

OCRA

ovarian cancer research alliance

Survivors Teaching Students[®]

An Ovarian Cancer Education Program for
Health Professional Students

Handbook for Program Volunteers 2023

Revised February 2023

Dear Program Volunteer:

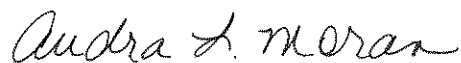
Welcome to Survivors Teaching Students[®], a program of Ovarian Cancer Research Alliance! You are joining an innovative and critical effort to educate students in health professional programs nationwide about ovarian cancer. The goal of the program is to enhance students' understanding of ovarian cancer, its risk factors and symptoms in order to facilitate diagnosis, appropriate treatment and care.

As you are aware, the majority of ovarian cancer cases are not diagnosed until the disease is advanced and survival is compromised. Symptoms are vague, and often do not appear until the disease is advanced, and too often those at high-risk are not identified and monitored. Survivors Teaching Students[®] brings the faces and voices of ovarian cancer survivors and caregivers into the classrooms of students of healthcare professions to teach them about individual's experiences with the disease. We are in a unique position to help students become more sensitive to the risk factors and symptoms of ovarian cancer so that when they go into practice, they will consider ovarian cancer in their differential diagnosis.

This handbook will provide you with the information you need to conduct the Survivors Teaching Students[®] program in your community. These materials are to be used in conjunction with training by a representative of Ovarian Cancer Research Alliance, and will aid you in implementing and maintaining your local Survivors Teaching Students[®] program. If you have questions regarding the program, please contact Ovarian Cancer Research Alliance at (212) 268-1002.

Thank you so much for your participation and commitment. You are a valuable partner and part of an international network of dedicated individuals who share your passion. Ovarian Cancer Research Alliance commends you for your efforts.

Sincerely yours,

A handwritten signature in cursive script that reads "Audra L. Moran".

Audra Moran
President and Chief Executive Officer
Ovarian Cancer Research Alliance

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Survivors Teaching Students® (STS) Program Overview

Background

Ovarian cancer is the fifth leading cause of cancer-related death among individuals assigned female at birth in the United States and causes more deaths than any other gynecologic cancer. The majority of cases are not diagnosed until the disease is far advanced and survival is compromised. Too often those who are at high risk are not identified or monitored.

To address this issue, Ovarian Cancer Research Alliance conducts the Survivors Teaching Students® (STS) program. The goal of the program is to enhance students' understanding of ovarian cancer, its risk factors and symptoms in order to facilitate diagnosis and appropriate treatment and care.

Program Description

STS achieves its goal by bringing survivors and caregivers into the classrooms of medical and nursing schools, nurse practitioner and physician assistant programs, and other allied health programs. These volunteers share their stories and key information on the disease.

A presentation lasts approximately one hour during which STS members deliver crucial messages about the risk factors and symptoms of ovarian cancer. They also explain appropriate referrals for those suspected of having ovarian cancer.

Participants

Any person diagnosed with ovarian cancer, fallopian tube cancer or primary peritoneal carcinoma or a caregiver of an individual diagnosed with one of these cancers is eligible to participate in the program. A caregiver is defined as someone who was or is closely involved in a patient's cancer journey and can knowledgeably speak to that experience from diagnosis through treatment. OCRA reserves the right to decline participation of a caregiver if his/her/their story does not compliment the presentation. Presenters must adhere to program guidelines and time limits. Volunteers who cannot comply with program guidelines will not be allowed to present.

Throughout this handbook and other STS materials the phrase "ovarian cancer" is defined to include ovarian cancers, fallopian tube cancer, and primary peritoneal carcinoma (PPC) unless otherwise specified.

Legal Disclaimer

The program is wholly owned and operated by Ovarian Cancer Research Alliance. All program materials are copyrighted. The term "Survivors Teaching Students" is a registered trademark of Ovarian Cancer Research Alliance. Unauthorized use of materials or trademarks will be prosecuted to the fullest extent of the law.

Program Values and Privacy Policies

Ovarian Cancer Research Alliance (OCRA's) Survivors Teaching Students® (STS) Program is dedicated to the health and wellness of the ovarian cancer patient community. Members of the STS team are at the forefront of educating future health professionals about ovarian cancer, its risk factors and symptoms. The work of our STS team reflects on OCRA as an organization and the ovarian cancer community.

Participants in the STS program come from across the nation and bring their diverse experiences with them. We think these experiences should be honored and appreciated as we do our work to educate future health professionals.

There are some key values that we expect all STS team members to recognize and uphold as they participate in STS activities to carry forward our collective goal of increasing ovarian cancer awareness and improving survivorship for individuals diagnosed with ovarian cancer.

Key Values:

- **Respect for all people.**

OCRA maintains professionalism and civility in all proceedings. As the only national ovarian cancer advocacy organization, OCRA interacts with a broad range of stakeholders including medical professionals, healthcare students, researchers, industry representatives, elected officials, as well as other like-minded advocacy organizations of all sizes at national and state levels.

- In the classrooms of healthcare students, STS team members are drivers of our awareness efforts. As such, OCRA expects that all stakeholders will be treated equally and with respect.

All of our experiences with ovarian cancer are different and valuable. As we come together and share our stories, we recognize that before any of us were touched by ovarian cancer, we were people with different identities, backgrounds, thoughts, and contributions.

- It is incumbent on STS team members to be sensitive and respectful of everyone's varied lived experiences.

- **Foster culture of inclusion.**

At OCRA, we do not tolerate or condone words or actions of discrimination, prejudice, or bigotry towards any person or group of individuals. OCRA does not and shall not discriminate on the basis of race, color, religion (creed), gender, gender expression, age, national origin (ancestry), disability, marital status, sexual orientation, political affiliation or military status, in any of its activities or operations.

- STS team members represent communities all across the nation and should feel respected and supported in any OCRA-affiliated space.

- As participants in the program, team members agree to not act in ways that threaten any member of the community's safety or undermine the lived experiences of others in relation to their identity and personal beliefs.

- **Active Engagement and Participation.**

To get the most out of the program, every STS team member will complete training and submit their written story to their Area Facilitator, Regional Coordinator, and/or National Program Director prior to participating in a presentation.

- We encourage team members to participate in team calls and review all updated/ revised program materials in a timely fashion.

- **Commitment to Equitable Outcomes for All Patients.**

Quality healthcare is fundamental to treating ovarian cancer patients and standard of care treatment is associated with improved survivorship. Unfortunately, not every patient has access to affordable standard of care treatment, and disparities resulting from geography, socioeconomic status, language barriers, and race all impact outcomes for members of our community. OCRA firmly believes that all individuals diagnosed with ovarian cancer across the country deserve treatment that meets or exceeds the standard-of-care—regardless of any other factor.

- As team members of STS, we work towards the ultimate goal that every ovarian cancer patient gets the best care possible.

Privacy:

OCRA recognizes that STS team members are sharing their personal stories in a public environment. Team members may choose to identify themselves by first name only or by a pseudonym. Team members will respect the privacy of other team members in all settings. Stories heard are not to be repeated outside of the presentation. Your story is yours alone to share.

OCRA shall collect identifying information to include name, address, email address, and phone number from each team member. OCRA will collect demographic information including date of diagnosis, stage of cancer at diagnosis, age at diagnosis and current age, race/ethnicity, gender, status of genetic counseling and/or testing, genetic mutation status, whether seen by a gynecologic oncologist, distance to major medical center, clinical trial participation, and unique story facts from each team member. Failure to provide demographic information shall not disqualify a member from participating in the STS program.

The use of Identifying Information collected shall be limited to team communication and to assist OCRA in development of diverse panels. Anonymized demographic data may be used by OCRA for statistical analysis for research. All information collected is for the exclusive use of OCRA in conjunction with administration of the STS Program. OCRA does not share or sell information obtained.

Written stories submitted to Area Facilitators, Regional Coordinators, and/or the National Program Director will be stored in a secure location, will not be shared with others, and will be destroyed when the individual leaves the program. An individual in possession of such stories who leaves their position as Area Facilitator or Regional Coordinator will ensure the stories are forwarded to the National Program Director. Upon leaving her position, the National Program Director will ensure that all documents related to team members will be forwarded to OCRA.

Use of photo and video materials:

- On occasion, photos may be taken during STS activities. It is understood that the Ovarian Cancer Research Alliance shall have exclusive reproduction and usage rights to the images for purposes relating to awareness, education and advocacy, consistent with the organization's mission. Individuals will not be identified by name in images without express written consent prior to publication. By participating in STS, members release OCRA from any and all claims in connection with the use of with the use of the images obtained by OCRA, including, without limitation, any and all claims of libel, false light and/or copyright infringement.
- On occasion, schools may seek permission to record a virtual presentation to be used throughout a school term. OCRA will exercise a written agreement with the school to ensure protection of the team members' privacy. Each team member will exercise a video/audio release for each such recorded presentation before recording takes place.
- On occasion, the team may be asked to present to the staff of a corporate sponsor. These presentations will be coordinated with the National Program Director and OCRA. If the sponsor asks to record the presentation, the NPD will have them exercise a written agreement to ensure protection on the team members' privacy. Each team member will exercise a video/audio release for each such recorded presentation before recording takes place.

SURVIVORS TEACHING STUDENTS (STS)[®]

The Presentation

STS presentations are not the typical class health professional students will encounter in their curriculum. We are not professors and it is not our job to teach the biology of ovarian cancer. We use a unique educational model to help students understand the challenges of diagnosing ovarian cancer, a disease for which there is no reliable detection test. Each STS member has a Ph.D. in ovarian cancer, a personal history of the disease. While we cannot teach the students the details of cancer staging, the differences in cell types or which chemotherapy is most effective for a particular patient's cancer, we do provide key messages which will hopefully increase the number of health care providers who recognize the risk factors and symptoms of ovarian cancer.

- Each presentation lasts approximately one hour adhering to the following schedule:
 - Introduction - 5 minutes (On-site Facilitator)
 - Students complete the first portion of the online evaluation – 5 minutes (On-site Facilitator)
 - Fact-based presentation delivering the key messages (On-Site Facilitator) interspersed with stories shared by three presenters - 25 – 30 minutes
 - Question and Answer session - 10-15 minutes (On-site facilitator will manage Q&A and presenters will participate if comfortable)
 - Closing - 5 minutes (On-Site Facilitator)
 - Students complete the remainder of the online evaluation; facilitator distributes handouts – 5 minutes (On-site Facilitator)
- The presentation typically includes three presenters and an on-site facilitator (a presenter may also serve as the facilitator).
- The On-Site facilitator is responsible for ensuring the key messages are delivered using the fact-based Power Point presentation provided by the STS program.
- Students should gain insights into listening to patient concerns and become sensitized to the psychosocial aspects of ovarian cancer, as well as the diagnostic and treatment process.
- After the presentation, the facilitator will open a dialogue between the presenters and students to enable direct and substantive interaction.
- The STS presentation is offered free of charge to health professional schools.
- As you conduct the program in your community, certain aspects of the presentation may need to be adapted or evolve to best serve the students and schools in your area. No changes will be made to STS program materials (including the Power Point or script) without approval of the National Program Director (NPD).

Only materials branded by Ovarian Cancer Research Alliance are to be distributed at presentations.

Virtual Presentations

Please see "Virtual Presentation Instructions" in the STS Toolkit for further information.

Key Messages

To achieve the goal of STS, we must ensure that students leave the presentation having learned key messages. All the points listed here are important; **the messages in bold font are critical take-aways.** It is not expected that every presenter address each of these points, but each message should be conveyed at least once in the course of the one-hour presentation.) These key messages are provided in the fact-based presentation and reinforced by our stories.

- Ovarian cancer is the most lethal gynecologic cancer and the fifth leading cause of cancer death among those assigned female at birth in the United States.
- **Anyone assigned female at birth (born with ovaries) is at risk of developing ovarian cancer.**
- The majority of patients are diagnosed when ovarian cancer is in an advanced stage.
- **There is no reliable detection test for ovarian cancer.**
- **Factors associated with an increased risk of ovarian cancer include a family history of breast, colon, uterine or ovarian cancer, increasing age, certain genetic mutations, being post-menopausal, increased number of menstrual cycles, obesity, endometriosis, and a personal history of breast, uterine, colon or rectal cancer. Protective factors associated with a decreased risk of ovarian cancer include oral contraceptive use, pregnancy, breastfeeding, and having a tubal ligation, removal of the ovaries or an opportunistic salpingectomy (removal of fallopian tubes).**
- Removal of ovaries does not eliminate the risk of developing primary peritoneal carcinoma (PPC).
- **Ovarian cancer may present with symptoms at different points in its course. Symptoms often do not appear until the disease is advanced. Symptom recognition could potentially reduce the time to diagnosis from presentation allowing time for referral to specialists, less complicated surgery, and an easier course of treatment dependent on the health of the patient at presentation. Studies have shown that these symptoms are much more likely to occur in individuals with ovarian cancer than in others in the general population:**
 - **Bloating**
 - **Pelvic or abdominal pain**
 - **Difficulty eating or feeling full quickly**
 - **Urinary symptoms (urgency or frequency)**
- Other symptoms often reported by patients with ovarian cancer include fatigue, indigestion, back pain, pain with intercourse, constipation and menstrual irregularities. These symptoms are not as useful in identifying ovarian cancer as they are found just as often in others who do not have the disease.
- Ovarian cancer may be suspected when these or other symptoms
 - occur frequently, approximately 12 times in a month
 - are persistent over the course of 2 or more weeks
 - are unusual and unexplained by other causes.
- Ovarian cancer should remain in the differential diagnosis until it is proven or definitively ruled out.
- If the symptoms suggest ovarian cancer, three examinations/tests should be performed: a complete pelvic exam, a rectal examination; a transvaginal ultrasound; and a CA-125 blood test.
- **If ovarian cancer is suspected, the patient should be referred to a gynecologic oncologist.**

Survivors Teaching Students® Presentation Team

Role of the Presenter

The stories of our presenters, survivors and their caregivers affected by ovarian cancer, are the heart of our program. These volunteers commit to share their stories with students to provide the context for our fact-based presentations. Training is provided to prepare presenters to tell their stories in a concise manner conveying both the facts and relevant physical and psychosocial impact of ovarian cancer. Working within guidelines, presenters will work to share their story in their own words.

Training

New volunteers can access training materials in the STS toolkit located at ocrahope.org/sts-toolkit. To access the toolkit, enter the toolkit key @stsocna

From the toolkit, volunteers should access the following program resources and materials if not provided previously:

- Handbook for Program Volunteers 2023
- Quick Start Training Guide
- Preparing to Share Your Story Worksheet
- Personal story slide template
- New member form

Volunteers will complete the following steps:

1. Review the "Quick Start Training Guide" and relevant materials in this Handbook.
2. Watch the "Presenter Training Webinar"
3. Review "Preparing to Share Your Story" Worksheet and begin writing your story (more detailed instructions below).
4. Reach out to your Area Facilitator or Regional Coordinator at any time with questions.

*NOTE: On some occasions Area Facilitators or Regional Coordinators may choose to host an on-site or virtual training. This may occur when a new team is being established or when there are several volunteers to complete training at one time. If you are interested in participating in this type of training session, please tell your Area Facilitator or Regional Coordinator. Some volunteers who complete the online training find it helpful to attend an on-site training session later. Volunteers may also be offered the opportunity to attend an actual STS presentation before being scheduled to present for the first time.

Writing your story

After completing training as described above, volunteers will write their story keeping the program guidelines in mind. Using the "Preparing to Share Your Story Worksheet" is a great place to start. Keep in mind that your story should take approximately 7 minutes to deliver at a normal rate of speech. This is approximately 1000 words when spoken at a normal rate of speech. When you have written your story, forward it to either your Area Facilitator or Regional Coordinator as directed for editing. The purpose of editing is to ensure that program guidelines are followed and that your story can be delivered in the time allotted. Editing is NOT done to change YOUR story, only to ensure that it helps convey the key messages of the program and adheres to program guidelines. Your Area Facilitator or Regional Coordinator will work with you to make sure that you are comfortable with the edits and your completed version.

Preparation of Personal Presentation Slides

Presenters may choose to prepare one personal story timeline slide to be displayed while they are sharing their story. These slides are to be prepared using the template provided in the toolkit. Presenters must provide these slides to the On-Site Facilitator PRIOR to the presentation. Using slides for personal stories is entirely optional. The slide can be a great tool in helping a presenter stay on story, and students sometimes find it easier to follow the story when accompanied with visual cues.

Criteria for an Effective Story

- Make it personal: use your own words and give audience members a few details about yourself (such as your age at diagnosis, marital status, children, career, etc.). For privacy, you may choose to give only your first name or use a pseudonym.
- Keep it simple: use plain language in your presentation. You may want to define medical terms or explain acronyms.
- Make sure the information you present is medically accurate.
- Work in a few of the key messages if they are relevant to your story.

Medical information versus medical advice

The presenter's role is to share medical information that relates to their individual story. Medical information is objective and consists of facts found in approved literature. It is information available to anyone seeking general knowledge about a disease and how it is treated. Medical advice consists of comments and suggestions that personalize medical information and makes a recommendation about what the audience should or should not do regarding medical choices.

A presenter MUST NOT:

- Recommend a particular type of surgery or other treatment.
- Suggest where a patient should go for medical care.
- Recommend or review a specific doctor or facility.
- Use the name of a physician or facility.
- Offer medical advice or medical instruction.

Submitting Your New Member Form

Once you have completed training and finalized your story, submit your STS New Member Form. This form is available in the STS toolkit under "New Volunteer Resources."

Travel Expenses Reimbursement

Participants may submit reimbursement requests for mileage to and from an in-person presentation, parking, or other transportation (taxi, bus, subway). Maximum reimbursement will be the equivalent of mileage up to 200 miles round trip per presentation. Travel reimbursement request form is available in the STS toolkit under "Current STS Team Member Resources"

WELCOME TO THE SURVIVORS TEACHING STUDENTS® TEAM

NOTE: Ovarian Cancer Research Alliance reserves the right to remove a presenter for failure to complete assigned tasks or failure to adhere to program guidelines.

Role of the On-Site Facilitator

One volunteer will serve as On-Site Facilitator for each presentation. The On-Site Facilitator must complete additional facilitator training prior to acting in this capacity.

Training

In addition to completing the presenter's training and writing their story, volunteers who will serve as On-Site Facilitators **MUST** read the following sections of this Handbook: Role of the Presenter, Role of the On-site Facilitator, Program Structure. Additionally, the volunteer **MUST** view the STS presentation in the toolkit. The toolkit is found at ocrahope.org/sts-toolkit . To access the toolkit, enter the toolkit key @stsocna. Your Area Facilitator and Regional Coordinator are available for questions and concerns and will certify completion of training.

There are **five** tasks for which the On-Site Facilitator is responsible:

- Opening and closing the presentation
- Ensuring that key messages are delivered
- Facilitating the question-and-answer session
- Explaining the use of the online evaluation tool.
- Ensuring students receive the Resource and Information Handout and symptom cards either physically or electronically.

*On-Site Facilitator checklist is available in the toolkit.

Additionally, the On-Site Facilitator is responsible for ensuring the presentation is completed within the allotted time period and that all program guidelines are followed.

STS Power Point Presentation

An ORCA-approved STS Power Point presentation is available in the toolkit under "Presentation Materials," and is to be used by **all** On-Site facilitators. In those cases where a school does not have projection capability On-Site Facilitators should print out copies of the presentation with companion notes for their use during the presentation. The OCRA Power Point will not be altered without specific approval of the NPD. On-Site facilitators may add the Personal Presentation Slides for each presenter without additional permission.

Preparing for the presentation

Once the Area Facilitator has notified you of a scheduled presentation and has given you the names of other team members who will act as presenters, you should:

- Verify the Area Facilitator has provided the presentation team with details of scheduled presentation (date, time, location, venue, parking, any special access instructions OR information to access a virtual presentation).
- Familiarize yourself with the stories of presenters and determine the order in which they should present. For example, a presenter who has a BRCA mutation may be slated to present when you are discussing risk factors or if a presenter had several of the four symptoms from the consensus statement, consider slating that story when you are outlining the symptoms.
- Notify the presenters of the agenda for the presentation explaining at what point they will be asked to share their stories.
- If presenting in person, ensure that you have sufficient symptom cards for distribution to students. To order symptom cards complete and submit the form at <https://ocrfa.activehosted.com/f/24>. There will be no charge for the cards or shipping. You

must enter your email address as it appears in the database. You may order a maximum of 250 cards each six months. If you require more, contact the NPD at sleighton@ocrahope.org. These cards are for use at STS presentations only. Note: if you are unable to provide symptom cards to the school while doing virtual presentations, ensure that the school distributes the Resource and Information Handout to students.

- Verify with the Area Facilitator that the school has the Power Point presentation including the link for the evaluations and copies of the Information and Resources Handout. Make sure that the Power Point includes appropriate timeline slides for presenters.
- Review the Power Point Presentation and companion notes as well as other program materials in the toolkit and verify you are using the most current versions.
- Practice your introduction, presentation facts, and conclusion.
- If you will be sharing your story, practice. It may be necessary for you to present your story if a scheduled presenter is not able to attend. You may also share small portions of your story to emphasize key messages not related in other presenters' stories.

Moving through the presentation

PRE-EVALUATION: Prior to beginning the actual presentation, instruct the students to access the online evaluation. Beginning January 2023, after completing the pre-evaluation, participants can do one of the following:

- Leave the evaluation open in their browser and return at the end of the presentation to complete the post-evaluation OR
- Navigate to the end of the survey and select DONE. They can then close their browser. At the end of the presentation, they can return to the same link and complete the post-evaluation. If they do not select DONE, the completed pre-evaluation will not be saved.

Explain this is not a graded test but a tool we use to help us evaluate the effectiveness of our presentations. This helps us with obtaining funding so that we can continue to offer this program free of charge to schools across the country.

INTRODUCTION: The On-Site Facilitator's introduction should last about five minutes. Below is a sample script that you can adapt to make it your own:

Hello, my name is [NAME]. I am joined today by [OTHER PRESENTERS]. We are pleased to have the opportunity to talk with you today about a subject that has great urgency: ovarian cancer. We are here as part of Ovarian Cancer Research Alliance's Survivors Teaching Students[®] program.

Our goal is to increase your understanding of the symptoms risk factors for and symptoms of ovarian cancer. You may already know this, but ovarian cancer is the most lethal gynecologic cancer and the fifth leading cause of cancer death among women in the United States. The majority of individuals with ovarian cancer are diagnosed when the disease is at an advanced stage. Survival rates are lower for those whose cancer has metastasized or spread, compared to those who have early-stage disease.

Currently, there is no reliable early detection test for ovarian cancer. I am sharing this information because we want everyone to understand the challenges we face with ovarian cancer. We are here today to share more than numbers. We are here to tell you our stories. You will hear stories today from individuals who have been diagnosed with ovarian cancer. (If a caregiver is slated to present, change this to say, "You will hear stories today from patients and a caregiver whose lives have been affected by a diagnosis of ovarian cancer.")

It is our hope that as you enter practice, you will remember our stories and apply the knowledge you will gain today when encountering women with risk factors and/or symptoms. After you hear our stories, you will have the opportunity to ask questions.

POWER POINT: At this point you will begin the presentation utilizing the PowerPoint and companion notes. **You may choose to present all of the PowerPoint and follow it with the presenters' stories or you may intersperse their stories throughout the PowerPoint (the majority of students responding to evaluations indicate they prefer the latter method).**

The On-Site facilitator needs to ensure that all the key messages are delivered during the presentation. The On-Site facilitator may choose to emphasize points made in presenters' stories:

"M described having many symptoms including all of the symptoms that are found in women with ovarian cancer more often than those in the general population - bloating, abdominal pain, feeling full quickly, and urinary frequency/urgency."

If the message was not clearly made in the story, the facilitator may need to offer the information in summary:

"M had a lot of different symptoms including constipation and heartburn. While these are not one of the four symptoms we described today, they were unusual and new for M. They occurred frequently. These facts prompted her physician to consider ovarian cancer in the differential diagnosis."

CONCLUSION: Your conclusion should last no more than five minutes. Below is a sample script that you can adapt as needed.

We hope that we have helped you learn more about ovarian cancer and the importance of recognizing its risk factors and symptoms.

While displaying slide 17 state "This slide lists the important take-away messages we conveyed today." Read this slide verbatim emphasizing as needed

In addition, this portion of the presentation is a good time to address any points that may not have been covered in the survivors' stories. For example, if no one discussed the possible risk associated with having a personal or family history of breast, uterine, colorectal, or ovarian cancer, this would be the appropriate time to raise it with the students.

POST-EVALUATION: Instruct students to return to the evaluation to complete the post-evaluation. *Please take a few minutes to complete the remainder of the evaluation you have open or return to it using the QR code on this slide (slide 19). Your feedback is extremely valuable to us. These evaluations help us ensure that we are providing information that is useful to you and your peers, and to understand how effective our program is. Your comments are anonymous, but we do review all the forms and take your input seriously. The evaluation should take only a few minutes to complete.*

MANAGING THE TIME AND HANDLING EMOTIONS

On-Site facilitators should develop techniques to ensure the presentation is completed in the allotted time. These techniques may include:

- Practice and time your portion of the presentation making adjustments where necessary

- Speak with the presenters and reinforce the need to stay within the 7-minute time limit
- Develop techniques to signal a presenter who is going "off subject" and over time. This could be as simple as standing up and moving into the presenter's line of sight. In the virtual setting, the On-Site facilitator may need to rely on verbal cues. For example, if a presenter is running long, you might politely interrupt and state "M, we running a little long and we want to leave time for questions. Perhaps you could summarize where you are now with your disease." Discuss these techniques with presenters before the presentation so they will recognize it and know how to respond.
- Be prepared to assist a presenter who is having a difficult time emotionally when sharing their story.
 - Have tissues on hand and discreetly pass one to the presenter if needed.
 - Prior to a virtual presentation, remind presenters to have a glass of water and tissues within reach.
 - If a presenter has difficulty regaining composure, compassionately step in and ask if they would like to take a minute before continuing.
 - If it is obvious that they cannot continue, ask if they would like you to share the remainder of their story. Always make sure that you have a written copy of each presenter's story with you so that you can tell it factually.
- Use a countdown timer to accurately gauge the time remaining for each section of the presentation. In the virtual setting you can send them a private message reminding them of the time remaining.

Facilitating the Question-and-Answer Session

The presenters have 10 to 15 minutes to address the students' questions. The On-Site Facilitator should field students' questions and assign them to the appropriate presenter for response. Facilitators should NOT answer all questions. This is a team effort.

- It can be difficult for audience members to hear one another's questions, so consider repeating the question before answering.
- If you are not sure you understand the question, paraphrase it and ask for confirmation.
- Include ALL presenters who are comfortable with participating in the Q&A session.
- Remember that we do NOT offer medical advice or medical instruction. *Medical advice* consists of comments and suggestions that personalize medical information and makes a recommendation about what the audience should or should not do regarding medical choices. If a question includes a request for medical advice or instruction, say: "I am not qualified to offer an opinion about a specific situation. However, I can say . . ." and answer the question in general terms. You can also refer students to the OCRA website and/or their instructor.
- Answer the question as simply and briefly as possible.
- Do not feel every question must be answered. Presenters may be uncomfortable with some questions or may not have the life experience to answer the question knowledgeably. For example, presenters may not want to answer questions about intimacy after surgery and treatment. A presenter who identifies as white will likely not be equipped to answer questions about health disparities faced by presenters of other races/ethnicities. It is far better to respond that you are uncomfortable answering a question or that you do not know the answer than to respond with an answer not founded in personal experience.
- If there are no questions, try using some of the questions listed in the next section to open the discussion.

- Select questions from all parts of the room. On a virtual platform you can ask students to type questions in chat or you can ask they use the “raise your hand” feature. You may want to ask one of your presenters to help you track questions.
- Monitor the time. End the Q&A session by saying “We have time for one more question.”
- Thank the audience members for their interest; if you can stay after the presentation is dismissed to answer any remaining questions express your willingness to do that. Remember that all STS guidelines still apply.

Questions students ask frequently include:

- How do you want bad news delivered?
- As a doctor talking to a patient, how can I balance the grim statistics with hope?
- How did your family react?
- What kinds of support were most helpful after receiving your diagnosis?
- Did you experience depression?
- How do survivors continue to lead normal lives in spite of the challenge of the diagnosis and the trials of treatment?
- How has the diagnosis affected your self-image and sexuality?
- How difficult was chemotherapy and its side effects?
- What kind of follow-up care do you continue to receive?

Additional discussion topics frequently include:

- Why CA-125 is not used for detection
- Genetic testing and its effect on family members
- The role of the gynecologic oncologist
- Health disparities
- Obstacles unique to those in the LGBTQIA+ community

Distributing Handouts

If it is an in-person presentation, distribute Information and Resources Handouts and symptom cards. In the virtual setting, ask the instructor to distribute the symptom cards if they have them and ask that they send the Information and Resources Handout to the students electronically.

REMINDER: Only OCRA branded materials are to be distributed at presentations.

Make sure to acknowledge the sponsors listed on slide 20 and then thank the students for their attention.

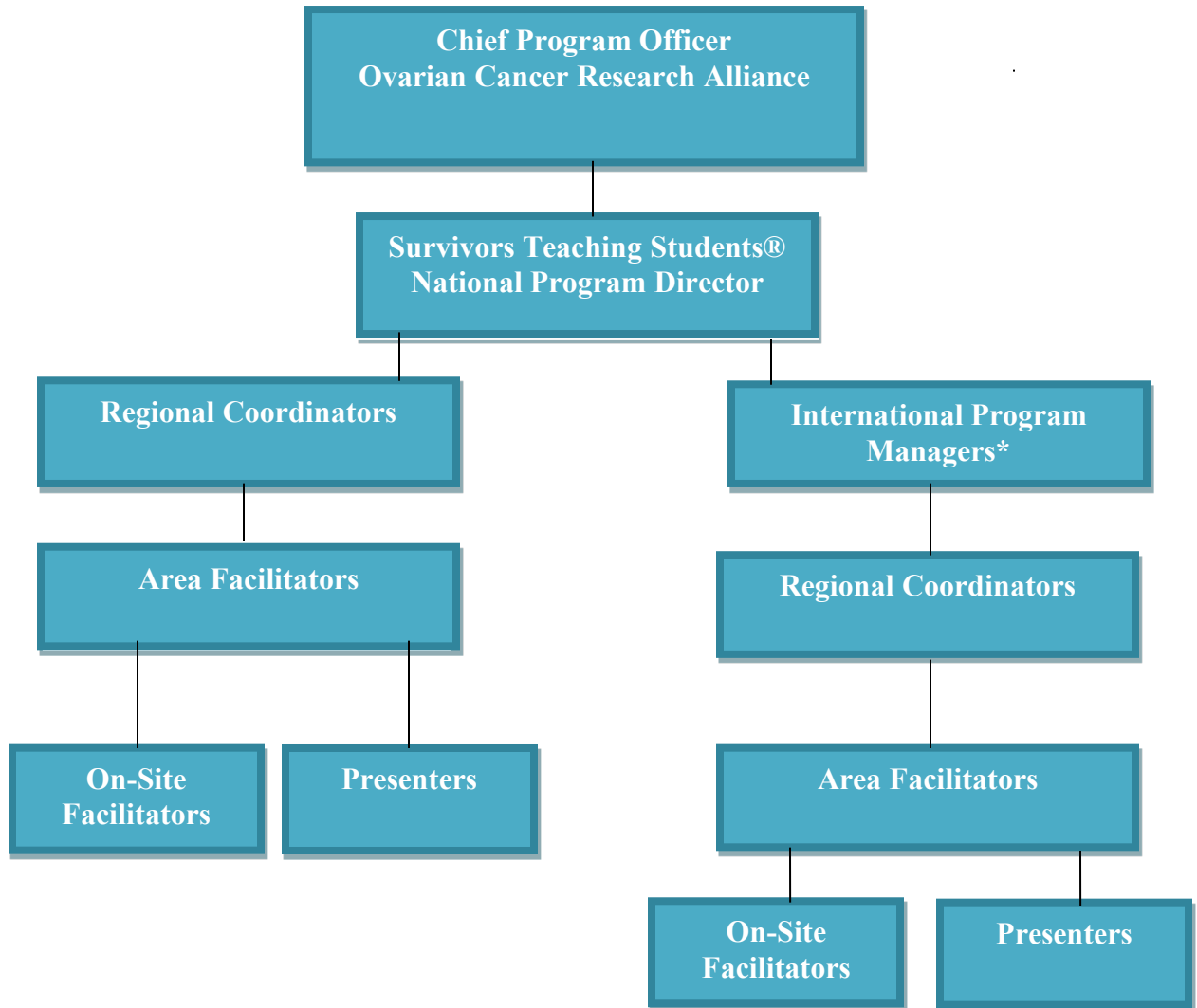
AFTER THE PRESENTATION:

- Send a thank you note to your school contact (this may be done by the Area Facilitator) and include a copy of the evaluation summary report you will receive from the National Program Director within a few days following the presentation.
- Thank each of the presenters and ask them for feedback - what did they like, what could have gone better, were they comfortable sharing their stories and participating in the Q&A session?
- Remind presenters that they may submit for reimbursement of travel expenses by submitting a Participant Travel Reimbursement Form available in the STS toolkit along with a link to submit the form online.
- Submit your own Participant Travel Reimbursement Form if needed.

- If you also serve as the Area Facilitator, enter the presentation in the STS database when you receive the Presentation Summary Report from the National Program Director.

NOTE: Ovarian Cancer Research Alliance reserves the right to remove an On-Site Facilitator from the position for failure to complete assigned tasks or failure to adhere to program guidelines.

Program Administration Program Structure



*International Programs are offered by organizations in Australia, Canada, New Zealand, and the United Kingdom through agreements with Ovarian Cancer Research Alliance.

Chief Program Officer: Sarah DeFeo oversees OCRA's grantmaking, programmatic, and educational initiatives. Working closely with the Scientific Advisory Committee, she manages OCRA's grant solicitation and review process. She also directs OCRA's patient support program, Woman to Woman, Survivors Teaching Students® Program, and all live and web-based patient education initiatives including the Ovarian Cancer National Conference.

National Program Director, Survivors Teaching Students® Program: Susan Leighton, an ovarian cancer survivor, is responsible for directing the Survivors Teaching Students® Program. She reports directly to the Chief Program Officer.

International Program Managers: Responsible for administration of the STS Program in their country in accordance with agreement with OCRA and program guidelines working in coordination with the Chief Program Officer and the National Program Director, Survivors Teaching Students® Program. Job title is at the discretion of the sponsoring local organization.

Regional Coordinators*: Primary point of contact for Area Facilitators in their region. The Regional Coordinators maintain a trained pool of volunteers, ensure compliance with reporting requirements and communicate with the National Program Director.

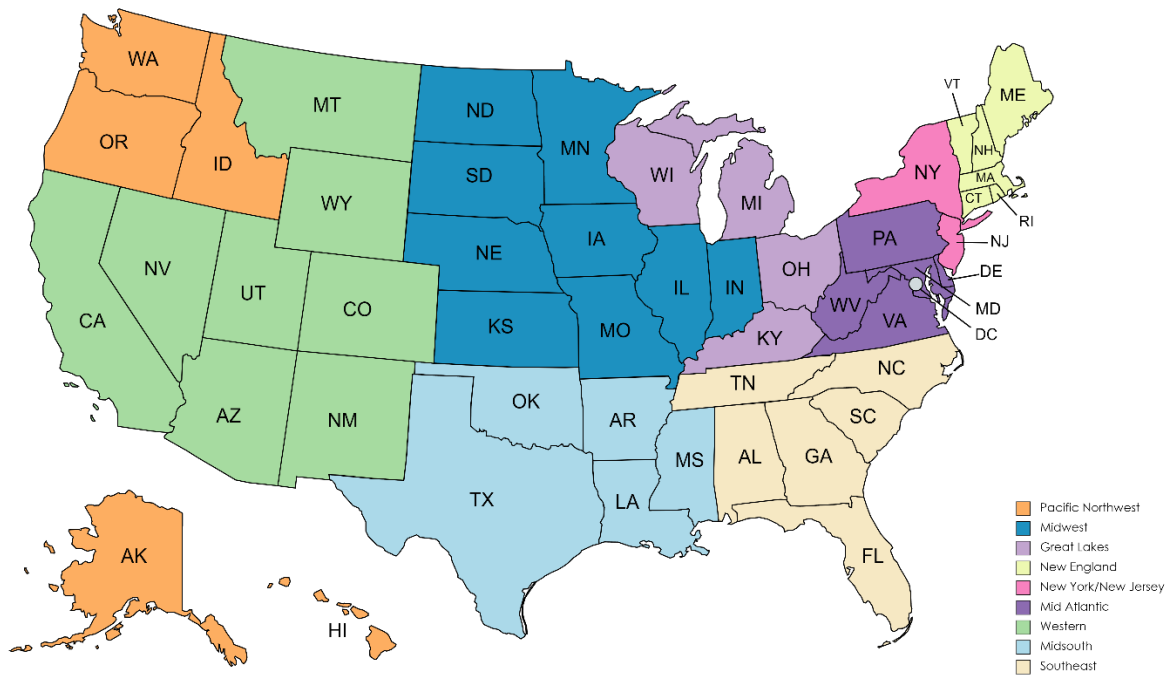
Area Facilitators*: Coordinate presentations by working with medical and health professional schools that have agreed to implement the STS program and by scheduling STS team members. Complete entry of presentation data in the STS database.

On-Site Facilitators*: Presenters who are designated to facilitate the presentation (opening and closing the presentation, ensuring the key messages are delivered, facilitating the Q&A session, administering and collecting the pre- and post-evaluations.

Presenters*: Participate in presentations by sharing personal stories in accordance with program guidelines.

**Note: Detailed descriptions of these roles are provided in this handbook.*

United States STS Regions



Created with mapchart.net

PACIFIC/NORTHWEST – Alaska, Hawaii, Idaho, Oregon, Washington, **Missouri**

MIDWEST - Illinois, Indiana, Iowa, Kansas, Missouri, Nebraska, North Dakota, South Dakota (**In absence of Regional Coordinator, these states have been assigned to other regions as indicated in red**)

GREAT LAKES - Kentucky, Michigan, Minnesota, Ohio, Wisconsin, **South Dakota**

NEW ENGLAND - Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont, **Iowa**

NEW YORK/NEW JERSEY - New Jersey, New York, **Nebraska**

MID ATLANTIC - Delaware, Maryland, Pennsylvania, Virginia, Washington DC, West Virginia, **Indiana**

WESTERN – Arizona, California, Colorado, Montana, Nevada, New Mexico, Utah, Wyoming, **Kansas**

MIDSOUTH - Arkansas, Louisiana, Mississippi, Oklahoma, Texas, **Illinois**

SOUTHEAST - Alabama, Florida, Georgia, North Carolina, South Carolina, Tennessee, **North Dakota**

ROLE OF AREA FACILITATOR

The Area Facilitator serves as the leader of a local STS team and is the main contact for Ovarian Cancer Research Alliance (through the appropriate Regional Coordinator), area health professional schools and members of the presentation teams in the assigned area. An Area Facilitator may have responsibility for one or multiple schools. Area Facilitators may be ovarian cancer survivors, caregivers, family members or a staff member of an advocacy group.

Training

Area Facilitators must complete training to include viewing of the "Presenter Training Webinar" and the STS presentation recording, and reading of this Handbook and "Database Instructions" found in the toolkit ocrahope.org/sts-toolkit. The toolkit key is @stsocna. An Area Facilitator who is new to STS must submit her/his/their story to the Regional Coordinator or National Program Director for editing before being certified to assume the role. The story requirement is waived for a staff member of an advocacy group who is not a survivor or caregiver and who will serve only as an Area Facilitator.

After completing training, an Area Facilitator who is new to STS must submit a New Member Form. This form is available in the STS toolkit along with a link to submit the form online. If the Area Facilitator is an active STS presenter, the Regional Coordinator will submit a Member Status or Role Change Form to the National Program Director (sleighton@ocrahope.org). The NPD will create a new database profile for the Area Facilitator or edit the existing profile and assign login credentials for database access.

The facilitator is responsible for the following tasks:

- Ensuring compliance with program guidelines as outlined in this Handbook
- Working with schools to schedule presentations
- Coordinating teams to ensure that there are enough presenters to conduct the presentation
- Providing logistical information to presenters (for example, time, location, directions, etc.).
- Communicating frequently with the Regional Coordinator about team successes and concerns
- Ensuring that the evaluation results are entered into the database
- Serving as primary point of contact for STS team and schools to answer questions or resolve issues
- Recruiting schools for future presentations
- Recruiting volunteers as needed in coordination with Regional Coordinator
- Maintaining inventory of and distributing STS recruitment materials for schools and volunteers. These materials may be ordered at <https://ocrfa.activehosted.com/f/24>
- Ensuring new presenters complete training, finalize written story, and submit New Member Form as outlined on pages 10-11 of this Handbook
- Editing stories in accordance with program guidelines (see Tips for Editing Stories in toolkit)
- Discussing edits with volunteer and helping her/him/they complete finalized version
- Coordinating and conducting on-site or virtual training sessions as needed
- Ensuring New Member Forms, Member Certification Forms, and Member Edit Forms are submitted to the NPD for entry in the database. These forms are available at ocrahope.org/sts-toolkit
- Ensuring that all materials used or distributed during an STS presentation are from the suite of materials provided by Ovarian Cancer Research Alliance and are the most current version

- Distributing program updates from the Regional Coordinator and National Program Director to the appropriate team members in a timely manner

An Area Facilitator may also serve as an On-Site Facilitator or Presenter. Area Facilitators will be invited to participate in OCRA's STS Regional Coordinators and Facilitators Facebook Group.

NOTE: Ovarian Cancer Research Alliance reserves the right to remove an Area Facilitator from the position for failure to complete assigned tasks or failure to adhere to program guidelines.

Role of Regional Coordinator

The Regional Coordinator is responsible for overseeing the administration of the STS Program in her/his/their designated region and acting as the primary point of contact for the National Program Director in that region. The Regional Coordinator is responsible for communicating with the NPD on a frequent basis concerning the status of the program in his/her/their region. This will include elevating concerns quickly for resolution. The Regional Coordinator will ensure that team members in her/his/their region are kept informed in a timely manner of any program changes.

Additionally, the Regional Coordinator is responsible for the following tasks:

Maintain Ovarian Cancer Research Alliance ownership of program and compliance with policies of OCRA by:

- Recognizing and crediting Survivors Teaching Students[®] as a program of Ovarian Cancer Research Alliance in any written or verbal descriptions of the program.
- Ensuring compliance with program guidelines as outlined in this Handbook.

Maintain trained volunteer pool by:

- Developing and executing a recruitment plan in the Region coordinating with Area Facilitators and requesting assistance of NPD as needed.
- Encouraging all volunteers to actively recruit participants.
- Overseeing the training of Area Facilitators.
- Monitoring training of presenters and On-Site facilitators.
- Assisting Area Facilitators in conducting training and story editing as needed.
- Coordinating on-site and virtual training sessions when needed with Area Facilitator.

Communicate with Area Facilitators and other volunteers by:

- Ensuring each Area Facilitator knows how to access the STS toolkit and is able to obtain a copy of this handbook.
- Ensuring each Area Facilitator receives any program updates or updated materials in a timely manner and informs appropriate program volunteers of the same.
- Contacting Area Facilitators in the region on a regular basis to discuss program successes and problems; provide feedback and solutions to facilitators; or refer unresolved issues and suggestions to the NPD.
- Being available to Area Facilitators on an as needed basis to handle issues/concerns requiring immediate attention.
- Expressing appreciation to volunteers on a frequent basis as they are the backbone of this program.

Ensure compliance with reporting requirements by:

- Instructing facilitators on use of the database found at <https://www.stsdatabase.org>. For additional questions please contact Susan Leighton, sleighton@ocrahope.org
- Stressing importance of the database to Area Facilitators. The statistics generated from the database serve to demonstrate the effectiveness of the program, guide changes that might need to be made and provide information to our sponsors and grantors to justify continued or increased funding for the program. Additionally, members' travel expense reimbursements cannot be processed unless participation in presentations is documented in the database.
- Communicating any difficulties with the database to the National Program Director or OCRA contact.
- Communicate with medical schools, nursing schools, NP and PA programs, and other allied health programs.
- Assist Area Facilitators with ongoing communication with schools that have agreed to implement the program.
- Work with Area Facilitators to identify other schools that could host the program. When possible, obtain contact information for these schools. Request assistance of the NPD in obtaining school contacts. Utilize School Recruitment Tools in the STS toolkit.

Communicate with National Program Director by:

- Participating in conference calls scheduled by the National Program Director.
- Compiling and communicating issues/concerns from volunteers to NPD.
- Communicating information from NPD to team members.
- Notifying the National Program Director if you become unable to perform your duties as Regional Coordinator either temporarily or permanently.

Regional Coordinators will be invited to participate in OCRA's STS Regional Coordinators and Facilitators Facebook Group.

NOTE: Ovarian Cancer Research Alliance reserves the right to remove a Regional Coordinator from the position for failure to complete assigned tasks or failure to adhere to program guidelines.

STS Directory

National Program Director

Susan Leighton

sleighton@ocrahope.org

(256) 883-4951

Mailing Address:

2002 Danbury Circle SW

Huntsville, AL 35803

Ovarian Cancer Research Alliance Staff

Sarah DeFeo

sdefeo@ocrahope.org

(212) 268-1002

Regional Coordinators

Great Lakes: Kentucky, Michigan, Minnesota, Ohio, Wisconsin, **South Dakota**

Ashley Schneider ashley@wisconsinovariancancer.com

Mid Atlantic: Delaware, Maryland, Pennsylvania, Virginia, Washington DC, West Virginia, **Indiana**

Betsy Wallace MidAtlanticSTS@ocrahope.org

New England: Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont, **Iowa**

Diane Riche diane@ovariancancer101.org

New York: New Jersey, New York, **Nebraska**

Gwen Harding-Peets GHardingPeets@ocrahope.org

Midwest: Illinois, Indiana, Iowa, Kansas, Missouri, North Dakota, South Dakota

Position vacant. States have been assigned to other regions as indicated in red.

Southeast: Alabama, Florida, Georgia, North Carolina, South Carolina, Tennessee, **North Dakota**

Strauss Moore Shiple SoutheastSTS@ocrahope.org

Mid South: Arkansas, Louisiana, Mississippi, Oklahoma, Texas, **Illinois**

Lori Clemens MidSouthSTS@ocrahope.org

Pacific/Northwest: Alaska, Hawaii, Idaho, Oregon, Washington, **Missouri**

Diane Rader O'Connor babygoosie@aol.com

Virtual:

Gwen Harding-Peets GHardingPeets@ocrahope.org

Western: Arizona, California, Colorado, Montana, Nevada, New Mexico, Utah, Wyoming, **Kansas**

Sheila Van Groningen sheila.vangroningen@gmail.com

STORY EDITOR: Elaine Greenberg, yasherke@gmail.com

Facebook STS Regional Coordinators and Area Facilitators Page: OCRA maintains this page as a place to communicate program updates, answer questions and exchange ideas. All Area Facilitators and Regional Coordinators will be invited to participate. The page is moderated by the National Program Director. <https://www.facebook.com/groups/430428117555083/?ref=bookmarks>

STS Program Materials

Program materials may be ordered by Area Facilitators and Regional Coordinators by completing the order form at <https://ocrfa.activehosted.com/f/24>. There will be no charge for these materials or for shipping. They are to be used only in support of the STS program.

Symptom Cards: Each Area Facilitator and Regional Coordinator may order 250 cards every six months. If you need more than 250 cards, send an email to the National Program (sleighton@ocrahope.org) including justification for the increased quantity for approval.

Volunteer Recruitment Postcards: These postcards are excellent tools to distribute where survivors gather (for example, physicians' offices, infusion centers, health fairs). They are also great to send to schools to introduce our program.

STS Toolkit

The STS toolkit contains many tools for the use of team members. The contents are protected and meant to be accessed by team members only. The toolkit is found at <https://ocrahope.org/get-involved/survivors-teaching-students/sts-toolkit/>. The toolkit key is @stsocna. Members should periodically verify that they are using the most recent revision of the selected tool.

Items found in the toolkit include:

- Presenter Training
 - U.S.STS Handbook for Program Volunteers
 - International STS Handbook for Program Volunteers
 - Presenter Training Webinar
 - Preparing to Share Your Story
 - Personal Timeline Story Slide Example
 - Personal Timeline Story Slide Template
 - Personal Timeline Story Slide Instructions
 - New Member Form
- Current STS Team Member Resources
 - Member Information Edit Form
 - STS Travel Reimbursement Form
- Regional Coordinator/Facilitator Tools
 - STS Tips for Recruiting and Training Presenters
 - Volunteer Recruitment Tools
 - Recruitment flyer
 - STS introduction to Program Email – Starting a New Team
 - New Presenter Training Tools
 - Quick Start Training Guide
 - STS Virtual Platform - New Presenter Training Agenda
 - Editing Stories for STS – Tips and Guidelines
 - STS Story Examples
 - New Member Certification Form
 - Experienced Presenter Training Tools
 - STS Virtual Platform - Experienced Presenter Training Agenda
 - Onsite Facilitator Training Tools
 - STS Virtual Platform – Facilitator Training Agenda

- Area Facilitator Tools
 - STS Database Instructions
 - Member Status or Role Change Form
- Presentation Tools
 - Virtual Presentation Instructions
 - Request for Online Evaluation
 - STS Area Facilitator Checklist – Virtual Presentation
 - STS Onsite Facilitator Checklist
- Release Forms
 - STS Agreement for Recording of Virtual Presentation
 - STS Presenter Video/Audio Release – Virtual Presentation
 - STS School Photo and Video Release
- School Tools
 - New School Form
 - School Information Edit Form
- School Recruitment Tools
 - List of Participating Schools
 - STS Recognized with C2 Award
 - Follow-up C2 Award Interview with Audra Moran, CEO Ovarian Cancer Research Alliance
 - School Endorsement Letters.
 - Washington Post Article
 - Mount Union Article
 - STS Boston Survivors Article
 - STS Letter of Introduction to Program
- Other Helpful member-developed tools
 - STS Presentation Key Points Power Point Example
 - STS Evaluation Link Tracker
- Sample virtual presentation
- Presentation Materials
 - STS Presentation
 - STS Presentation Companion Notes
 - Evaluation Link Slide
 - STS Information and Resources (Infographic)
 - STS Information and Resources (Text)

Ordering Symptom Cards and Recruitment Postcards: To order symptom cards complete and submit the form at <https://ocrfa.activehosted.com/f/24>. There will be no charge for the cards or shipping of the cards. You must enter your email address as it appears in the database. You may order a maximum of 250 cards each six months. If you require more, contact the NPD at sleighton@ocrahope.org. These cards are for use at STS presentations only. Area Facilitators and Regional Coordinators may also order postcards using this link.



PRESENTATION EVALUATIONS

SURVIVORS TEACHING STUDENTS[®] Ovarian Cancer Presentation Pre-Evaluation

(Circle any/All that apply)

1. In general, I have a basic understanding of ovarian cancer including:
 - a. Risk factors
 - b. Signs and symptoms
 - c. Diagnostic protocols
 - d. None of the above

2. There is an early detection test for ovarian cancer.
True/False

3. A family history of which of the following raises the risk of ovarian cancer:
 - a. Breast cancer
 - b. Ovarian cancer
 - c. Uterine cancer
 - d. Colon cancer
 - e. Lung cancer

4. A personal history of which of the following raises the risk of ovarian cancer:
 - a. Breast cancer
 - b. Never having children
 - c. Cervical cancer
 - d. Birth control pill use

5. Studies have shown that individuals diagnosed with ovarian cancer generally have a better likelihood of prolonged survival if treated by (select one):
 - a. A gynecologist
 - b. An oncologist
 - c. A gynecologic oncologist

6. Which of the following symptoms, if persistent, would lead you to consider ovarian cancer in the differential diagnosis:
 - a. There are no symptoms
 - b. Bloating
 - c. Feeling full quickly/early satiety
 - d. Urinary frequency/urgency
 - e. Pelvic/abdominal pain
 - f. Other (Please specify)



SURVIVORS TEACHING STUDENTS[®]
Ovarian Cancer Presentation Post-Evaluation

(Circle any/All that apply)

1. In general, I have a basic understanding of ovarian cancer including:
 - a. Risk factors
 - b. Signs and symptoms
 - c. Diagnostic protocols

2. There is an early detection test for ovarian cancer.
True/False

3. A family history of which of the following raises the risk of ovarian cancer:
 - a. Breast cancer
 - b. Ovarian cancer
 - c. Uterine cancer
 - d. Colon cancer
 - e. Lung cancer

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 - a. There are no symptoms
 - b. Bloating
 - c. Feeling full quickly/early satiety
 - d. Urinary frequency/urgency
 - e. Pelvic/abdominal pain
 - f. Other (please specify)

7. How has the presentation changed the way you think about ovarian cancer?

8. Would you consider this form of experiential learning an effective method of learning more about ovarian cancer or another condition?

9. How can the presentation be more effective in conveying survivors' experiences, the importance of the symptoms or difficulties in diagnosis?

Revised March 2021

SURVIVORS TEACHING STUDENTS[®]
Ovarian Cancer Presentation
Answer Key – Correct answers highlighted in yellow

1. In general, I have a basic understanding of ovarian cancer including:
 - a. Risk factors
 - b. Signs and symptoms
 - c. Diagnostic protocols
 - d. None of the above

2. There is an early detection test for ovarian cancer.
True/**False**

3. A family history of which of the following raises the risk of ovarian cancer:
 - a. Breast cancer**
 - b. Ovarian cancer**
 - c. Uterine cancer**
 - d. Colon cancer**
 - e. Lung cancer

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 - c. Feeling full quickly/early satiety**
 - d. Urinary frequency/urgency**
 - e. Pelvic/abdominal pain**
 - f. Other (please specify)

Revised March 2021

Ovarian Cancer Research Alliance

Ovarian Cancer Research Alliance (OCRA) is the largest global organization dedicated to advancing ovarian cancer research while supporting survivors and their families. As the voice for ovarian cancer, OCRA funds private research, advocates for increased federal research and awareness dollars and furthers policies that give patients access to the services they need, as well as supports survivors and their families affected by a diagnosis of ovarian cancer before, during and after a diagnosis. Collectively, the organization has invested over \$70 million in private ovarian cancer research and helped to secure over \$2.2 billion federal dollars dedicated to ovarian cancer research and awareness since 1998. OCRA engages the survivor community with programs like Woman to Woman, pairing gynecologic cancer patients with gynecologic cancer survivors and Survivors Teaching Students®, an educational program connecting ovarian cancer survivors with health professional students to present their unique stories and facts about the disease. Visit www.ocrahope.org to learn more.

For more information and resources, please visit the Ovarian Cancer Research Alliance website at www.ocrahope.org.

Ovarian Cancer Research Alliance
14 Pennsylvania Plaza
Suite 2110
New York, NY 10122
P: (212) 268-1002

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) and Ovarian Cancer Research Alliance's Survivors Teaching Students® Program

Purpose: HIPAA is meant to protect individually identifiable health information.

Application: Ovarian Cancer Research Alliance is not a covered entity and does not need to comply with HIPAA provisions.

The law, like all laws, does not apply to everyone. Covered entities include health providers, insurance plans, and health clearinghouses. Ovarian Cancer Research Alliance is not subject to HIPAA (see <http://www.cms.gov/HIPAAGenInfo/Downloads/CoveredEntitycharts.pdf>)

Waiver: Patients may waive their legal rights, including rights provided under HIPAA. If OCRA were a covered entity, the transmission of electronic information about medical conditions would be protected. However, people participating in the STS program are speaking publicly about the health condition. If they want that information to be private, public speech about said issue would not be appropriate for them.

Confidentiality: Ovarian Cancer Research Alliance does not sell its mailing or other lists. We will not share your information with external organizations as a facilitator or survivor.