What kind of doctor did you see? **Family Practice**

Were you diagnosed with something else first only later to be diagnosed with ovarian cancer? **Irritable bowel syndrome and acid reflux disease**

What tests were done? When symptoms did not improve, gallbladder ultrasound, referred to GYN and then GYN/oncologist. **CA-125, pelvic–rectal exam, CT scan**

Did you have surgery and, if yes, what was done? **Suboptimal debulking, removal of ovaries, masses, omentum, numerous spots of cancer on peritoneum, previous partial hysterectomy.**

How did your physician deliver the news of your diagnosis? Is there something you wish he/she would have done differently? **GYN said “I am 99% sure you have ovarian cancer and women die from this.” GYN/oncologist sat down with my husband and I and had a discussion about the diagnosis and what it meant.**

If you want to share how you felt when diagnosed or how your family was affected by the diagnosis, this would be a good place to include that information. **Impact on daughter who was leaving for college**
What was the stage of your cancer? *Stage IIIC*

Did you have chemotherapy, and, and if so, what type and how many treatments? This is the time to talk about side effects of the surgery and chemotherapy. *Six cycles of carboplatin and Taxol. Felt good for two days and had a “Susan has left the building day,” muscle aches, tired, GI upset, neuropathy, hair loss*

How did treatment affect your life? Were you able to continue working? Were you limited in your activities? How did it affect your family? *Worked through treatment, difficult on daughter*
How many months or years was your cancer in remission? 18 months

Where did the cancer recur? Pelvic tumor (benign), wait and watch, large chest tumor

What treatment did you undergo? Wait and watch, thoracotomy

Are you currently in treatment? No. NED x 12 years, stage I invasive ductal breast cancer 2013

Was or is treatment for the recurrence more difficult than your original treatment? How? Worse, fear of where it was. Chest surgery way more difficult than previous abdominal surgeries
What has life been like since you were diagnosed? *Good with a new focus*

Have you had long term side effects of your treatment? *Neuropathy, bone loss, dental problems, menopausal symptoms secondary to medications*


What is your family's new normal? *We came through it just fine. Want Mom to add new color to her wardrobe*
Your Story

- After you gather your facts weave them into a written story
- Approximately 1000 words
- Take it for a test drive. Do you like the way it sounds? Can you deliver it in no more than 7 minutes?
- Send it to your Area Facilitator or Regional Coordinator for editing.
Shaping Your Story

Your Area Facilitator, Regional Coordinator or National Program Director will read your story and make suggestions if needed. Discuss suggestions with them and make revisions as needed.

PRACTICE, PRACTICE, PRACTICE

Update your story periodically as changes happen with the disease and in life.
My Story
A few Last Comments

Emotions – Anger and Sadness

Props and photographs

Handouts
Fielding Questions

- Only if you are comfortable answering
- Be mindful of time
- Share the wealth
- Staying after the session
Thank You for Sharing Your Story!