

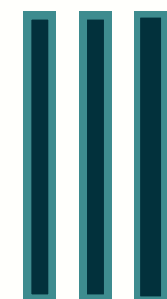
# VOICES OF LOW-GRADE SEROUS OVARIAN CANCER (LGSOC) PATIENTS

**Externally-led Patient-Focused  
Drug Development (EL-PFDD)  
Meeting Results**

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VOICES  
of LGSOC

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## EXECUTIVE SUMMARY AND KEY MEETING THEMES

Low-grade serous ovarian cancer (LGSOC) is a rare epithelial ovarian cancer subtype typically diagnosed in younger women. Symptoms of LGSOC are often ascribed to more common and less serious conditions, especially among younger patients, and appropriate testing is often delayed. Thus, LGSOC is challenging to detect early, and thus most people are diagnosed with LGSOC in advanced stages. Menopause from early oophorectomy, the initial step in managing LGSOC, is extremely distressing and robs young women of the chance to have children, permanently changing their lives. LGSOC does not end after surgery but continues to have sequelae, and patients worry about disease recurrence, as 80% will face this reality. In addition to menopausal symptoms, intense fatigue, chronic pelvic and bone/joint pain, and anxiety and depression are incredibly problematic, affecting not only the person afflicted with LGSOC but the entire family.

Currently, there is no clear standard of care for LGSOC, and no treatments are approved by the Food and Drug Administration (FDA) to stop the progression of this disease. Chemotherapy and aromatase inhibitors are mainstays of treatment after surgery, but serious side effects limit their usage and have tremendous negative impact on quality of life. Research is ongoing for novel, targeted therapies for LGSOC, and new treatment options are desperately needed.

On October 13, 2023, STAAR Ovarian Cancer Foundation hosted an Externally-led Patient-Focused Drug Development (EL-PFDD) public meeting on LGSOC. The goal of the meeting was to provide the FDA and other LGSOC drug development stakeholders an opportunity to hear directly from patients with LGSOC and their caregivers about their stories of living with LGSOC and undergoing treatment.

Key themes that emerged from the stories, perspectives, and comments shared at the meeting are summarized in the table below and throughout the report.

Topic	Key Themes
<b>LGSOC symptoms</b>	<ul style="list-style-type: none"><li>● Fatigue is the most frequently reported symptom of LGSOC; other debilitating symptoms of the disease and side effects of treatment include bone/pelvic pain, abdominal discomfort, problems with sexual relations, menopausal issues, and anxiety and depression.</li><li>● Symptoms of LGSOC and its treatments are numerous and have tremendous impact on daily living, including everyday activities, jobs, relationships, and mental health.</li><li>● Additional troublesome symptoms and side effects include bowel motility, bladder/urinary frequency, and bloating/abdominal distention issues; menopausal issues, including hot flashes, night sweats, lack of libido, and loss of bone density; pain during</li></ul>

	<p>intercourse; memory loss; vision trouble (blurriness); lower back pain; and pain when touching the abdomen.</p> <ul style="list-style-type: none"> <li>● Menopausal symptoms associated with surgery and/or the aromatase inhibitors many of these young women are receiving have a tremendous effect on their relationships and sexual health.</li> </ul>
<b>Activities of daily life</b>	<ul style="list-style-type: none"> <li>● Sexual activity, working or having a career, having children, sleeping, and personal care or household chores are the most common activities of daily life that are impaired by LGSOC.</li> <li>● Maintaining a job or career while coping with the barrage of daily symptoms is extremely challenging and mentally taxing.</li> <li>● Simple everyday tasks and social activities can become impossible, leading to loss of independence and/or despair, anxiety, and depression.</li> <li>● Dietary changes are often needed to improve symptoms, and exercise, while helpful for some symptoms, can be daunting or impossible.</li> </ul>
<b>Future worries</b>	<ul style="list-style-type: none"> <li>● People with LGSOC worry most about the cancer spreading in the body, dying prematurely, having a reduced quality of life, and enduring worsening symptoms.</li> <li>● Patients with LGSOC live with a daily fear of the unknown, including disease recurrence, which makes planning for the future formidable.</li> </ul>
<b>Medications and treatments</b>	<ul style="list-style-type: none"> <li>● Managing LGSOC is complex and can include multiple surgeries, chemotherapy, endocrine therapy, and other interventions and procedures.</li> <li>● Most LGSOC survivors take an oral aromatase inhibitor as maintenance therapy and use over-the-counter medications to help with symptoms.</li> <li>● LGSOC requires chronic medication use that may also include antidepressants or anti-anxiety medications, pain medications, bowel or bladder medications, sleep medications, and other drugs.</li> <li>● The biggest drawbacks of LGSOC treatment approaches are side effects and ineffectiveness of the medication to treat all symptoms.</li> </ul>

<b>Supportive care</b>	<ul style="list-style-type: none"> <li>● Supportive care is needed to help manage symptoms of LGSOC and its treatments.</li> <li>● Lifestyle changes, such as exercise or avoiding stressful situations, massage, dietary supplements, counseling or psychotherapy, and support groups help alleviate symptoms.</li> <li>● Strategies for sexual symptoms include pelvic floor therapy, dilators, and lubricants.</li> </ul>
<b>Characteristics of an ideal treatment</b>	<ul style="list-style-type: none"> <li>● The main attributes of an ideal treatment are that it will prevent disease progression and treat the underlying cancer.</li> <li>● Ideal treatments should be easy to use or administer and provide quality of life.</li> </ul>
<b>Current needs</b>	<ul style="list-style-type: none"> <li>● Education and awareness of LGSOC amongst healthcare professionals</li> <li>● FDA-approved treatments for LGSOC</li> <li>● Better education about the side effects of aromatase inhibitors</li> <li>● Communication about sexual health with healthcare professionals or caregivers</li> <li>● Early detection tools and tests for diagnosis before symptoms start</li> <li>● Noninvasive treatment options</li> </ul>

**INTRODUCTION**

On October 13, 2023, STAAR Ovarian Cancer Foundation hosted an EL-PFDD public meeting to provide patients with LGSOC and their caregivers an opportunity to voice their perspectives and tell their stories of living with LGSOC and undergoing treatment. The meeting was held as part of the FDA’s Patient-Focused Drug Development (PFDD) Program, an effort to systematically gather individuals’ perspectives on their condition and therapies available to treat the condition to inform therapy development and evaluation.

The information obtained at the meeting and summarized in this report is anticipated to lead to more dialogue between stakeholders in the LGSOC community, with the goal of aiding in decision-making for drug development and clinical trials for LGSOC, to ultimately improve the overall quality of life for patients living with this disease.

**OVERVIEW OF LOW-GRADE SEROUS OVARIAN CANCER (LGSOC)**

LGSOC is a rare subtype of epithelial ovarian cancer that accounts for < 10% of epithelial ovarian cancers.<sup>1</sup> LGSOC may originate in the ovary, fallopian tubes or peritoneum and may arise de novo or following a diagnosis of serous borderline tumor. The disease is clinically characterized by younger age at diagnosis (where fertility preservation is of greater concern than in the overall ovarian cancer population), relative insensitivity or resistance to chemotherapy, and a slow clinical course with prolonged survival compared with its high-grade serous counterpart.<sup>2</sup> LGSOC is molecularly characterized by estrogen and progesterone receptor positivity, aberrations in the mitogen-activated protein kinase (MAPK) pathway, and wild-type TP53 expression pattern.<sup>3</sup> The majority of women with LGSOC are diagnosed at advanced stages, and the disease is relatively insensitive or resistant to chemotherapy. Despite the slow clinical progression of LGSOC, up to 80% of these cancers eventually relapse or recur. Cytoreductive surgery remains the mainstay of treatment for all stages of LGSOC, with adjuvant chemotherapy the standard of care for LGSOC outside the ovary. Maintenance hormone therapy with an aromatase inhibitor or tamoxifen is commonly administered. Outside of clinical trial enrollment, treatment of recurrent disease varies and may include chemotherapy, hormone therapy, anti-angiogenic (eg, bevacizumab), or targeted therapy (eg, MEK inhibitor).<sup>1</sup> Coupled with the critical importance of effective therapies for LGSOC is the proactive management of treatment-related side effects (eg, peripheral neuropathy, musculoskeletal symptoms, chronic pain, osteoporosis, skin reactions), which vary depending on the treatment. With its molecular and clinical distinction, LGSOC represents a rare disease whose management remains incompletely understood but requires a unique approach to maximize patient survival. Many women with LGSOC endure months or years of incorrect diagnoses, underscoring the critical need for accurate diagnosis in routine clinical practice. Moreover, they may endure years of ineffective treatments with major impacts on both physical and emotional quality of life. Practice patterns for LGSOC vary due to the paucity of randomized clinical trial data to inform evidence-based treatment decisions and the lack of FDA-approved effective treatments.<sup>4</sup>

## MEETING OVERVIEW

The EL-PFDD meeting was designed to give patients with LGSOC, their caregivers, and other patient representatives an opportunity to convey their experiences living with LGSOC directly to the FDA, to better inform their understanding. Patients and caregivers were encouraged to participate in the meeting and share their experiences by submitting comments online in advance of the meeting, as well as during the meeting via online portal or telephone. The discussion focused on two main topics: (1) living with LGSOC symptoms and daily impact and (2) perspective on current and future treatments for LGSOC (see [Appendix 1](#)).

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<sup>1</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10511962/pdf/ijgc-2023-004610.pdf>

<sup>2</sup> <https://erc.bioscientifica.com/view/journals/erc/29/1/ERC-21-0191.xml>

<sup>3</sup> <https://ijgc.bmj.com/content/33/3/377.long>

<sup>4</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8871133/>



The meeting commenced with welcoming remarks from Nicole Andrews, STAAR Ovarian Cancer Foundation Board Chair and meeting co-moderator. She welcomed participants, outlined the importance of the meeting and the challenges faced by people with LGSOC, and expressed her hope that the meeting will encourage future research and successful new product development for people living with LGSOC.

Dr. Laleh Amiri-Kordestani from the Office of Oncologic Diseases/Division of Oncology I, Center for Drug Evaluation and Research (CDER), acknowledged that the FDA recognizes the need for more progress and work to further advance the treatment and management of LGSOC. Hearing directly from patients, their families, caregivers, and patient advocates about the symptoms that matter most to them, the impact the disease has on patients' daily lives, and specific aspects that patients look for in an ideal treatment to manage their condition will help inform and advise the focus of new drug development and future clinical trials.

Dr. David Gershenson from the University of Texas MD Anderson Cancer Center and Dr. Rachel Grisham from Memorial Sloan Kettering Cancer Center provided clinical overviews of LGSOC and its treatment. Considerations highlighted by Dr. Gershenson included the following: (1) residual disease is the most important prognostic factor in LGSOC; (2) LGSOC is similar to hormone receptor-positive breast cancer; and (3) the MAPK pathway plays a prominent role in LGSOC, with improved survival in those with MAPK-mutated disease. Considerations highlighted by Dr. Grisham included the following: (1) current treatments for LGSOC are focused on alternatives to traditional chemotherapy; (2) LGSOC is a molecularly distinct disease that warrants treatment tailored to its molecular and clinical behavior, and the use of molecularly targeted therapy for LGSOC has progressed over the last decade; and (3) much is being learned from ongoing clinical trials.

James Valentine, JD, MHS, of Hyman, Phelps & McNamara, served as the meeting moderator and outlined the format and guidelines for the interactive meeting, which was organized into the two overarching sessions/topics.

Each session began with powerful pre-recorded video testimonials about experience with LGSOC from patients and caregivers. These testimonials were followed by a live facilitated discussion that included pre-selected patients living with LGSOC sharing their stories and building on the video testimonials. [Appendix 2](#) provides information on the meeting panelists.

Meeting participants were periodically invited to respond to polling questions to help provide demographic information and their experiences with LGSOC. To supplement the input gathered at the meeting, people with LGSOC or their caregivers were encouraged to submit written comments before the meeting; call into the meeting or submit written comments through the webcast platform; and/or submit written comments up to 30 days after the meeting.

At the end of the meeting, Larry Bauer, RN, MA, of Hyman, Phelps & McNamara, provided a summary of the presentations, testimonials, and discussions. Nicole Andrews delivered closing remarks.



The recording of the EL-PFDD Meeting for LGSOC can be found at <https://www.staaroc.org/voices.html>.

### **Meeting Participants**

Approximately 150 people attended the virtual meeting through the live webcast, including 57 people living with LGSOC or LGSOC survivors and 29 caregivers or family members. Fifty-one participants engaged in the polling questions. Patient advocates, FDA colleagues, and stakeholders from the healthcare industry also participated in a listen-only capacity.

Demographic polling questions ([Appendix 3](#)) revealed the following:

- Of the polling participants, 85% were people living with LGSOC and 15% were caregivers, family members, or someone providing direct care of someone living with LGSOC.
- Most participants were currently 31 to 50 years of age (58%) and had been diagnosed with LGSOC between the ages of 21 and 50 (77%).
- Most participants have LGSOC that has metastasized (59%); 31% have no evidence of disease post-treatment, and 6% had a loved one who passed away from LGSOC.
- Most participants joined from the US in the Eastern or Central time zones (72%), with representation from other parts of the US as well as Europe.

## **REPORT OVERVIEW**

This Voice of the Patient report provides a summary of the input shared by patients living with LGSOC and their caregivers who participated in the EL-PFDD meeting. The report also includes a summary of the written comments submitted to the public platform. This report is intended to help strengthen the FDA's, drug developers', scientific researchers', and clinicians' understanding of the burden of LGSOC on patients as well as the challenges with the current treatments used to treat LGSOC. The scrupulous feedback on the physical and emotional toll LGSOC takes on daily life coupled with the dearth of effective treatments is anticipated to help guide future drug development for LGSOC and inform clinical trial designs.

This report aims to summarize the specific symptoms, impacts, and treatment experiences candidly expressed by the patients and caregivers who participated. The views and experiences shared in this report may not be representative of the broader population of patients with LGSOC, and there may be other symptoms, impacts, treatments, or other aspects of LGSOC that are not included in this report.

## **TOPIC 1: LIVING WITH LGSOC: SYMPTOMS AND DAILY IMPACT**

In the first discussion, patients living with LGSOC and their caregivers shared how LGSOC symptoms affect daily life, and their worries or fears for the future.

## Living With LGSOC Testimonials

Five panelists ([Appendix 2](#))—four people living with LGSOC and one caregiver—shared powerful stories related to living with LGSOC. A summary of their video testimonials is presented below, and the full statements from each panelist can be found in [Appendix 4](#).

- **Ellie—30 years old, teacher, married with no children**

Ellie was diagnosed with stage 3C LGSOC in 2021 at the age of 27. Prior to her diagnosis, Ellie had vague symptoms that included bloating, sudden onset of pain during sex, and extreme fatigue, which were dismissed by her healthcare professionals. She is currently experiencing a range of symptoms, which are mostly related to the menopausal state her body is in due to the aromatase inhibitor therapy she is receiving for the LGSOC. One of Ellie’s continual symptoms is constant joint pain throughout her body, which has impacted her job and requires occupational therapy. In addition to the chronic pain, Ellie experiences hot flashes, loss of libido, vaginal dryness, fatigue, memory loss, and osteopenia. She will not be able to have children, which “has been emotionally devastating.” Compounding Ellie’s infertility are worries of worsening side effects, effects on her marriage, lack of awareness and treatment options for LGSOC, and recurrence of disease. She is crippled by these thoughts and some days she “just feels absolutely defeated emotionally.”

- **Laura—37 years old, mother of two children and has a partner**

Laura was diagnosed with stage 3C LGSOC in 2016. She received chemotherapy and underwent surgeries, which included a total hysterectomy, throwing her into menopause at the age of 29. She recently discovered that the cancer has returned. Laura struggles with hot flashes and sweats, stubborn weight gain, sleeplessness, and depression. From before her initial diagnosis, Laura suffered from pelvic discomfort, bloating, and severe lower back pain. She describes her lower back pain, which continues to be problematic, as feeling “like there are heavy bricks attached to [her] back,” making even the shortest of walks unbearable. Intensifying Laura’s physical symptoms are her emotions related to living with LGSOC: self-consciousness about her weight, unbearable guilt of potentially leaving her children motherless, the uncertainty of her time remaining with an incurable disease, and living with side effects the rest of her life. She bluntly states, “There is no light at the end of my tunnel.”

- **Dima—44 years old, married mother of teenage triplets**

Dima has spent the better part of her life struggling with malfunctioning ovaries, being seen by countless gynecologists and doctors and being told her experiences were normal. She underwent an oophorectomy at the age of 21, with both ovaries fully removed a few years later due to a recurrent borderline ovarian cancer. Dima was thrown into early menopause in her twenties, with the saving grace of having been able to harvest eggs before her last surgery. Her pain escalated throughout her thirties, which her doctors attributed to the previous surgery. In 2020, Dima was diagnosed with LGSOC despite her ovaries having been removed. After another surgery, she received four of six planned chemotherapy cycles, having to discontinue treatment early due to unbearable side effects. Dima’s oncologist then prescribed a hormone blocker, which

Dima continues to receive. Dima is perplexed by the treatment options for LGSOC being the same as for breast cancer and pleads for “hope of possible effective treatment...hope for better outcomes...and hope of a life.”

- **Emma—29 years old, engaged with no children**

Emma was diagnosed with LGSOC at the age of 26 and underwent three surgeries and chemotherapy. She laments the fact that she will never experience the joys of pregnancy (waiting for a pregnancy test, sonogram photos, baby kicking) and that LGSOC has “robbed [her] of the opportunity to experience any of those moments [she] has spent [her] whole life envisioning.” Though Emma was able to freeze eggs, a surrogate and a hefty budget will accompany that venture. Becoming menopausal at age 26 symbolized a “loss of youth and vitality” to Emma. She takes an aromatase inhibitor and is coping with its unpleasant side effects of osteoporosis, joint pain, and exacerbated menopausal symptoms. Emma’s relationship with her partner has been adversely affected both physically (eg, ribs being cracked from a hug) and emotionally. She equates the loss of her fertility with mourning, resentment, trauma, and anger. Emma remains fearful of disease recurrence but will not accept being robbed of the opportunity to begin her adult life.

- **Lisa—recently lost her daughter, Lexi, to LGSOC at 29 years old**

Lisa’s daughter, Lexi, vowed she would not give up after receiving the diagnosis of LGSOC two years ago. Despite being the picture of good health, Lexi struggled with recurring abdominal pains for much of her life, resulting in misdiagnoses and procedures. After an emergency ovarian cystectomy leading to her LGSOC diagnosis, Lexi underwent surgery and sailed through chemotherapy treatment. Lexi immediately went into “gladiator mode,” becoming a staunch advocate for new treatments and funding for LGSOC. Unfortunately, Lexi’s cancer was very aggressive and began rapidly progressing. Serious symptoms of her disease and side effects of each new treatment were devastating to Lexi’s body, and activities of daily living became impossible. Despite her downward spiral in physical health, Lexi continued advocating for LGSOC and its sufferers through social media and blogs. Ultimately, treatments were withdrawn, and Lexi lost her life to LGSOC in June 2023.

### **Patient/Caregiver Panel 1**

After the video testimonials, a live Zoom panel of people living with LGSOC ([Appendix 2](#)) shared their experiences and concerns about day-to-day life impacts from LGSOC.

- **Amanda** was diagnosed with LGSOC in November 2020 when she was 31 years old. She experienced excruciating abdominal pain, which was dismissed by her doctors, for years before her diagnosis.
- **Kat** was diagnosed with LGSOC in 2019 when she was 19 years old. Since before her diagnosis, Kat has struggled to find a qualified medical professional who understands LGSOC. Her symptoms were perpetually dismissed by healthcare professionals until she ultimately underwent surgery for supposed endometriosis only to find out that she had cancer. Kat remembers having gynecologic symptoms and pain since childhood that

evolved into problematic periods. Moreover, she underwent surgery at 17 to remove a tumor that she was told was a neuroma (she doesn't believe pathology was even performed).

- **Tami** was diagnosed with LGSOC in August 2018. Due to scar tissue and disease progression, abdominal discomfort/pain and GI motility are daily concerns for Tami.
- **Lili** was diagnosed 3 years ago with stage 4 LGSOC at the age of 28. Her symptoms were also dismissed because of her young age. She recalls having “tough periods,” indigestion, and what she thought was constipation. Lili also suffered from episodes of sharp lower back pain that would intermittently appear and disappear. She now realizes that was related to the cancer growing on her colon, which has since been removed. Lili stressed that education about LGSOC “needs to start with our providers and with everyone in the healthcare field.”
- **Monica** was diagnosed with LGSOC in December 2021. As a teacher, Monica finds her memory loss following a full hysterectomy has had the most significant impact on her life, along with joint pain and hot flashes.

In addition to the panel discussion, live polling questions were asked throughout the moderated discussion to help gain perspective from all participants on their struggles with LGSOC. Selected written comments from patients and caregivers were shared by the moderators, and others called in to share their experiences.

### ***Most Significant LGSOC-related Health Concerns and Symptoms***

The first group of questions for the panel addressed the symptoms that have the most significant impact on daily life currently, at any time, and at the time leading up to their LGSOC diagnosis. Audience polling revealed a wide burden of debilitating and disabling health concerns related to their or their loved ones' LGSOC ([Appendix 5](#), Topic 1, Question 1). Most frequently reported symptoms included **fatigue**, followed equally by **bone/pelvic pain**, **abdominal discomfort**, **problems with sexual relations**, **menopausal issues**, **night sweats**, and **anxiety/depression**.

In selecting which of these concerns are most troublesome (top three) to people with LGSOC ([Appendix 5](#), Topic 1, Question 2), **fatigue**, **anxiety/depression**, **bone/pelvic pain**, **abdominal discomfort**, and **problems with sexual relations** ranked highest. **Menopausal and fertility issues** were also troubling.

Written and caller comments echoed the sentiments of the panelists, with people describing myriad symptoms from LGSOC that included excessive fatigue; bowel motility, bladder/urinary frequency, and bloating/abdominal distention issues; menopausal issues, including hot flashes, night sweats, lack of libido, and loss of bone density; pain during intercourse; anxiety and depression; memory loss; vision trouble (blurriness); bone pain, lower back pain, and pain when touching the abdomen.

“It’s exhausting living every day with these side effects, not knowing if it’s from the medications or if it’s from the actual cancer.” –Amanda

“I struggle to come up with the words that are going through my head.” –Monica

“After debulking and treatments, I am still dealing with bowel, bladder, and bloating issues that come and go, and excessive fatigue.” –Betty

### ***Impact of LGSOC Symptoms on Daily Life***

Participants were asked to select the top three life activities they are no longer able to do or struggle with due to LGSOC ([Appendix 5](#), Topic 1, Question 3). Top responses included **impaired sexual activity, working or having a career, having children, sleeping, and personal care or household chores.**

Participants described their struggles of trying to maintain a career while coping with the barrage of daily symptoms. They have experienced job loss or fear of job loss, disability, loss of independence, pausing relationships, and delaying college or graduate education. Several people mentioned having to work more slowly and relying on assistance for tasks, such as typing, that were once easy or for simple everyday tasks like opening a jar or putting on socks. One panelist lost her job because of all the surgeries she was undergoing and had to move back in with her parents. Her loss of independence coupled with the uncertainty of her future have provoked tremendous anxiety and frustration.

Other topics raised by meeting participants were diet and exercise. Several panelists have changed their diets to try to improve symptoms so that they do not interfere with day-to-day activities. A common concern was the loss of ability to exercise or participate in athletic activities. Several participants described bone breaks or fractures that occurred because of their LGSOC or the aromatase inhibitor treatment.

“I’m single, I’m 31. I’d love to date, and aside from just dealing with having cancer and having to break that news to someone, actual sexual intimacy is a huge thing, and keeps me from even wanting to meet other people and put myself out there.” –Lili

“I was a full-time paramedic, I worked 80 hours a week because I wanted to...And today, I am in a wheelchair. I require care 24/7.” –Shannon

“I know I need to work for a living to be able to afford all the treatments and medical bills that I have, but also, I could sleep all day.” –Amanda

“I plan things, but my body won’t cooperate. It’s become a task to enjoy those events you plan to have.” –MaryAnn

“My bones are becoming so fragile and I’m afraid to exercise now.” –Hannah

### ***Worries About LGSOC and the Future***

Participants were asked to select their top three worries about their condition in the future. The most common worries were **cancer spreading in the body and dying prematurely**, followed by **overall quality of life** and **worsening of symptoms** ([Appendix 5](#), Topic 1, Question 4).

During the moderated discussion, participants universally expressed the daily fear of disease recurrence and mortality that they must endure. A panelist who recently went back to graduate school expressed the difficulty of life with various doctors' appointments, pain, and concentrating on anything other than having cancer, capturing the group's sentiment. Discussing these fears and anxieties with significant others and family members is difficult, as is trying to plan for the future. A panelist mentioned that dating and friendships have been deprioritized in her life because she does not want to hurt more people than she has to. The fear of the unknown, including disease spreading or recurrence (and not being detected until it is widespread), is a concern of many participants in thinking about the future.

Panelists added additional worries that they did not see on the survey. These include the fear that more people will be diagnosed with LGSOC in the future with the same treatment options and survival outcomes we have today. Education and awareness of LGSOC amongst healthcare professionals needs considerable improvement. Lastly, the lack of FDA-approved treatments for LGSOC is another concern.

“This disease doesn't affect just the patient; it affects their entire family and their support system and their friends.” –Shannon

“I fear the pain and discomfort. I also fear having my kids see me decline. I don't want to be a burden on anyone, and I don't want their lives to revolve around my illness.” –Karen

“It is a daily conversation with myself to not let this consume me mentally.” –Tami

“I wish the FDA, insurance companies, doctors would put more emphasis on LGSOC to help us, because it is scary and we don't have a lot of options, even though some doctors say otherwise. My biggest fear is running out of those options.” –Amanda

## **TOPIC 2: PERSPECTIVE ON CURRENT AND FUTURE APPROACHES TO TREATMENT**

The second discussion focused on the different approaches for treating LGSOC currently and in the future.

### **LGSOC Treatment Experiences Testimonials**

Five panelists ([Appendix 2](#))—all people living with LGSOC—shared their experiences with treatment for LGSOC. A summary of their video testimonials is presented below, and the full statements from each panelist can be found in [Appendix 4](#).

- **Deana—47 years old living with LGSOC for >25 years**

Deana's first experience with LGSOC was at the age of 22 when she had a hysterectomy to remove two softball-sized cancerous tumors from her ovaries. Her disease course since then has been long and complicated, with multiple recurrences of the LGSOC, surgeries, treatments, and genetic testing. Deana has received hormone replacements, hormone blockers, multiple chemotherapy regimens, and targeted therapy drugs; she has been told there are no more options (until an opportunity to receive an immunotherapy drug, which she is currently receiving). She has lost the chance to birth her own children, lost her hair, felt nausea and heartburn, had a metal mouth, felt so tired she could not get out of bed to go to work, had sore muscles and body aches, had miserable blisters on her hands and feet, and had a rash so bad on her face that she "wanted to die."

- **Ginger—diagnosed with LGSOC at 41 years old**

Ginger's treatment for LGSOC included hysterectomy, colon resection, omentectomy, appendectomy, and lymph node removal, which was followed by six cycles of chemotherapy administered intravenously and intraperitoneally. Ginger was frequently hospitalized for dehydration; she lost all independence, including the ability to drive; she was vomiting, in severe pain, constipated, and "ready to give up." She states that after chemotherapy treatments, she went from "fighting for my life to fighting for a life." After finally recovering from severe toxicities, including neuropathy and internal damage from constant vomiting related to the chemotherapy, Ginger started taking an aromatase inhibitor orally. This treatment has brought on numerous other daily symptoms and struggles that include blurry vision, bone pain, joint swelling, dryness (vaginal, oral, skin, nail), severe anxiety, loss of libido, brain fog, fatigue, and a 25-pound weight gain that limits everyday activities.

- **Tiffany—diagnosed with LGSOC at 29 years old**

As a professional dancer with a life deeply rooted in health and athleticism, Tiffany's diagnosis of LGSOC has "challenged the very essence of the vibrant, active person" she once was, thrusting upon her "a multitude of both physical and emotional tribulations." Her early-onset menopause has caused disruptive mood swings, uncomfortable hot flashes, urinary infections, and disrupted sleep due to night sweats and distress. Tiffany is currently receiving combination treatment with a commonly used regimen for breast cancer: an aromatase inhibitor and a targeted kinase inhibitor, ribociclib. This regimen has resulted in chronic nausea, persistent bone pain, abdominal discomfort, and the unwavering challenge of fatigue, which over-the-counter remedies and dietary changes cannot improve. Tiffany would like a treatment that will help her "regain the ability to partake in normal activities without the constant presence of debilitating symptoms" and that "tackles the root cause of LGSOC." Tiffany's relentless symptoms have taken a toll on her personal relationships and serve as a constant reminder of hurdles she faces, yet she remains hopeful that the future holds better days where LGSOC is not the defining chapter of her life.



- **Kari—diagnosed with LGSOC in 2020 at age 44**

Kari has undergone surgery, which included removal of 10 inches of her colon, received chemotherapy for her LGSOC, and most recently was taking an aromatase inhibitor. She fears that she will die of LGSOC and wonders if she will be around for events in the not-so-distant future. Kari states that she feels like she is 80 years old, walking slower, joints and back hurting, with every new onset of pain sending her spiraling with the idea it is a sign that her cancer has returned. Kari takes antacids and stool softeners daily to keep her gastrointestinal symptoms in check; she has also gained a lot of weight, which is impossible to lose. Everyday tasks, such as washing dishes or opening a jar, have become excruciating, and her job as a writer has become miserable. Kari has tried numerous remedies for the pain, including cortisone shots, but to no avail. She has discontinued the letrozole, yet still feels disabled by it. Kari stated, “I am suffering every day from the side effects of the treatment I did have, not even from the cancer.”

- **Morgan—diagnosed with LGSOC at 30 years old**

After her diagnosis of advanced LGSOC, Morgan underwent a complex surgery. There was no chance to freeze eggs, and Morgan received six rounds of chemotherapy after the surgery. She likens her chemotherapy experience to “an arduous journey,” with hair loss, severe diarrhea, a painful rash covering her face, and anemia that led to shortness of breath even walking across a room. She continued treatment after chemotherapy with an aromatase inhibitor that led to intense hot flashes, crippling joint pain, and a 30-pound weight gain. Morgan faced her first recurrence in the fall of 2022 and has been frustrated with the lack of treatment paths. She enrolled in a clinical trial studying a MEK inhibitor, whose side effects are “almost as brutal as chemo.” Morgan has suffered from an extreme acne-like rash covering her face; nausea leading to blood vessels in her eyes bursting and facial swelling; muscle weakness, pain, and cramps; blurred vision; and fatigue that makes daily tasks a challenge. The clinical trial experience, with its multitude of doctors’ appointments, blood tests, and toxicities, has been challenging for Morgan, a single adult relying on her employer for health insurance, to manage. In her own words, “I hope for a future where I can cherish the simple moments.”

## **Patient/Caregiver Panel 2**

After the video testimonials, a live Zoom panel of people living with LGSOC (Appendix 2) shared their LGSOC treatment experiences.

- **Connie**, a 1-year LGSOC survivor, has undergone debulking surgery, received six rounds of chemotherapy, and is currently taking an aromatase inhibitor. Connie stated that support groups of other LGSOC survivors have been valuable in understanding and discussing the toll that LGSOC takes on people and how to navigate treatment effects with life.
- **Jane** has been taking an aromatase inhibitor and zoledronic acid for the past six years. Jane stated that dietary changes and active management of her symptoms have eased her discomfort.

- **Jess** has been living with LGSOC for three years, with her first recurrence behind her. Jess pointed out that many people with LGSOC are focused on fertility and longevity after surgery without considering the impact of LGSOC treatments on daily food and bathroom habits. She recommends movement for physical and mental balance.
- **Bailey**, originally diagnosed with LGSOC in 2019, is currently facing her second recurrence in the bowels. She is optimistic that a third surgery will be the most successful treatment.
- **Katelyn** diagnosed with LGSOC in 2009 when she was 29 years old, has been through multiple surgeries and treatments for the LGSOC diagnosis and recurrences. She identifies screening and education on side effects as the biggest gaps in preparing patients for LGSOC.

In addition to the panel discussion, live polling questions were asked throughout the moderated discussion to help gain perspective from all participants on their treatments for LGSOC and remedies for treatment-related symptoms and side effects. Selected written comments from patients and caregivers were shared by the moderators, and others called in to share their experiences.

### ***Medications and Tools to Manage LGSOC and Its Symptoms***

The first group of questions for the panel addressed the medications or medical treatments used, currently or previously, to treat LGSOC symptoms. Audience polling showed **aromatase inhibitor** and **over-the-counter products** as the top two medications used to manage LGSOC and its symptoms ([Appendix 5](#), Topic 2, Question 1). These were followed closely by **antidepressants or antianxiety medications, pain medications, and chemotherapy**; with bowel or bladder medications, sleep medications, and other types of medications closely behind that. **No one reported that they have not used medications or medical treatments recently.**

Attendees were next asked about supportive care used to help manage symptoms of LGSOC ([Appendix 5](#), Topic 2, Question 2). Audience polling revealed **lifestyle changes, such as exercise or avoiding stressful situations**, was the top strategy to manage LGSOC and its symptoms, followed closely by **massage, dietary supplements, counseling or psychotherapy, and support group**. Additionally, CBD, physical therapy, and herbal remedies were among the top responses. Once again, **no one reported that they have not used supportive care to help manage symptoms.**

In the next audience polling question ([Appendix 5](#), Topic 2, Question 3), close to two-thirds of respondents felt that their current treatment regimen **somewhat** treats the most significant symptoms of LGSOC, with close to one-third voting the treatment helps **very little**.

Written and caller comments reflected the complexities of treatments for managing LGSOC and its symptoms, with people describing complex surgeries, interventions, infections, and treatments, including colon resections, nephrostomy, chemotherapy, biologic therapies, and CDK4/6 inhibitors.

“Heating pad and foot massage tend to take away the neuropathy symptoms; the massages relax my body and mind.” –Nadina

“I’m lucky that I only am on letrozole, so there are no chemo side effects.... But I do feel older and less able to take an active part in my life than I believe I would have if it weren’t for this disease.” –Bobby

“I finally found a palliative medicine doctor to be my one shining light in this whole disaster.” –Shannon

### ***Biggest Downsides to Current Treatments and Effects on Daily Life***

After discussing some of the treatment options for LGSOC and their effects, the discussion was broadened to the limitations of treatments. The top three biggest drawbacks of LGSOC treatment approaches based on audience polling are as follow: **side effects, only treats some but not all of the symptoms, and not very effective at treating target symptom** ([Appendix 5, Topic 2, Question 4](#)).

Menopausal symptoms associated with surgery and/or the aromatase inhibitors many of these young women are receiving have a tremendous effect on their relationships and sexual health. Several panelists emphasized the importance of better education about the side effects of aromatase inhibitors, as well as discussing sexual health with healthcare professionals or people supporting their journey. Most expressed frustration at being so young and not being able to have a healthy sex life, with the added stress of sexual health being a taboo subject. Strategies for sexual symptom management that panelists shared included pelvic floor therapy (via videos from YouTube or brochures from healthcare provider/hospital), dilators, lubricants (eg, coconut oil, vitamin E oil, aloe-based oil), and Botox injections in the vaginal wall.

“I really encourage you all to not be ashamed about asking these questions because you're only going to get better if you get some options to explore.” –Jess

“I had difficulty with chemo and on reflection, I wish I hadn't had it, as my body is really only feeling like it belongs to me now and some bits are still numb and don't work as well.” –Alex

“I've had numerous scans and been referred to other surgeons, but no one will operate, and I'm told that I have stable disease. Still on no treatment, but still have abdominal pain.” –Linda

“I’m afraid of taking meds that could cause more back fractures.” –Betty

“Being 38 years old and the impact this has had on my sexual health and my relationship is huge.” –Connie

### ***Characteristics of an Ideal Treatment for LGSOC***

The last audience polling question ([Appendix 5](#), Topic 2, Question 5) focused on specific things that people would look for in an ideal treatment for LGSOC (short of a complete cure). The top characteristics of an ideal treatment were **preventing disease progression** and **treating the underlying cancer**. These were followed by reducing pain and helping with bowel/bladder function, which were much lower priorities. The panelists discussed other considerations for the future of diagnosing and treating LGSOC. Feedback included ease of use or administration, quality of life, early detection tools and tests for diagnosis before symptoms start, noninvasive treatment options, and more familiarity with LGSOC amongst healthcare providers.

“I just wish that there was a treatment option that I could have that would slow disease progression without being in debilitating pain, because the pain just impacts every part of my day, and I have to spend a lot of time and money outside of treatment to try to help myself with those side effects.” –Ellie

“Ultimately, I need to be here for my family.” –Bailey

“If I were to speak to the FDA, we need more medications that one, elongate our life, but two, just enhance the quality while we're working through this chronic disease.” –Connie

“I would love to see more doctors ...more aware and familiar with this disease and understanding the need for early screening and understanding the impact that it will have on somebody's life and providing resources for a patient once they are diagnosed and knowing that it impacts every aspect of your life, especially when most of us are so young.” –Katelyn

“Why is there no playbook on LGSOC?” –Rachel

## WRITTEN COMMENTS

Fifty-seven people submitted multiple written comments before, during, and up to 30 days after the meeting. Selected written comments have been included in the sections above, and others are excerpted below. A full list of submitted written comments can be found in [Appendix 6](#).

“My wife, Suzanne, succumbed to her LGOC on July 14, 2021. Her treatment was standard - surgery to remove tumors followed by several rounds of chemo, which were severely debilitating and ultimately useless. She participated in several clinical trials, without success. In September 2020, Suzanne's cancer had spread to her intestines, causing inoperable blockages. She survived until late June 2021 thanks to a portable iv nutrition regime and an indomitable force of will to live and love. At that point the cancer actually grew through the skin of her abdomen and she decided that hospice was the appropriate option. She passed away 12 days later.” –Mike

“Some days, survival feels overwhelming because it carries so much loss and grief over every aspect of life: sex, infertility, weight gain, fear, anxiety and depression, panic, physical pain, and discomfort. Then I am reminded of how precious life is and I am grateful for each day, week, months, and years, despite a continued struggle to form an identity of a person's life I never wanted to be living or envisioned.”—Katelyn

“I was diagnosed with LGSOC 3a in September 2021. I went through 3 debulking surgeries and finished chemotherapy in May 2022. I've been on Letrozole since, and I was told 'forever.' I've had pretty much all the advertised side effects of chemo, but I think the worst 'side effect' was what happened as I was finishing chemo--I became depressed, because nobody prepared me for facing the rest of my life and living in surgical menopause, while constantly fearing a recurrence. I am on an antidepressant and see a psychiatrist regularly.... My marriage is hanging by a thread—on top of having no libido, sex is physically difficult due to vaginal dryness and atrophy.”—Luiza

“Symptoms of LGSOC haven't changed much since surgery. I'm just living with the new me, not able to do what I used to but just glad to be here.”—Claire

“LGSOC has affected every aspect of my life. Anxiety at an all-time high, joint pain, memory loss, loss of libido and sexual function. Financial hardship due to having to travel to Houston, due to the lack of knowledge here locally by gyn-oncologists that my insurance will approve.”—Sara

“What I fear most is progression.... Clinical trials are not an option in New Zealand. I worry that I don't have any real options if/when this treatment stops working.”—Fazilah

“Being women, and for me a woman of color, we're often not taken seriously by doctors. While there are many great doctors like Dr. Gershenson, there are also a number of doctors out there who tell us we probably have food allergies or anxiety.”—Sarah

“I would love for a standard of care to be created for LGSOC so that all patients with this horrible disease receive the same options and the best care possible.”—Rachel

## CONCLUSIONS

This externally-led patient-focused drug development meeting for low-grade serous ovarian cancer provided the FDA, drug developers, researchers, advocates, and other stakeholders with foundational knowledge on LGSOC and an opportunity to hear directly from individuals living with LGSOC and their loved ones. Participants shared their perspectives about the impact that LGSOC has on daily life and illustrated the daily challenges and burdens of living with LGSOC. They described their fears and worries about their jobs, relationships, and future. They described the difficulties of living with LGSOC over the long and arduous course of their disease:

from the time of disease onset and symptoms to diagnosis, to complex surgeries, to tough chemotherapy courses, to maintenance treatments, and, ultimately, to recurrence.

Participants were candid about their frustrations with the current treatment options, the lack of a standard of care, and the side effects these treatments produce. In particular, early menopause due to total hysterectomy robs young women of the chance to have children. These perspectives emphasized the severe emotional impacts of LGSOC and the need for more effective, safe, and convenient therapeutic options.

STAAR is grateful to the individuals living with LGSOC, as well as their loved ones and representatives, for courageously sharing their personal experiences and perspectives and making their voices heard. The meeting allowed the FDA and LGSOC stakeholders an opportunity to gain insights into the desperate need for new treatments for this life-altering disease.

## APPENDIX 1: MEETING AGENDA AND DISCUSSION QUESTIONS

### MEETING AGENDA

10:00-10:05 AM	Welcome Nicole Andrews, STAAR Ovarian Cancer Foundation, Board Chair; meeting co-moderator
10:05-10:10 AM	FDA Opening Remarks Dr. Laleh Amiri-Kordestani, CDER, Office of Oncologic Diseases/Division of Oncology I
10:10-10:25 AM	LGSOC Clinical Overview Dr. David Gershenson, The University of Texas MD Anderson Cancer Center
10:25-10:30 AM	Introduction and Meeting Overview James Valentine, Hyman, Phelps & McNamara; meeting moderator (live from the studio)
10:30-10:40 AM	Demographic Polling

#### **Session 1 – Living with LGSOC: Symptoms and Daily Impact**

10:40-11:05 AM	Patient/Caregiver Panel 1 Video Testimonials
11:05-12:30 PM	Audience Polling and Moderated Discussion
12:30- 1:00 PM	Lunch

#### **Session 2 – Perspective on Current and Future Approaches to Treatment**

1:00- 1:10 PM	LGSOC Treatment Overview Dr. Rachel Grisham, Memorial Sloan Kettering Cancer Center
1:10-1:35 PM	Patient Panel 2 Video Testimonials
1:35-2:45 PM	Audience Polling and Moderated Discussion
2:45-2:55 PM	Summary Remarks Larry Bauer, Hyman, Phelps & McNamara (live via Zoom)
2:55- 3:00 PM	Closing Remarks Nicole Andrews

#### **Adjourn**



## DISCUSSION QUESTIONS

### TOPIC 1 – LIVING WITH LGSOC: SYMPTOMS AND DAILY IMPACT

1. Of all your symptoms of LGSOC, which one to three of those symptoms have the most significant impact on your life?
2. How does LGSOC affect you on your best days and on your worst days? Describe your best days and your worst days.
3. Are there specific activities that are important to you that you cannot do at all or as fully as you would like because of LGSOC?
4. What worries you most about the future of living with your condition?

### TOPIC 2 – PERSPECTIVE ON CURRENT AND FUTURE APPROACHES TO TREATMENT

1. What are you currently doing to manage your LGSOC symptoms?
2. How well do these treatments treat the most significant symptoms of your LGSOC?
3. What are the most significant downsides to your current treatments and how do they affect your daily life? (Examples of downsides may include bothersome side effects, going to the hospital for treatment, etc.)
4. Short of a complete cure, what specific things would you look for in an ideal treatment for LGSOC?

## APPENDIX 2: MEETING PARTICIPANTS

Nicole Andrews	STAAR Ovarian Cancer Foundation, Board Chair; meeting co-moderator
James Valentine	Hyman, Phelps & McNamara; meeting moderator
Larry Bauer	Hyman, Phelps & McNamara
Dr. Laleh Amiri-Kordestani	US Food and Drug Administration, CDER, Office of Oncologic Diseases/Division of Oncology I
Dr. David Gershenson	The University of Texas MD Anderson Cancer Center, Department of Gynecologic Oncology and Reproductive Medicine
Dr. Rachel Grisham	Memorial Sloan Kettering Cancer Center, Director, Gynecologic Medical Oncology

### TOPIC 1: LIVING WITH LGSOC: SYMPTOMS AND DAILY IMPACT

#### ***Video Testimonials (pre-recorded):***

Ellie	LGSOC Patient
Laura	LGSOC Patient
Dima	LGSOC Patient
Emma	LGSOC Patient
Lisa	LGSOC Caregiver

#### ***Panelists (live Zoom audience):***

Amanda	LGSOC Patient
Kat	LGSOC Patient
Tami	LGSOC Patient
Lili	LGSOC Patient
Monica	LGSOC Patient

### TOPIC 2: PERSPECTIVE ON CURRENT AND FUTURE APPROACHES TO TREATMENT

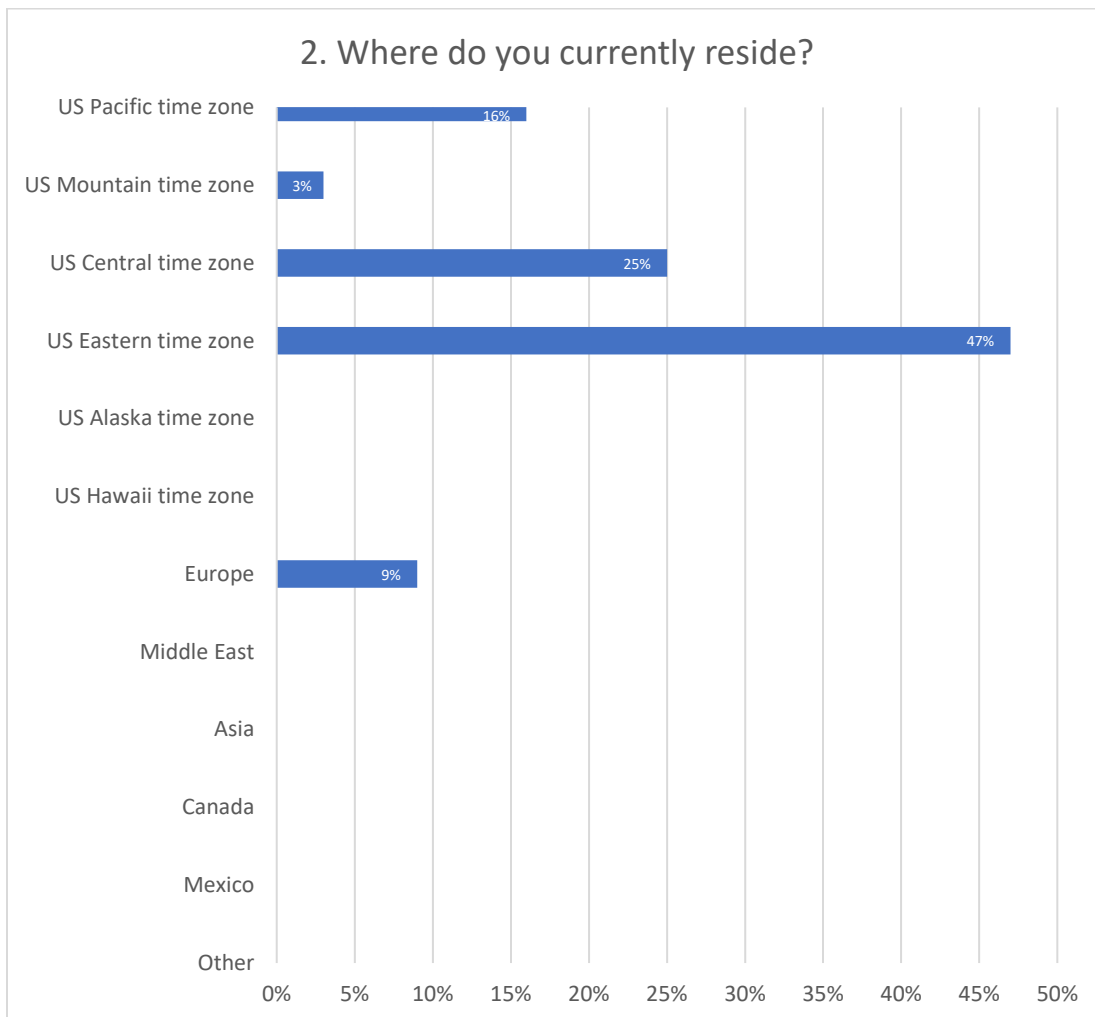
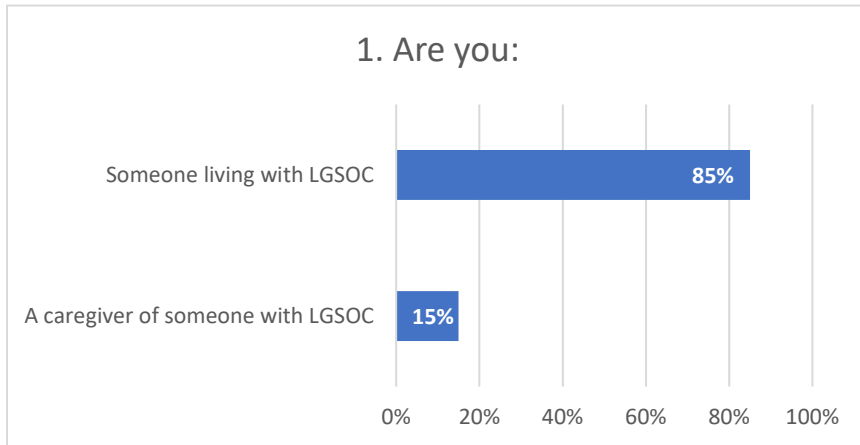
#### ***Video Testimonials (pre-recorded):***

Deana	LGSOC Patient
Ginger	LGSOC Patient
Tiffany	LGSOC Patient
Kari	LGSOC Patient
Morgan	LGSOC Patient

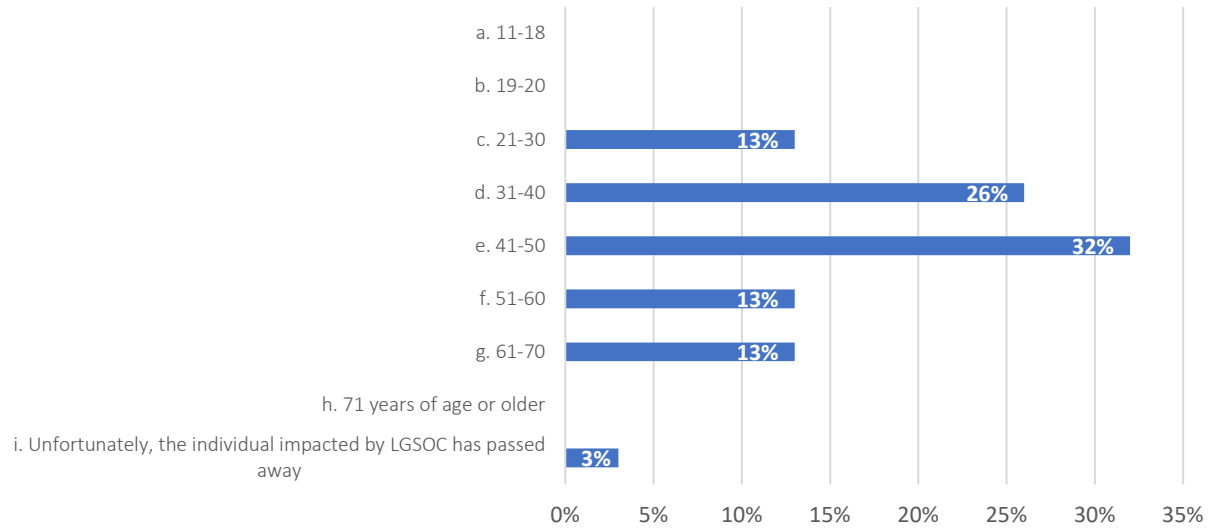
#### ***Panelists (live Zoom audience):***

Connie	LGSOC Patient
Jane	LGSOC Patient
Jess	LGSOC Patient
Bailey	LGSOC Patient
Katelyn	LGSOC Patient

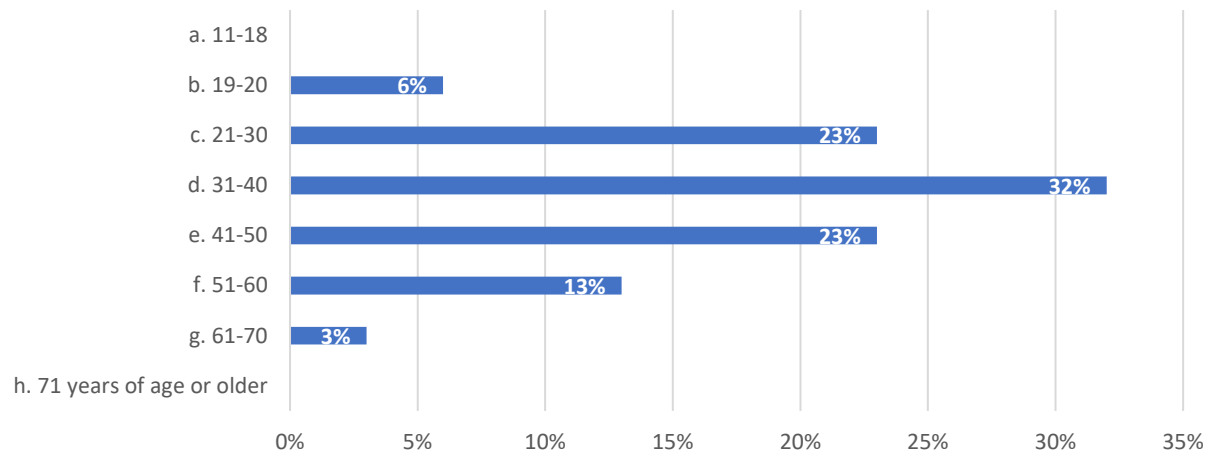
## APPENDIX 3: DEMOGRAPHIC POLLING QUESTIONS AND RESULTS



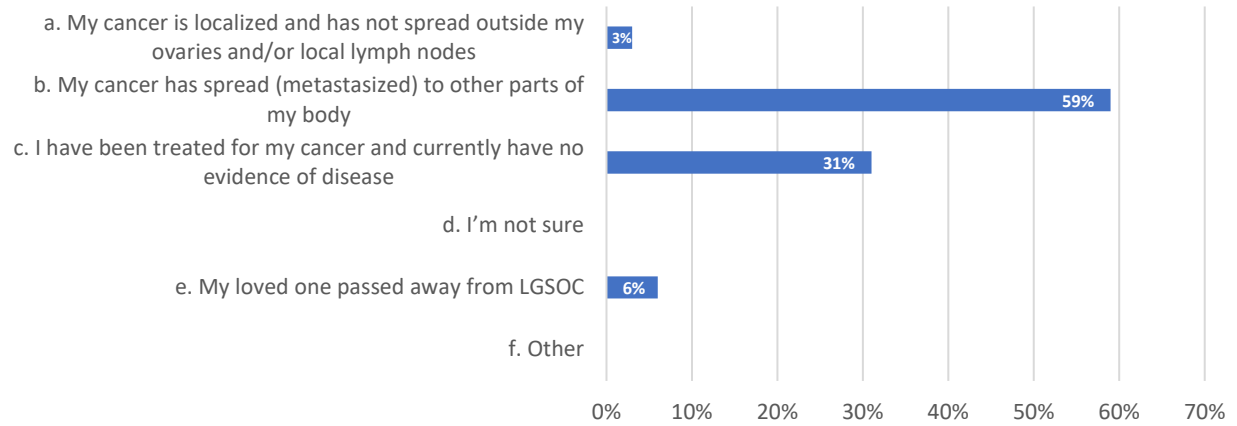
### 3. How old is the individual with LGSOC?



### 4. At what age were you or your loved one diagnosed with LGSOC?



### 5. Which of the following best describes you or your loved one's current condition?



## APPENDIX 4: LGSOC PATIENT AND CAREGIVER TESTIMONIALS

Transcripts of the pre-recorded video testimonials of LGSOC patients and caregivers are presented below by topic.

### TOPIC 1: LIVING WITH LGSOC: SYMPTOMS AND DAILY IMPACT

#### Ellie's Story

My name is Ellie. I'm 30 years old and I live in New Jersey with my husband and my two dogs. I was diagnosed with stage three C low-grade serous ovarian cancer in 2021 at the age of 27. Prior to my diagnosis, I had a variety of very vague symptoms that were dismissed by medical professionals, such as bloating, a sudden onset of pain during sex, and extreme fatigue. I now experience a new range of symptoms related to living with this disease. I would say that the most significant symptoms I have are everything that comes along with menopause and what my body has been through. My aromatase inhibitor medication causes an intense version of menopause, since it blocks all estrogen from being produced in my body. So I have all of the symptoms of menopause in a heightened state. I'm in constant pain.

As a result of menopause, my current treatment, and previous chemotherapy, the fatigue and brain fog that I experience now has taken a huge toll on me. Things such as word retrieval and short-term memory are significantly more challenging for me than they were previously. At age 30, chronic joint pain has definitely had a huge impact on my day-to-day, and every single joint in my body aches, from my shoulders to my ankles and toes. I'm not able to do some of the things that I used to do or do them to the extent that I would like to. Professionally, I'm a teacher of the deaf and I use sign language at work. Due to the pain and stiffness in my hands and fingers, I have had to make time to go to occupational therapy to work on the fluidity of moving my fingers again, so that I could continue to be proficient at my job. While these types of therapies help, it does not take away the pain, and that is something that I'm learning to live with.

Other symptoms of menopause include things like hot flashes and sexual changes. Because I have no estrogen in my body, I also have no libido, and I'm somewhat newly married, and it's something that impacts my life on a day-to-day basis. I want to want to have sex like I used to. So not only does it impact me, but, of course, my husband's life. In order to help make sex less painful, when I force myself into the mood, I have to regularly use non-hormonal creams to provide any sort of moisture in my vagina. And I'll be losing even more of my free time to coping with the effects of this cancer and treatment as I start a pelvic floor physical therapy routine. I am not able to carry a child, and that has been emotionally devastating for me. After sex, I turn away from my husband, so he can't see that I'm holding back tears, because his semen has nowhere to go inside my body. It's something that I have to work on every day in therapy to come to terms with and accept. And I just want to be who I was before cancer.

A good day for me includes waking up with my hands tightly fisted. I have to stretch them out before I get out of bed or I won't be able to hold my toothbrush. When I walk to the bathroom, all of my joints crack and ache until I get moving through the morning. Then I go to

work where I find myself embarrassed about my slower productivity and memory loss. I cannot adjust to temperature changes and have had to stop teaching in the middle of lessons due to feeling ill from hot flashes. When I get home from work, I'm completely exhausted. I feel sad and guilty that I don't want to jump into bed with my husband. I'm too tired to exercise or play with my dogs. I have to ice or heat my bones and joints regularly. I have osteopenia and I'm concerned that as I continue to be on an aromatase inhibitor that I will continue to lose bone density and function in my joints. I'm terrified that the statistics show that most likely my cancer will return, yet we lack treatment options.

I'm worried that the side effects of living with this disease will continue to worsen. What will that mean for my marriage if my vagina continues to atrophy? If I lose functioning in my hands, how will I continue to do the job that I love so much? I wish that there was more visibility for people living with this disease and for advancements in the treatment of the disease itself and the side effects that come along with living with low-grade serous ovarian cancer.

There are certainly those especially bad days where I just feel absolutely defeated emotionally. I might be scrolling on social media and see a pregnancy announcement and cry for a while over the fact that I've lost my fertility to this disease. Then I spiral more and cry about the people that we've lost to this disease, the lack of awareness, and the terrifying lack of treatment options that will be available to me when I likely have a recurrence of disease. Then I take my medication and if I'm lucky enough to fall asleep between hot flashes, I'll wake up the next day and do it all again. Thank you.

### **Laura's Story**

Hi, I'm Laura from England. I'm 37 years old and mother to Dylan who is 13 and Amelia who is 11. My journey with low-grade serous ovarian cancer started back in 2016 when I was diagnosed with Stage 3C. This was discovered when I ended up in hospital with pain in my pelvis. The doctors originally thought this was down in my appendix, but a scan showed large ovarian cyst and later a biopsy showed cancer. Two surgeries later, I had a discussion with the oncologist and it was decided that a total hysterectomy and chemotherapy would be the route for me. After all, I am one of the lucky ones—I already have my children. However, this still was not an easy decision as who knew what the future would hold, and, as it happens, I'm now with a new partner and the decision to ever have a child together has been taken away from me.

After the chemo, I was no evidence of disease until this year when I learned the cancer had reared its ugly head again. I knew even before the blood work and CT scan results were in that it was back. I felt exactly the same as I had seven years ago. I was bloated and had severe pain in my pelvis and lower back. The blood work and the scans confirmed what I already knew and I now find myself living with LGSOC. Being thrown into surgical menopause at the age of 29 was utterly horrendous. I knew when I woke from surgery, I felt different. I wasn't myself and the moment the first hot sweat hit me was like the slap in the face. They take over your whole body and within seconds you're drenched in sweat.

The weight gain has been hard. I've never been a particularly slim person, but this is a different type of weight gain. It doesn't matter how little you eat; it still finds a way of clinging



on my tummy and it really gets me down. The sleepless nights when the rest of the house are sleeping and I find myself alone in my own head is a very lonely place to be. The bad thoughts take over. The thoughts of my parents having to bury their daughter, my children having to bury their mother—it's heartbreaking. It really is. The weight gain, hot sweats and sleepless nights definitely hit me hardest and I found myself slipping into a depression. The side effects from the cancer, previous chemo, and menopause all became too much.

Looking back before my diagnosis, the first symptoms for me were severe lower back pain and discomfort in my pelvis and the bloating. The lower back pain is constant and still with me after seven years. It makes even the shortest of walks unbearable. It feels like there are heavy bricks attached to my back and it aches so much. The discomfort in my pelvis is constant, too. It feels like pressure and pushing and makes sex uncomfortable. This also really, really gets me down. The bloating makes every meal feel like a chore, feeling so full that my own insides are going to burst open, and as a bigger lady who was already self-conscious about my weight, the bloating makes it a hundred times worse. On a bad day, I just don't want to get out of bed.

Going back to the hot sweats I mentioned earlier, I have a new partner and it should be fun and exciting. Well, not when you're constantly dripping in sweat and worried what he will think of me. Does it repulse him? Does it make him not want to touch me? It's so embarrassing and this leads me onto my mental health, which has been affected dramatically since my diagnosis. There is a constant battle in my head. The not knowing how long I have left, being told at 37 that the cancer is incurable, knowing that I'll be living with the side effects for the rest of my life, always wondering how many Christmases and holidays I'll have left with my children. Maybe it would be easier knowing how long I'm going to be around for.

Then there is the unbearable guilt I feel. I feel it towards my children. I brought these little people into the world and in the not-so-far future maybe I'll be leaving them without a mother. My parents, my siblings, my partner and family, the hurt I see in them because my diagnosis is heartbreaking. I'd like to sit here and say the side effects and mental impact gets easier for me. It doesn't. This is my life now battling with pain, constant discomfort, and depression. There is no light at the end of my tunnel.

### **Dima's Story**

Hello, my name is Dima. I'm 44 years old. I'm a lucky mom to three teenagers, 16-year-old triplets. They are two girls and a boy. I am a sister, I'm a daughter, and I'm a wife. I have a successful career and a full life. I've been dealing with malfunctioning ovaries ever since I could remember. Painful, heavy and irregular periods ever since I could remember. I've seen more gynecologists and doctors than I care to remember. I've been brushed off, told everything I am experiencing was normal. "It's nothing to worry about," I've also been told more times than I care to remember. At 21, I had one ovary and a portion of another removed due to a borderline ovarian cancer after a large mass was discovered. A few years later, I had what's left on my other ovary removed due to a recurrence of the borderline ovarian cancer.

Menopause and all of its glory hit me hard. Birth control followed by hormone replacement therapy was my doctor's answers. That meant more heavy, more irregular, long and very painful periods while dealing with menopause and the fact that I no longer had my ovaries in my twenties. I can't really put it into words, especially at a young age, what it feels

like. "Coming down with something?" people would ask me when I had one of my hot flashes. "It's menopause," I would reply. They would giggle and say, "Right." No one really understood my struggle. I mean, how could they? A young female in my twenties full of life, but yet I'm dealing with menopause in silence. Believe it or not, though, I was one of the lucky ones. He was able to harvest eggs prior to my last surgery. At 28, I would be blessed with my triplets.

In my thirties, the pain got worse. The periods got heavier and more irregular. I was dealing with abdominal pain. At that point, I had to use FMLA because of how severe it got and how frequent it was. I also started exhibiting new symptoms like frequent urination. I repeatedly asked for answers. I repeatedly asked for tests. I would be told that the pain is probably due to the multiple surgeries and that my other symptoms could be explained with getting older and the fact that I carried triplets. In 2020, in the middle of the pandemic that we all dealt with, my pain and discomfort got to a whole new, different level. An ultrasound would reveal ascites, which at the time I did not know what it was. A CAT scan a few days later would reveal ovarian cancer. I'm a woman who got ovarian cancer more than a decade after getting my ovaries removed. Terrified doesn't even begin to explain what I was feeling, but I was very angry, too, and then I had to deal with all the what-ifs.

I went on an emotional and a mental roller coaster. What did I do wrong? I was experiencing ovarian cancer symptoms for years by that time. Oncologists actually confirmed that I probably did have ovarian cancer for years before it was finally discovered. A major surgery to try to remove all the low-grade serous ovarian cancer was performed, which again would determine that's exactly my diagnosis—low-grade ovarian cancer. A few weeks later, I started chemotherapy. I was so desperate for treatment that I consented to chemotherapy knowing all the awful side effects, knowing it will probably do nothing to the cancer because chemotherapy is not an effective treatment for low-grade serous ovarian cancer. I was supposed to have six infusions. I ended up with four out of the six because chemotherapy nearly killed me. I nearly needed another blood transfusion. I could not get up from my chair without running out of breath. I lost all of my hair, my eyelashes, I lost me. It was a terrible time for me.

My oncologist recommended that I stop at four treatments. As I suspected, low-grade serous carcinoma was not affected at all by that chemo treatment. So after being on hormone replacement therapy prior to the surgery, I was finally put on the right treatment, that being hormone blockers after the surgery and after finishing my four infusions of chemotherapy. There is a misconception about cancer treatment and options out there. People think that cancer treatments came a long way and that's true for a lot of the cancers, for most of the cancers, but not for low-grade serous carcinoma. Currently, most of our options come from breast cancer. How could that be? We need hope. Hope of possible effective treatment for us, hope for better outcomes for me, hope of a life because I deserve it.

### **Emma's Story**

My name is Emma. I'm 29 years old and I was diagnosed with low-grade serous ovarian cancer at the age of 26. The three surgeries and grueling chemotherapy regimens of CarboTaxol that followed my cancer diagnosis were unpleasant, but my hair grew back, the scars across my abdomen faded with time, and the tingling and numbness in my limbs dissipated. I'd like to help

you understand that this insidious cancer has effects that outlast and outweigh even the most gruesome side effects of cancer treatment. Women in their twenties are told to embody agency and be a girl-boss, date who you want, don't have kids until you want, run the world. When you're diagnosed with ovarian cancer as a young woman, you lose agency in so many ways, particularly in the family planning decision-making process.

I will never have that moment of waiting in the bathroom with my partner for the pregnancy test result to appear on the test strip. I will never get to give a sonogram photo of the life growing inside of me to my parents or in-laws for Mother's Day or Father's Day. I will never get to feel a baby kick or move inside of me, or have my partner hold my pregnant stomach in amazement of what we have created together. Of course, there are so many ways to build a family in 2023, but this cancer has robbed me of the opportunity to experience any of those moments I have spent my whole life envisioning. While I was privileged enough to freeze my eggs in between surgeries, I will need a surrogate to carry our child, and the expenses of that are inordinate. While most couples my age are saving for things like a first house, their honeymoon, or a car, we save up hundreds of thousands of dollars to pay for a woman to carry our child in organs that I no longer have access to because of this cancer.

Aside from the loss of fertility, being diagnosed with menopause at the age of 26 has symbolized a loss of youth and vitality. I take an aromatase inhibitor, letrozole, daily that blocks estrogen and causes very unpleasant side effects such as osteoporosis, joint pain, and exacerbated symptoms of menopause. This drug is not even approved for this cancer, and I have been told I will be taking it until it stops working or until I can no longer handle the side effects, whichever comes first. In turn, I have full-fledged osteoporosis that cannot be reversed. This makes me feel old, fragile, and, frankly, pathetic. My fiancé has inadvertently cracked my ribs from hugging me too tightly. I wake up in pain and I feel like I'm a hundred years old. Every time a new doctor asks me when the last date of my period was or if there's a chance I could be pregnant, I hold back tears and I think, "I wish."

Without sharing the details of my personal intimate life, menopause at my age takes a huge toll on a relationship with a partner both physically and emotionally. I love and desire him more than anything in this world, and yet my body and I are at war. Most people feel betrayed by their bodies when they're diagnosed with cancer, and even though I've had no evidence of disease for over two years, I feel betrayed by mine almost every single day.

When you lose your fertility and your youth suddenly and dramatically, there's a lot of mourning, resentment, trauma, and anger. There's also fear. Will this scan be *the* scan? Will this MyChart message be the one showing my CA 125 is above 35 again? Will this Facebook post show another person in our community having a recurrence or, worse, someone's husband or daughter posting for their wife or mom who is now passed? I have a whole life. I have a whole and full life. I want to live and I deserve better.

By the time you're hearing this, I'm on a beach in Colombia on my honeymoon, and I'm about to begin a new chapter of my life with someone who has been by my side through it all. I won't accept the statistics that interrupt my sleep and keep me incessantly refilling my Ativan prescription so that I can take full inhaled. I won't accept that we don't have our own medications and treatments. I won't accept having to "like" post after post of tributes and

memorials to women who look like me in their twenties, ready to begin their adult lives robbed of that opportunity. I won't accept it.

### **Lisa's Story**

Good morning. My name is Lisa. I lost my beautiful daughter, Lexi, to low-grade serous ovarian cancer three months ago. Yesterday would've been her 30th birthday. Lexi had no family or genetic history and in spite of receiving care from some of the best experts in the world, we lost her within two years. Lexi, while not even five feet tall, had the spirit of a giant. She was a natural-born leader, a lifelong athlete, extremely intelligent, and was always an advocate and defender of the vulnerable. She traveled the world and arguably she lived more in her short life than many her seniors. "No" was never an option for Lexi. She often said, "Mom, there is no losing. There is only giving up." When she was diagnosed, she vowed she was not giving up. Although Lexi appeared to be the picture of health, looking back, she had recurring abdominal pains for much of her life, which had resulted in a cholecystectomy and a hospitalization for what we believed was IBS.

The pains became more intolerable and two years ago led her to the emergency department and an emergency ovarian cystectomy. Thankfully, a small single row of cells on the peritoneal wall was biopsied, leading to a diagnosis no one ever wants to hear. Lexi had a wonderful husband, a strong support system, and a medical family. She vowed to beat the odds, staying strong and healthy while awaiting future research. She sailed through the 10-hour debulking surgery and responded beautifully to the standard-of-care platinum-based chemotherapy with virtually no side effects. In fact, she felt better than she had in years. Lexi was able to eat foods she hadn't tolerated for many years, and that left upper quadrant pain she had felt daily for almost 10 years was completely not present.

We now know that pain was probably a result of the cancer, but the gloves were now on for my Lex. She went into gladiator mode and she was ready to take it to the mats. She was featured on "TV for Mother's Day," interviewed for podcasts, and her picture was displayed in Times in Piccadilly Square for World Ovarian Cancer Day. The lack of treatment options and funding for low-grade serous ovarian cancer led Lexi to meet with local and national politicians and personally raise almost \$100,000 towards research before her death. During this time, Lexi and her husband, David, tried their very best to live and thrive. She attended a cancer camp in Maui and learned to surf. The camp physician aptly named her "The Little Firecracker." The couple fulfilled a life dream in moving to Manhattan, but Lexi now began a journey of multiple failed treatments. No longer did she sail through without symptoms. She would initially respond to each treatment and endure the terrible side effects, hoping each time this will be the one that holds.

Unfortunately, Lexi's cancer was much like she was—very smart and very aggressive, nothing held. Trametinib destroyed her beautiful face and her scalp. She worked from home so no one could see her. She developed severe gastritis and gastroparesis, resulting in a hospitalization. She developed bilateral pleural effusions, which required permanent drains, expensive supplies, and limited her ability to dress normally, shower, or swim. Still, she fought on. By this time, Lexi had 10,000 Instagram followers, mostly low-graders. She began making many videos, documenting her experiences, sharing symptoms awareness, tips for living with

low-grade, and poking fun at the many sad gaps in our systems of care. The disease progressed further. She developed severe lymphedema, anasarca, blood clots and peritoneal ascites. Her weight was 163 pounds before removing 11 liters of fluid; that's 33 pounds in a single day. Her true weight was probably about 85 pounds.

Activities of daily living were impossible. Just putting on compression stockings alone took over 30 minutes. Finding foods she could eat to try to help her to gain real weight and keeping her labs within normal limits was a full-time job. She was in severe pain and her mobility was extremely compromised. Another seven rounds of carboplatin, Avastin, and gemcitabine temporarily improved her status, and Lexi and David enjoyed Broadway shows, Harry Potter Butterbeer, and the Metropolitan Museum of Art. But symptom overload ultimately caused withdrawal of all treatments and disqualified Lexi from a new research study. She became physically and emotionally exhausted. As she said, "Mom, there is no losing. There's only giving up." On June 4th, my little firecracker gave up. I've given you just a glimpse of what these young women experience, but to truly understand, I want you to read Lexi's blog and watch her videos. Thank you.

## **TOPIC 2: PERSPECTIVE ON CURRENT AND FUTURE APPROACHES TO TREATMENT**

### **Deana's Story**

How do you put 25 years of pain, misery, disappointment, loss, and pure torture into a few paragraphs? It's not easy, but I'm going to try. My name is Deana. I am 47 years old. I've been living with LGSOC for over 25 years. I am trying various treatments to stay alive. My first experience with this disease was at the age of 22. I had two softball-sized cancerous tumors in my ovaries, and had to have a hysterectomy, ending all dreams of birthing my own children at the young age of 22. And all we knew was it was ovarian cancer; there was no type. At this point, I started drug therapies. I was given hormone replacement pills to hold off early menopause, only about six years later to find out that it was actually growing my cancer. I switched to a hormone blocker, and we began monitoring my blood work for the CA 125.

I had another large tumor in my spleen at the age of 37. I went through a second major surgery, and was given six rounds of carboplatin chemo combined with Taxol. Unfortunately, four and a half years later, I had my second recurrence, so I was given doxorubicin. We stopped that after three of the six treatments because it wasn't working. My tumors were growing, and the side effects were even worse than the first chemo. I went through genetic testing on my blood, which showed I had a BRCA2 gene mutation, so I was prescribed Rubraca. It worked to keep the tumor stable for about four years, and then it grew again.

I then went through genetic testing on the sample of the tumor on my spleen, and was prescribed trametinib, my fifth drug therapy to target my specific mutation. I only lasted 30 days on that drug, because the pain of the rash was so bad on my face. We tried to keep adjusting the dosage to help side effects, but the cancer broke through again. At 47 years old, in June of 2023, I went through my third major surgery for tumors on my stomach, colon, liver, and all in my bowels. I woke up, and they found that they had done no tumor debulking at all because they felt it was better to close me back up and let me heal faster to get to a treatment.

And the last 25 years, I have lost the chance to birth my own children, lost my hair, felt nausea, heartburn, could only eat certain foods, had a metal mouth, and felt so tired I couldn't get out of bed to go to work. I've had sore muscles and body aches; I sit in the shade in long sleeve shirts and long pants in the summer. I have had miserable blisters on my toes and my hands that would take weeks to go away, and a rash so bad on my face that I wanted to die.

But the worst that I've ever felt was this year after surgery, when there was no plan for a new medicine because Michigan had run out of options for the amount of times that I have had reoccurring LGSOC. So, I sat and I waited to see what was next, and if there was anyone out there that could help me. And I will tell you the waiting, it breaks a person's spirit. And all the years I spent training myself on positive attitudes and smiling and keeping your spirit up, that was a long, dark tunnel to look down.

Finally, almost six weeks later, I had an appointment five hours away from my home in OSU. They had a drug trial they felt could help my cancer. The downside is I have to be in Ohio more than I'm at home. I'm currently on that drug trial combining with an immune therapy called cemiplimab. This will be my sixth medicine we have tried. I have been fighting this disease for over 25 years, and I feel sometimes I am stuck in an elevator going from the basement to the penthouse of a high-rise building, and I cannot get off, back and forth I go. I have two teenage boys that we were lucky enough to adopt and that are being taken care of at home, not by us, while my husband and I spend three out of seven days a week in Ohio, trying to keep me alive.

### **Ginger's Story**

Hey, my name's Ginger. I'm a registered nurse, and I live in Bristol, Tennessee, with my husband of 13 years, Mike. Symptom management has included so many failed attempts, with very few creating a long-term tolerable state. The only thing that I've found is to listen to my body. When I need rest, I rest. When I need movement, I try to move. I'm always open and creative with researching symptom management. At 41, I was diagnosed with low-grade serous ovarian cancer. My treatment included a complete hysterectomy from the cervix up, colon resection, omentectomy, appendectomy, and a lymph node removal.

During those last few presurgical moments, even surrounded by my family, friends, and pastor, I never felt so alone, and knew that was the last time I would feel whole as a woman. My gyn onc performed my surgery, but prior to it, he warned me the recovery would be long and painful, and he was going to make me very sick with chemo. The chemo regimen was a treatment for high-grade ovarian cancer, which acts and reacts completely different than my low-grade. Low-grade did not typically respond to chemo, but in early 2017, it was my only shot, so I took it. Little pain control existed for the surgery. And just as my body was beginning to heal, it was time for frontline chemo infusions of six 21-day cycles of Taxol and cisplatin intravenously and hyperthermic intraperitoneal chemo. My electrolytes were at critical levels from the chemo.

This led to hospitalizations and weeks of daily IV infusions for hydration, potassium, and magnesium. These critical levels caused my extremities to draw [pull], and was so severe that I had bruising on my joints and tremendous pain. I then lost all independence because it was unsafe for me to spend time alone. I couldn't drive, eat or drink, could barely walk, and could

not stop vomiting. I was in unbearable pain, and had severely painful constipation. I was ready to give up. I had no idea how my husband, momma, and family survived this, either. This diagnosis and treatment shifted something inside of me. I had so many fears and would not commit to any plans outside of the immediate future for so many years afterwards. I'm thankful time has stilled those memories, because it was painful, and I considered giving up. I'm a fighter all the time, but this treatment was so incredibly terrible.

My oncologist agreed to IV Toradol on infusion days, which is a chemo no-no. Toradol decreased the pain slightly, so we kept using it. The nausea and vomiting were never controlled, and I tried every single drug available. At that time, I resorted to occasional marijuana use. I'd sit out on my front porch, and occasionally smoke some weed to get through the worst of days. It at least did allow me to sleep through some of the pain and vomiting. After chemo, it wasn't over. I went from fighting for my life to fighting for *a* life. Chemo toxicities caused neuropathy and made walking and use of my hands almost impossible. I was so weak, tired, and had chemo brain. I slowly added a very grounded yoga to my routine, eased back into work, and added frequent walks. I had surgery to repair hernias from my debulking, which failed.

I had an endoscopy and took medication due to damage from chronic intense vomiting. A couple of years later, I joined a CrossFit gym, and slowly built up my stamina and strength. Once my cancer was considered chronic, or as a chemical recurrence in 2021, I began aromatase inhibitors because it finally was approved for low-grade patients. The drugs are for certain breast cancer patients, and taken if tolerated, for about five years. But it's the only option for low-grade patients, and are used for as long as they work. Yet again, I'm not taking a drug for my cancer, but it's my only shot. The AI side effects led to utter exhaustion. Within three weeks of AI, I was laying on the CrossFit floor in tears because I just could not move anymore.

I now have blurry vision, bone pain with joint swelling, and dryness, including vaginal, oral, hair, skin, and nails. I have symptoms of severe anxiety, lack of mental clarity, and no desire for intimacy. There was an immediate 25-pound weight gain that caused me to feel short of breath and limits my activities. It impacted my self-confidence because now I look like a fat old lady with a handlebar mustache, and I appear about 10 years older than I should. I am so damn tired. It's frustrating and very expensive to find effective symptom relief. With severe pain, I alternate between ibuprofen and acetaminophen. Plus, I use topical CBD creams. I go to bed and rest. I have massages to ease my joint pain and I use so many products on my body and hair to alleviate dryness. I have juggled multiple vaginal moisturizers to stop pain from dryness and to prevent tears and yeast infections. I'm on a supplement regimen for bone loss caused by these drugs. I take a drug for ADHD now, which helps with focus and energy. And because of aromatase inhibitors, I can't read without glasses.

I am so fearful of having a short life and leaving my husband. There are so many places I want to experience and a life I want and deserve to live. I deserve a treatment that allows me to truly live. I need and deserve therapeutics, including holistic and medicinal, to treat this cancer and mitigate side effects. I deserve a surgical intervention, after all this treatment, that puts my bowels back in their normal position and holds them in place and repairs the

abdominal muscle damage so I can do normal activities. I deserve this, and all these women and our families deserve this.

### **Tiffany's Story**

Hello, my name is Tiffany, and I am from Palm Beach Gardens, Florida. At the age of 29, I was diagnosed with low-grade ovarian cancer. This unexpected turn of events has had a profound impact on my life as it has forced me to adjust to a new normal that is far from what I had envisioned for myself. Before my diagnosis, I lived a life deeply rooted in health and athleticism. I was a dedicated professional dancer, pouring my passion into every graceful movement. Sports had been an integral part of my life from an early age, and I thrived on the thrill of competition.

Whether it was dancing, playing sports, or simply staying active, I had always embraced a lifestyle that had celebrated physical vitality. Being healthy was not just a choice, it was a way of life that I cherished. Little did I know that my world would be forever altered by the unexpected diagnosis of low-grade ovarian cancer, a curveball that challenged the very essence of the vibrant, active person I once was. Low-grade ovarian cancer has thrust upon me a multitude of both physical and emotional tribulations. Experiencing early menopause at a young age has brought a range of challenges. Mood swings disrupt my emotional well-being, hot flashes are physically uncomfortable, and urinary infections are recurring issues. Night sweats further affect my sleep and add to the overall distress.

These symptoms highlight the complex nature of the challenges I face alongside my cancer journey. Currently, I am on a treatment involving hormonal therapy, a combination of Kisqali and letrozole. Regrettably, even with this treatment, the relentless battle continues. Nausea, persistent bone pain, abdominal discomfort, and fatigue continue to be an unwavering challenge, making the treatment intolerable at times. In pursuit of relief, I've turned to over-the-counter remedies like Tylenol and Advil, but they offer little comfort. Moreover, the choices I make regarding my diet and what I consume or drink can often provoke further discomfort.

For instance, indulging in fried foods or alcohol can exasperate my symptoms, intensifying the struggles I face daily. In my ideal world, the treatment I seek wouldn't just address the physical manifestations of this disease, but it would also encompass the emotional toll it imposes. I long for a remedy that not only calms the bone pain and fatigue, but rejuvenates my spirit and vitality. To regain the ability to partake in normal activities without the constant presence of debilitating symptoms would be an immeasurable relief.

I envision a treatment that goes beyond just managing symptoms—one that actually tackles the root cause of low-grade ovarian cancer. This, in my mind, offers a glimmer of hope for a future unburdened by the captivity of this disease. My dreams are fueled by the belief that advancements in medical research and technology will usher in breakthrough treatments capable of not only offering a cure, but also significantly enhancing the quality of life for individuals like myself.

My life has reshaped in ways I could have never anticipated. These relentless symptoms I endure and the toll they take on my personal relationships serve as persistent reminders of the hurdles that I face. Yet I remain steadfast in my resolve to continue this journey, hopeful



that the future holds the promise of better days where low-grade ovarian cancer is no longer the defining chapter of my life. Thank you.

### **Kari's Story**

Hi, my name is Kari. My awareness of having cancer in my body lasted less than three months. I hadn't been feeling sick at all when I found out I had ovarian cancer in April 2020. I realized later that I'd had sporadic back pain, heartburn, and frequent urination, but nothing that seemed worth mentioning to a doctor. I wouldn't even have found out I had ovarian cancer if it hadn't traveled up my umbilicus and out my belly button. After unsuccessful chemo in April and May, all visible cancer was removed by my awesome surgeon in June. Afterward, I heard the term low-grade serous for the first time.

As far as I knew, the cancer itself never made me feel sick. I didn't even know it was there. Chemo sucked and surgery recovery was awful, but that was the treatment, not the disease. Every step of the way I reported to others that I'm doing as well as can be expected. Since the surgery, I've had no evidence of disease for more than three years, but I'll be living with LGSOC for the rest of my life. When you're in active treatment, if you're lucky, which I was, you have a plan of action and a team of medical professionals taking care of you. Afterward, knowing the high recurrence rates and poor survival statistics, there is no going back to normal after LGSOC treatment.

Everyone wants to hear that I'm fine now or in the clear, when I won't ever be in the clear. It could come back any day and it's probably what I'm going to die of. I think about the money in my retirement plan that I'll never be able to spend, and I look ahead to events five or 10 years in the future and wonder if I'll still be here. On my best days, I know I should be grateful to be in as good health as I am, but I feel like I'm 80 years old. I walk slower, my joints hurt, my back hurts, and every new onset of pain sends me spiraling, thinking this is a sign my cancer is back.

During my surgery, I had 10 inches of colon removed, which has resulted in my needing to take Senna every day to stay regular. I have hiatal hernias, maybe from surgery, maybe from straining to poop, or maybe from weight gain, and these give me heartburn unless I take Pepcid every day. I'd gained a lot of weight before my diagnosis, which at the time I blamed on eating too much, but maybe it was a symptom of cancer. Since a lot of people associate cancer with weight loss, it feels like a failing that I've continued to gain weight and it is impossible to lose it.

I did Peloton rides six to seven times a week for the first two years after cancer treatment, and I didn't get any smaller. I've had trouble maintaining that routine because I'm so fatigued all the time, and because of the joint pain from the hormone blocker letrozole. I started taking letrozole immediately after surgery. I had some knee and foot pain within a few weeks, but it was manageable. Then I tripped and broke my ankle 12 weeks to the day after my cancer surgery, which might be unrelated because there was no indication I'd experienced any bone loss yet. But now I wonder if the joint stiffness from the letrozole made me clumsier.

After almost two years on the letrozole, I developed unbearable joint pain in my hands. Everyday tasks like doing dishes or opening a jar became excruciating, and my job as a writer became miserable. I worked on a PowerPoint presentation for a few hours and had crippling aching pain for weeks afterwards. When I asked around in the support groups, I found a lot of

people had experienced similar pain and I tried everything they suggested. Tart cherry, turmeric, Voltaren, massage, CBD, THC, acupuncture, and finally I received relief from cortisone shots in both of my thumb joints.

The first time I got them, I overheard a tech say, "She's getting them in both hands?" And the doctor said, "Yeah, she must be in a lot of pain." Honestly, the shots were not any worse than the pain I was already in. Unfortunately, the pain came back, and successive cortisone shots didn't alleviate it. I tried the other aromatase inhibitors with no improvement and eventually cleared it with my doctor to stop taking them altogether. It wasn't worth the pain. Earlier in my treatment, I'd heard others say that they couldn't tolerate the side effects of letrozole, and I thought they were out of their minds to go off the drugs. If it has the slightest chance of preventing a recurrence, isn't that worth staying on it?

But then two years later, there I was saying out loud to anyone who would listen that I would rather die than wake up in this much pain. I rationalized: who even knew if the letrozole was doing anything? What if the cancer was gone forever, and I was suffering for no reason? There was no way to know unless I stopped taking it and the cancer came back, then I'd have my answer. And I guess I'd go back on it if I knew for sure it was keeping me cancer free, but I don't even know if it would be worth the pain.

It's funny the things we feel most emotional about. I have told my cancer story to a lot of people, almost always with the attitude of, "Yeah, it sucked, but I'm doing as well as can be expected," and some silly little joke to reassure them that I'm fine now. But tears streamed down my face every time I had to explain that my hand pain was preventing me from doing some simple task like carrying a salad bowl.

I continue to feel disabled by it. It's been months since I've stopped taking any hormone blockers and I've been in occupational therapy and had another pair of cortisone shots, but I'm still having pain. So even though I'm a success story—my treatment worked, I have no visible sign of disease, I'm not currently on any treatment— I'm suffering every day from the side effects of the treatment I did have, not even from the cancer. Thanks.

### **Morgan's Story**

Hello, I'm Morgan, and my journey with LGSOC has profoundly altered my life. It all began September 17th, 2019, when, at age 30, I received a Stage 4 low-grade serous ovarian carcinoma diagnosis. Before I became a cancer patient, I was a healthy single woman who had just entered her 30s, and I faced a significant life decision: preserving my fertility by freezing my eggs. Having children was something that was important to me in the future, not at this moment.

I felt perfectly fine at the time, but an ultrasound, not routine but done to determine my eligibility for egg preservation, revealed multiple ovarian cysts. This led to a series of tests and scans including a follow-up CT that unveiled extensive suspected borderline or low-grade ovarian cancer throughout my abdomen and chest. We wouldn't know for sure until we did surgery. My CA125 measured 582, a stark contrast to the normal range of below 35.

By the weekend before my surgery, I was painfully bloated and the spotting I'd complained about since my original IUD placement three and a half years earlier had become nearly constant. Surgery was performed on September 17th, 2019, by a gynecologic oncologist

surgeon. It included a bilateral oophorectomy, a total abdominal hysterectomy with a vaginal cuff, a total omentectomy, splenectomy, and multiple resections of my valves, among other procedures. The operation lasted over nine hours, but remarkably, I left the hospital just five days later with no evidence of disease.

This all began because I had hoped to preserve my fertility by freezing my eggs. It was a dream of the future, but cancer had other plans. Cancer doesn't wait and it doesn't care about our dreams. It strikes swiftly and without warning, and it took away the opportunity I had hoped for. Six weeks later, I began the standard six rounds of chemotherapy and a combination of carboplatin and Taxol from October 2019 through February of 2020. This was an arduous journey with hair loss, severe diarrhea, painful Taxol rash that covered my face, and anemia that made me short of breath just walking across the room.

Recovery was another challenge. Disability lasted eight weeks following surgery, and when I returned to work, I navigated part-time hours between treatments and worked from home on the days I felt my worst. My life has changed in other ways. I immediately entered menopause at age 30 and I continued with the standard of care for ovarian cancer by taking a daily hormone blocker to prevent estrogen production for three years. Finding the right one of these drugs was a Goldilocks experience. I struggled with intense hot flashes, crippling joint pain, and gained over 30 pounds.

Ultimately, none of the four options worked, and I faced my first recurrence last Thanksgiving in 2022. After standard treatments, there's no clear path once recurrence happens. This disease is often described as a chronic illness because treatments will work for a while and then stop. My only options right now are clinical trials. Earlier this summer, I began a MEK inhibitor protocol, which has side effects almost as brutal as chemo, but with a little less hair loss. The visible manifestations of my treatments have been the hardest to accept.

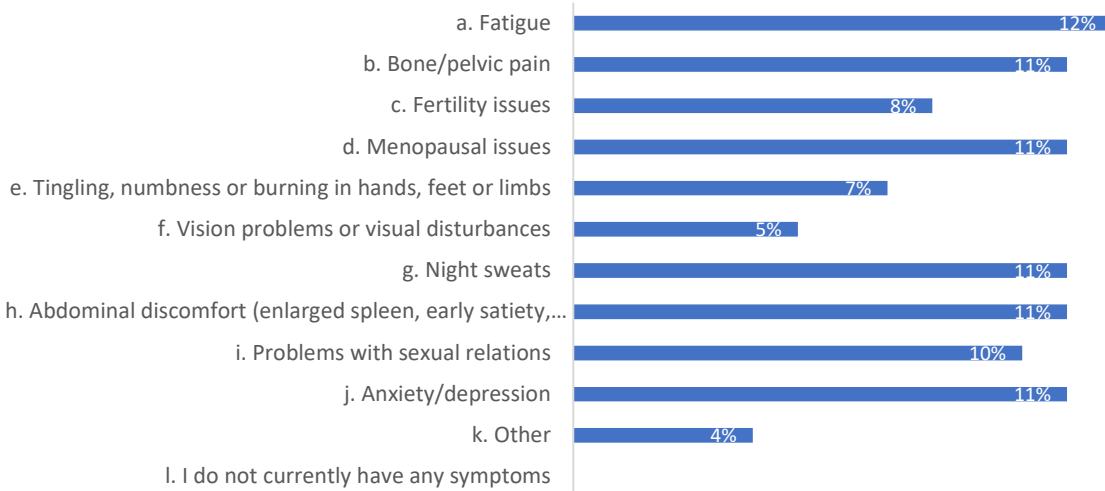
I've experienced an extreme acne-like rash, so raw and red at times that my eyes were the only visible part of my face. I've spent hundreds of dollars on topical and oral medications and washes to calm my skin. I've also purchased hair extensions to try and hide how much my hair is thinning. Nausea on these medications has been more intense than during chemo, causing me to burst blood vessels in my eyes and experience facial swelling.

I have muscle weakness, pain and cramps, severe diarrhea, dry mouth, blurred vision, swelling, and intense fatigue that make daily tasks a challenge. The clinical trial experience has also been challenging. I underestimated the number of appointments, with over 20 in just three months. This is especially taxing as a single adult relying on my employer for health insurance. Managing the schedule with various doctors was at times overwhelming. Some side effects require frequent blood tests, and my treatment has had to pause twice due to toxicity levels, ultimately leading to a dosage reduction. In closing, my journey with LGSOC has been a roller coaster of challenges and uncertainties, but I choose to keep fighting. Why? Because I'm 34 and I hope for a future where I can cherish the simple moments like watching my brand-new niece grow up and being there for all of her milestones. Thank you.

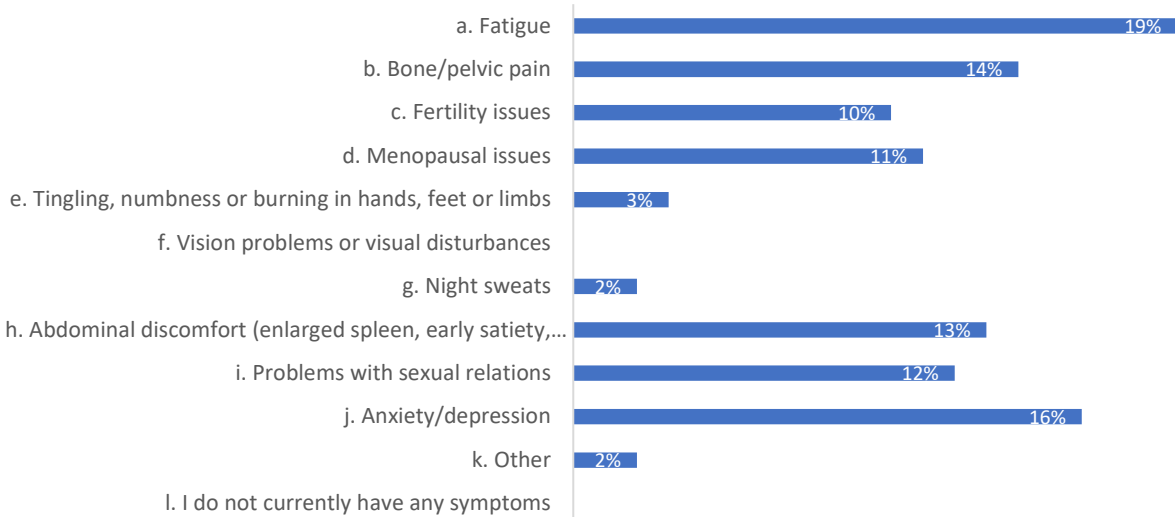
## APPENDIX 5: POLLING QUESTIONS AND RESULTS FOR TOPICS 1 AND 2

### TOPIC 1: LIVING WITH LGSOC: SYMPTOMS AND DAILY IMPACT

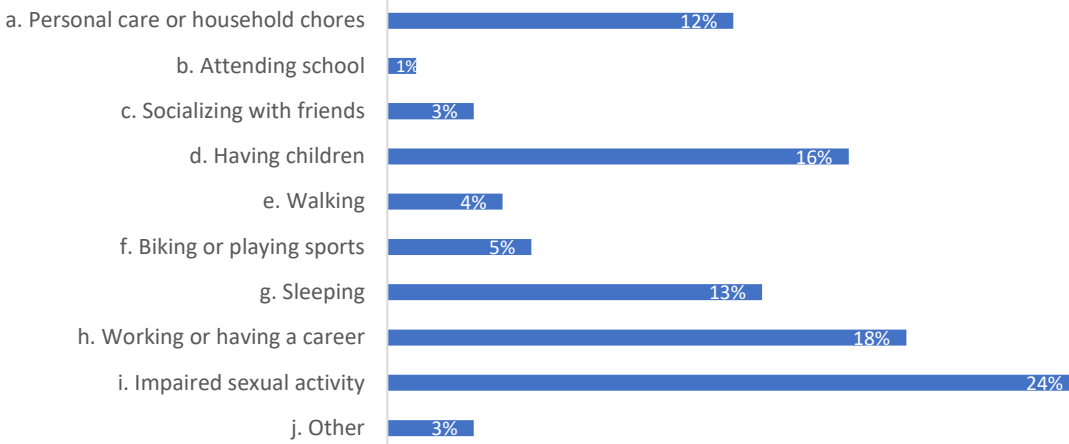
1. Which of the following LGSOC-related health concerns have you or your loved one ever had? Select ALL that apply.



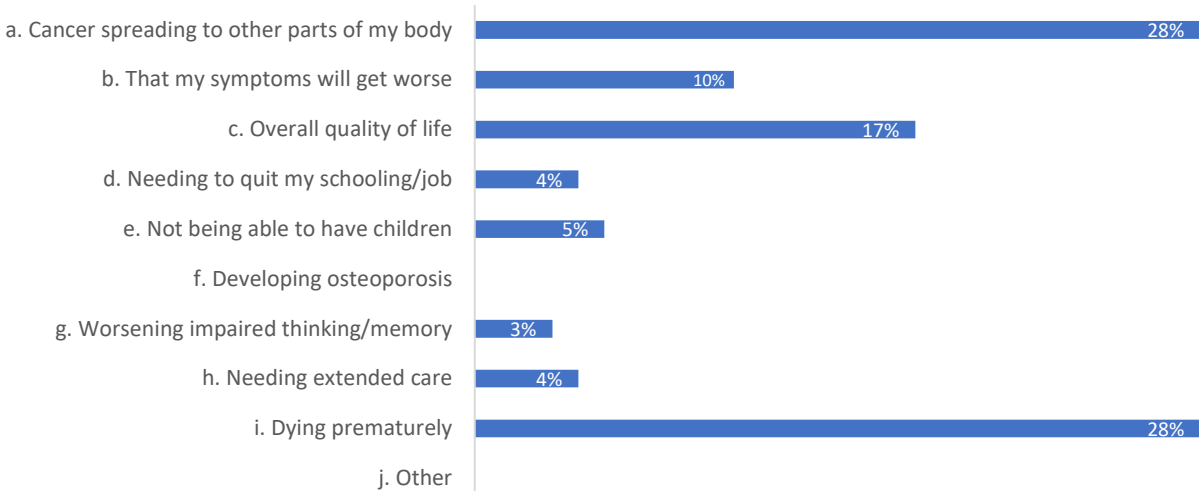
2. Select the TOP 3 most troublesome LGSOC-related health concerns that you or your loved one have ever had.



3. What specific activities of daily life are important to you (or your loved one) that you/they are NOT able to do or struggle with due to LGSOC? Select TOP 3.

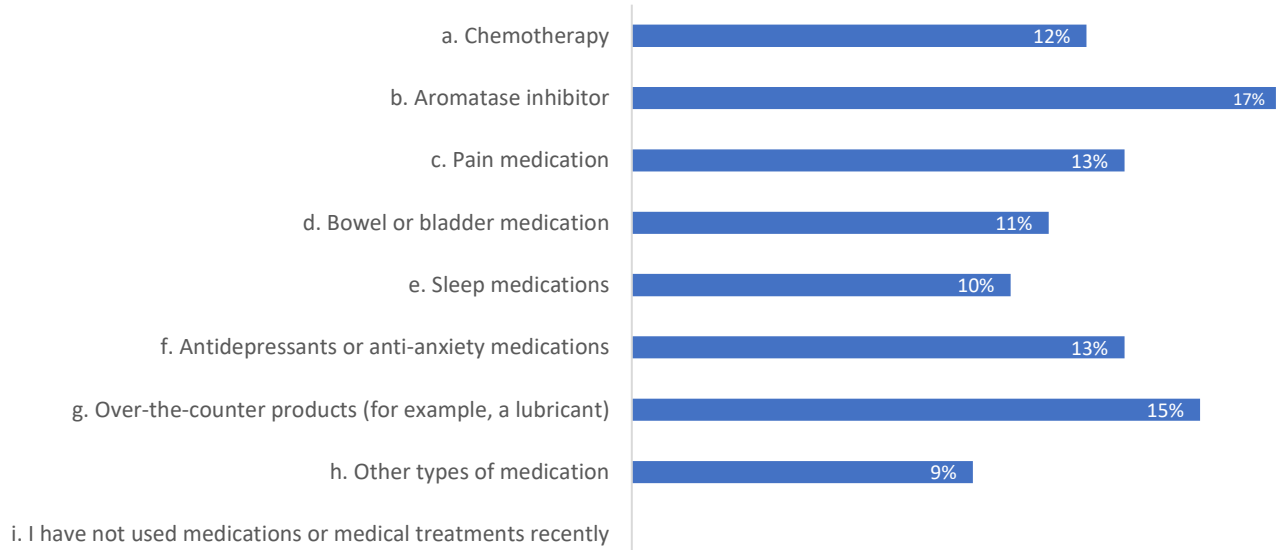


4. What worries you most about your or your loved one's condition in the future? Select TOP 3.

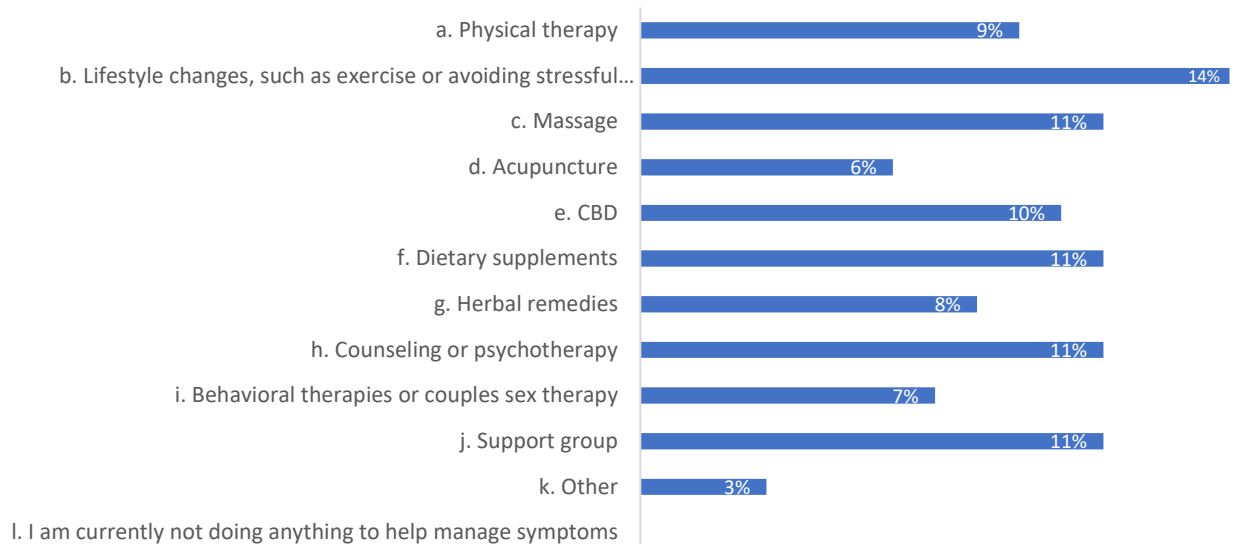


**TOPIC 2: PERSPECTIVE ON CURRENT AND FUTURE APPROACHES TO TREATMENT**

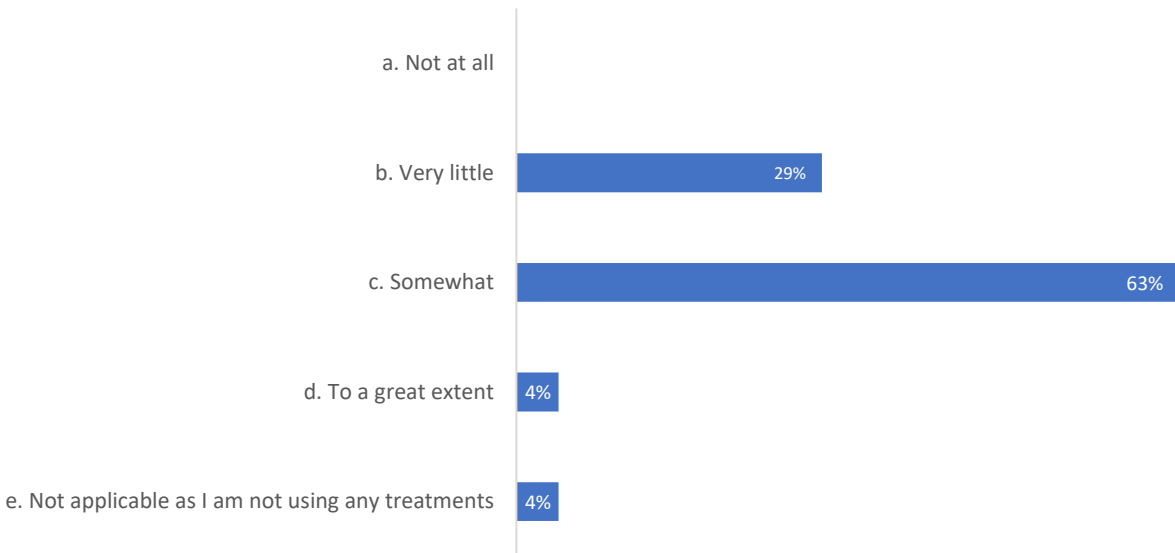
1. What medications or medical treatments have you or your loved one used (currently or previously) to treat LGSOC symptoms? Select ALL that apply.



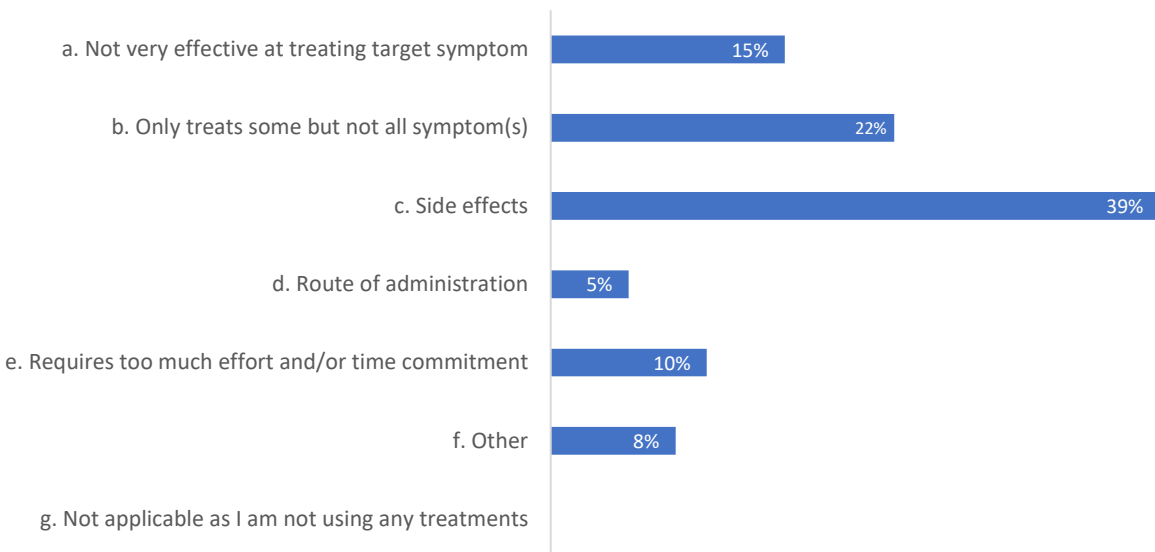
2. Besides medications and treatments, what have you or your loved one used to help manage LGSOC symptoms? Select ALL that apply.



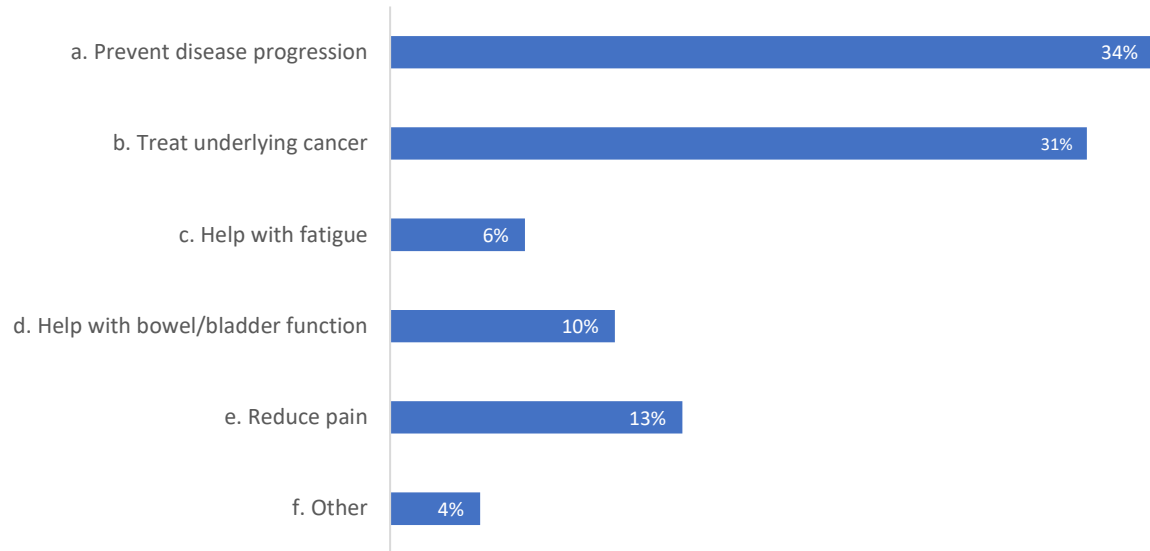
3. How well does your current treatment regimen treat the most significant symptoms of LGSOC?



4. What are the biggest drawbacks of your or your loved one's current approaches? Select TOP 3.



5. Short of a complete cure, what specific things would you look for in an ideal treatment for LGSOC? Select TOP 3.





## APPENDIX 6: WRITTEN COMMENTS

Written comments from the LGSOC community were received via email during the Voices of LGSOC EL-PFDD Meeting held on October 13, 2023, as well as for up to 30 days after the meeting. Written comments received during the meeting are presented first, followed by those received after the meeting.

In addition, the responses to the LGSOC patient survey conducted prior to the meeting are presented at the end of this section.

### During the Meeting Written Comments (October 13, 2023)

Luiza	<p>I was diagnosed with LGSOC 3a in September 2021. I went through 3 debulking surgeries and finished chemotherapy in May 2022. I've been on Letrozole since, and I was told "forever." I've had pretty much all the advertised side effects of chemo, but I think the worst "side effect" was what happened as I was finishing chemo--I became depressed, because nobody prepared me for facing the rest of my life and living in surgical menopause, while constantly fearing a recurrence. I am on Zoloft and see a psychiatrist regularly. Antidepressants gave me bad insomnia, so I have to take Lorazepam nightly to be able to sleep. My marriage is hanging by a thread—on top of having no libido, sex is physically difficult due to vaginal dryness and atrophy. Last time my husband and I had sex was before my diagnosis.</p> <p>For the past month I've been experiencing above-average heavy fatigue. Within the last 2-3 weeks, I also noticed abdominal discomfort and I've been having diarrhea a lot, as well as bladder pressure. I am worried I may be having a recurrence; that would mean I'd have recurrence within less than 2 years. My CT scan was moved to next week.</p>
Hanna	<p>I had three debulking surgeries, and have tried all kinds of chemo regimen. Nothing works for long; the drug resistance is the big problem for LGSOC. Hope this issue can be priority for addressing.</p> <p>I just had my bone density tested after 11 years of LGSOC. My bone is becoming so fragile that I am afraid of any exercise now.</p>
Dan	<p>Many of the women with LGSOC are taking the same medications or no medications, yet some are recurring, and some are no evidence of disease (NED). There must be some differences of what NED are doing at home. Can you ask NED what diet or what supplements they may be taking that they feel may be helping to keep the cancer at bay?</p>
Dim	<p>Please help us live longer!</p>
Sara	<p>We need more advocates to help with research for a cure and help with getting the FDA to approve more treatment options.</p> <p>LGSOC has affected every aspect of my life. Anxiety at an all-time high, joint pain, memory loss, loss of libido and sexual function. Financial hardship due to having to</p>

	<p>travel to Houston due to the lack of knowledge here locally by gyn oncologists that my insurance will approve.</p> <p>I will continue to advocate in hope that an 85% recurrence rate is extremely lowered and that there will a cure in the near future. We need more oncologists educated on LGSOC. We need more treatments approved by the FDA.</p>
Courtney	<p>Treatment options. I started Mekinist but when it stops or doesn't work - what do I do then?</p>
Sarah	<p>Prior to my surgery, I was running half-marathons, practicing yoga, playing tennis every weekend. Now, I can *maybe* walk a few miles before the inflammation kicks in. It also comes with consequences the next day--waking up exhausted. Additionally, there is the mental struggle of having to explain to folks that even though we may look healthy (since we don't match the image of chemo + cancer), that we are actually very tired. Being taken seriously by both doctors and the community can be really difficult since we might look well.</p> <p>I want to thank my counterparts for being so brave to share their stories and it's comforting to know that we're in this together.</p> <p>I think everyone who has spoken has done a great job of sharing the PRIMARY concerns such as fatigue, joint pain, memory fog, hot flashes, and more.</p> <p>I think I just wanted to share sort of the SECONDARY impacts of this disease. Many of us chose not to do chemo, so we don't match the image of what a cancer patient looks like. People often don't believe us when we share how we're feeling because many of us do still have hair on our head.</p> <p>Secondly, being women, and for me a woman of color, we're often not taken seriously by doctors. While there are many great doctors like Dr. Gershenson, there are also a number of doctors out there who tell us we probably have food allergies or anxiety.</p> <p>Lastly, there is the financial concerns. I'm one of the lucky few who has great insurance through my grad program at school, but many people don't have access to the care they need. Additionally, the accumulation of bills while concurrently not having enough energy to work and pay these bills is very real. Having disability is helpful, but not nearly enough to live a normal life.</p> <p>Acupuncture has been one of the most useful treatments for joint pain (from what I can tell), in addition to massage. Also removing alcohol and sugar from my diet and sticking to cruciferous veggies has really helped with keeping inflammation down.</p> <p>Daily yoga has also helped tremendously with recurring joint pain. The hardest part of all of this is if you stray for a day or a week, you start from square one.</p>
Karen	<p>I recommend trying low-fiber diet for women with severe constipation. I learned the hard way, eventually having a small bowel blockage. Daily Miralax and low fiber have been life savers.</p>
Kim	<p>Lack of libido, gastro issues, fatigue, joint pain, Memory FOG, and eye blurriness! It is a daily struggle.</p>
Lindsey	<p>More research on distinction or progression from BOT to LGSOC. Are hospital pathologists truly able to do this? It's important for treatment and mental well-being, judging by the diversity of symptoms, genomic profiling, prognosis etc. It's a total</p>

	<p>mess. My daughter (27) had 3b LGSOC.. Genomic profiling nothing at all looked normal yet classed as cancer. How can they be sure it wasn't BOT? They wanted to stuff her full of chemo. We refused and went for letrozole—3 yrs out still stable. We need better classification, let alone drugs. More hormone research.</p>
Jan	<p>Good morning. I was diagnosed with OC, stage 3c, in 1992 at age 32. In the last 10 years I was made aware of the low-grade aspect of my disease. Currently I have lymph nodes in my chest that are diseased. I am trying to get approval from insurance to take a CDK 4/6 inhibitor such as Kisqali and am in the appeal process. This young lady's words are giving me so much déjà vu.</p>
Dawnie	<p>The fatigue, menopausal issues, and anxiety/depression are the 3 most bothersome health concerns to me. There are days that the fatigue is barely there, but there are days that the fatigue kicks my butt and keeps me in bed. It prevents me from doing a lot of the stuff that I need to be doing. The menopausal issues, night sweats and hot flashes keep me awake a lot during the night, preventing me from sleeping. And the anxiety/depression somedays doesn't bother me that much; other days, I am terrified, anxious, feel guilty, feel like I am about as useful as a white crayon. Bone pain, bothers me as well, but I can deal with the pain. I just push through it.</p>
Shannon	<p>I have gone from being an active 32-year-old paramedic to now living my days in a wheelchair as a result of complications from the multiple surgeries I have had to fight my multiple recurrences. I have a full-time caregiver and my world has literally come to a standstill. There has not been an effective treatment to date to keep my cancer from progressing. My life literally depends on new treatments to be made available. To talk on what Kat is saying about finding a doctor to help with pain: I finally found a palliative medicine doctor to be my one shining light in this whole disaster. They have been able to help so very much with my pain. I wish more women knew that palliative medicine is not just for patients in active hospice.</p> <p>I had hyperbaric oxygen therapy for a radiation injury to my pelvis. This happened to be the first time that the growth of my tumors had slowed slightly. It would be wonderful to research more on the effects of hyperbaric oxygen therapy and tumor growth.</p> <p>I wish a transvaginal ultrasound was part of a woman's yearly exam. There are no preventive options available. An ultrasound was how my cancer was detected.</p>
Kate	<p>I'm waiting to know my next treatment option: chemotherapy or trametinib. I've had to do my own research to find out the side effects.</p> <p>I have a daily struggle with bowel problems after seven years. In 2016, as well as removing tumours, they removed 1/3 of my lower intestine. I manage it with loperamide and diet.</p>
Katelyn	<p>I have never related more to anyone than Ellie. This is our life as a result of this disease. It changes everything in our life, every day. Some days, survival feels overwhelming because it carries so much loss and grief over every aspect of life: sex, infertility, weight gain, fear, anxiety and depression, panic, physical pain, and discomfort. Then I am reminded of how precious life is and I am grateful for each day,</p>

	<p>week, months, and years, despite a continued struggle to form an identity of a person's life I never wanted to be living or envisioned.</p> <p>My first gynecological oncologist told me, "You don't have cancer, you never did, go on living your life, but come see me every six months." A couple of years later, he prescribed an estrogen patch when I discussed painful intercourse with him.</p>
Amy	<p>Symptoms from chemo affected my life but, now that I'm on Letrozole for maintenance, my major symptom is joint pain and stiffness. I also have digestive symptoms that are hard to deal with and which worry me. I would like to see treatments that have a significant impact on extending life without seriously degrading quality of life. I would like to live to see my grandchildren be born and for them to live long enough for us to have been in each other's lives. I would like to be able to use my brain effectively, as I write and study a lot as a retired professor, and I would like to return to the level of activity I had before my diagnosis about a year ago. As someone who had borderline tumor before (with debulking then) and now has LGSOC, there should be clearer, standardized surveillance guidelines. I am now inoperable and thus have a worse prognosis; perhaps that would not have been true if the monitoring would have been different. I strongly support greater funding for LGSOC to find ways to prevent recurrence and disease progression.</p>
Jen	<p>CA 125 was 210 at diagnosis. I am 12 months post surgery November 2022. Debulking hysterectomy etc. Stage 4b. Ileostomy. Reversal June 2023. Chose to stop after 2 chemo in February 2023 as everything I read mentioned of its resistance. CA 125 was 14 in February 2023. Rising each test. 3 tests and October 2023 was 118. PET / CT scans are reassuring. Medical onc wants me to start chemo this coming Monday and I would prefer to do a watch and wait and rescan in 3-6 months. I'm feeling overwhelmed that I'm expected to do chemo. Do you think a watch and wait would be a possibility, and, if so, what kind of timeframe? Does a rising CA 125 usually mean the beginning of a recurrence? I am not taking any other medications or inhibitors. Thank you for your time.</p>
Stacey	<p>I am 51 years old and 4 months in to taking Letrozole, following 6 rounds of front-line chemo. Joint stiffness/pain is the worst symptom/side effect that has the most significant impact on my activities. Additionally, the hot flashes and night sweats are challenging for quality sleep. I continue to work a stressful management role virtually but wonder how much longer I balance that stress with the stress of managing my treatments/side effects. I worry that I will not have a quality treatment option if the cancer progresses. I am trying to increase exercise and movement into my daily routines. I worry that the significant downsides to treatments are the harmful or degrading side effects, so an ideal treatment short of cure would be for treatments without the awful side effects. I worry that we do not get the funding for research and development.</p>
Annabel	<p>I've been living with LGSOC since 2008 (with a brief period of remission until 2011). I'm grateful for the surgery and treatments I've already had but would like more time with my family.</p>

	The next plan for me is to try trametinib, but it worries me what is available after that? Is there anything else being developed other than MEK inhibitors?
Dianne	What is the recurrence rate for 3c NED after surgery?
Lisa	May be more of a question: I know sleep is so important, for overall health, healing, immune response, etc... However, I work nights, indeed, I am a sleep tech, working 3 x 12-hour shifts in a week. I flip to normal during days off (sleep at night, awake during the day). My sleep is not well consolidated during days I work (including not enough sleep, but I am a great napper!). Wondering how impactful this lifestyle can be for LGSOC and tumor growth despite treatment with Mekinist. I am almost 60, can't afford to retire just yet, as I need the health care insurance benefits. Is my job literally slowly killing me??
Bonnie	I'm very fortunate to have been NED (knock on wood!) and back to all my usual activities for about a year now, but the fear of recurrence never really leaves my mind. My biggest fears are that I'll have a recurrence that won't show up on scans until it's really widespread, or that I'll have really bad side effects if I need to take Mekinist. Affordability of MEK inhibitors is something I worry about, too.
Susan	I have had three operations and have a colostomy and nephrostomy now and am trying palbociclib and Fulvestrant. I have retroperitoneal fibrosis in with my cancer metastasis so they can't operate in my abdomen. Can retroperitoneal fibrosis be taken away somehow? Are there any different treatments if you have retroperitoneal fibrosis mixed with your cancer in your abdomen? I would like to have heard from some older women who have LGSOC. I am 72 years old and would like to have heard the symptoms and the impact on a few women my age.
MaryAnn	Treatment has improved my ability to walk farther. But only since I have had my last dose. For the doctors to be more transparent. Explain some long-term hopeful treatments (preferences for future treatments).
Ann	I'm terminal and on letrozole for the last 18 months to keep the active cancer left in small bowel slow growing. Seems to be doing the job.
Dawn	After going through chemo, I continue treatment with bevacizumab and exemestane. I cope by comparing the side effects from chemo vs now. My current side effects are not as bad. I also try to exercise, see a therapist and participate in my local support group.
Adrienne	Due to Celiac disease, I have issues with absorption so I have to do at-home hydration 3 times a week along with managing my ileostomy which is a lot to handle mentally, physically and emotionally. I did 6 rounds of Doxil and Carboplatin along with monthly Lupron injections with great success. My cancer is currently stable and in the No Evidence of Disease category. I maintain stability through Avastin infusions and have continued the monthly Lupron. While I am happy with how well I am doing overall, I

	<p>endure joint pain, hot flashes, insomnia and mild fatigue on a daily basis. I know it could be worse and for that, I am grateful.</p> <p>I underwent a total hysterectomy, debulking and removal of all visible cancer. While in surgery, they found my colon completely covered in disease and I woke up with a colectomy and end ileostomy, which I had never heard of.</p>
Shannon	<p>My joint and muscle pain has increased since starting letrozole in February 2023. Hot flashes decreased some with Effexor, but I don't like the side effects and want to try something else to reduce hot flashes and night sweats. Currently NED and dealing with a heightened state of menopause at just 38 is brutal. The dry vagina, hot flashes, joint/muscle pain, and fatigue/insomnia negatively impact my life. Also constipation since my colon was resected.</p>
Jennifer	<p>In surgery, they accidentally severed my right iliac artery, right ureter and perforated my bladder. I now have a nephrostomy on the right side as well. I've battled multiple rounds of sepsis and the cancer continues to grow. I had a round of SBRT radiation in March of 2023.</p>
Mike	<p>My wife, Suzanne, succumbed to her LGOC on July 14, 2021. Her treatment was standard - surgery to remove tumors followed by several rounds of chemo which were severely debilitating and ultimately useless. She participated in several clinical trials, without success. In September 2020, Suzanne's cancer had spread to her intestines, causing inoperable blockages. She survived until late June 2021 thanks to a portable iv nutrition regime and an indomitable force of will to live and love. At that point the cancer actually grew through the skin of her abdomen and she decided that hospice was the appropriate option. She passed away 12 days later.</p>
Karen	<p>A treatment that does not reduce your immunity or cause such fatigue (preferences for future treatments).</p>
Ashley	<p>An understanding what CA 125 means for low-grade patients. An understanding what calcified tumors mean in your lymph nodes (preferences for future treatments).</p>
Ann	<p>For chemotherapy to work on everyone who's going through this horrible rare disease, rather than operations. At my age, 63, too many operations can't be good (preferences for future treatments).</p>

**Post-Meeting Written Comments (October 14, 2023 through November 14, 2023)**

Rachel	<p>I would love for a standard of care to be created for LGSOC so that all patients with this horrible disease receive the same options and the best care possible. I have met so many women through the course of my three-year cancer diagnosis that have gone through so many different avenues as it relates to being diagnosed, the treatment they received, the after-care they received, and the continued monitoring and maintenance of this disease. Why is there no playbook on LGSOC? Why is it that someone in a small town in Kansas has a smaller chance of survival than someone being seen at a major cancer center in a large city? We all live in the US where the top medical treatments, doctors and options are available and should be available for all, regardless of where you live, your background, where you grew up, and most of all, your financial situation. This is not okay. And while our disease might have slight differences between each of us, the overall disease that is being treated is LGSOC and there shouldn't be the countless differences in treatment that are occurring day in and day out. Women's lives are at stake and these differences shouldn't be why one woman lives and one woman dies. Cancer is not discriminatory as we all sadly know, but neither should the journey to proper care and feeling well again be, either.</p> <p>I have so many fears as I get older. I think first and foremost, will I get older? What does older even look like? What's my expiration date among these horrible statistics? And if I do get older, will I have my first recurrence? Will I have several recurrences? And what do those look like as it relates to treatment options. Will I have options or run out of them? I worry that my side effects and symptoms will continue to get worse or I will continue to run out of patience and energy to overlook them. I also worry that I will continue to push people away because I cannot keep up with them. I'm worried that I will continue to push my husband away as I feel like we are completely not on the same page anymore. I don't feel myself and I hate it. Where did I go? What happened to me? I used to be so confident in everything I did and now I wonder how I'm even keeping up. And then of course I worry about my husband if things do get worse. Will he be able to take care of me, physically, emotionally and financially? Will this disease completely tear us apart? Have I completely stripped away every hope and dream he had for us and our future? Will he resent me as all of our other friends continue to have children and we're completely left out? The worries, fears and frustrations are never-ending and I wish this was just not my life and I could wake up from this horrible nightmare.</p> <p>I do not feel as though my symptoms have changed over time, but I feel my ability to cope with them has gotten better. It's such a catch-22, as in you'll deal with the side effects and symptoms, because you know they could be way way worse. But as young adults, we shouldn't be dealing with this at all. I don't complain as I was never raised to do so, in fact, me sharing all of these comments are probably the most complaints I've voiced since being diagnosed. I push through things really well and all with a smile on my face. And sadly I say to myself, well at least you're not in a wheelchair like your other LGSCO sisters, or at least you can still eat and feed yourself and go to the</p>
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bathroom. It's a constant mind game to be able to cope with this all and having been diagnosed with both breast and LGSCO concurrently, you have to learn to play the game well. After all, what's the alternative, doing nothing, sitting around hoping for a cure or worst yet, death...so you do what you need to do each and every day and make the most of each day that is this beautiful gift of life.

One of the reasons that I completely fell in love with desert living is all of the incredible outdoor activities that it has to offer. Sadly, because of LGSOC, those activities are few and far between and not nearly at the frequency or intensity as they used to be. I used to play competitive kickball and no longer can because I feel like I'm not playing at the full potential that I used to. I've enjoyed learning pickleball but also feel like I cannot play as well as I would have years ago. Everything makes me tired, although I was likely very tired to begin with before starting the activity. I haven't paddleboarded in several years because I lack the balance needed for long paddles and the dexterity to be able to stand when large waves come my way. In fact, I had to go out and get a kayak so I can sit and have more opportunities to rest, but still at least get out on the lake and have some fun in the water. And then there's mountain biking, hiking and running that have gone by the wayside because I simply do not have the energy to do them. Or because I'm worried, I'll fall, which has happened several times now since being diagnosed. Not to mention the weights and exercise I used to do daily as I wanted to look fit and beautiful since it's always bathing suit season here in Arizona. I was your classic tomboy growing up with three older brothers and a Dad who was so into sports. I did them all, I was so active, some might say too active, but I loved being busy, being competitive and kicking some butt. I really miss those days.

On my worst days, I have trouble even getting out of bed. I'm anxious and cannot sleep worrying about the days ahead and my future. When I'm finally able to fall asleep at night, morning comes so quickly after the hours I spent tossing and turning during the night because I could not get comfortable. My knees hurt, I'm too hot, my back hurts, it's never-ending. I don't even know what a good night's sleep is anymore. After rising, I slowly get out of bed, with my knees bent and barely able to walk to the bathroom. I feel like a ninety-year-old woman as I attempt to get my day going. From there a nice hot shower relaxes my joints and bones so I can move around more easily. However, when I step out of my shower, I need to blast the AC and move a tall standing fan into the bathroom so I can continue with my morning routine without drenching myself in sweat. All I want is to leave the house, looking fresh and beautiful, with my makeup and hair on point, my eyes not completely dark and swollen from my lack of sleep and anxiety, my legs moving as they should and my brain open to the possibility of a new day where I'll be able to focus at work and throughout my day. Then as the day progresses, I hope to just stay on top of all the things I need to do without having to pause to rest or to re-gain my train of thought on things that used to come so easily to me. I can no longer even work a full-time job and am on disability while working part time to supplement the sad reality that is permanent disability income. I'm not the quick-witted, spry, energetic, bubbly, outgoing person I once was, that truly was a force to be reckoned with. When I get home from work, I have hopes



	<p>of exercising, taking my dogs for long walks and having a nice dinner with my husband, but that usually ends up with me annoyed about something because I cannot do it anymore or don't have the energy to do it anymore. I miss the girl that was unstoppable and could go-go-go. And for me, on my best days, that's when I don't have to put on makeup and head out the door to work, so the sweats don't make a difference, the lack of sleep doesn't matter since I can sleep in and no one is going to see how awful I really look in that moment, whether it's sad on the outside or the inside. I think a best day with LGSOC is simply an oxymoron.</p> <p>The symptoms of LGSOC that have the most impact on my life are the severe neuropathy, bone and joint pain, brain fog, lack of sex drive, extreme fatigue, terrible hot flashes and night sweats, insomnia, the inability to have children, and sadly as the time goes by, with the lack of hormones, my carefree and fun-loving personality.</p>
Alisa	<ol style="list-style-type: none"> <li>1) Menopausal symptoms, particularly joint/bone pain and impacts on sexual health, in addition to anxiety/fear of recurrence.</li> <li>2) My best days involve the days where I don't/hardly think about cancer. My worst days are the days where I am consumed by fear of recurrence and/or survivor's guilt and the grief of losing other teal sisters.</li> <li>3) Anything that could worsen my hot flashes.</li> <li>4) My symptoms (particularly those related to being on Letrozole) have varied greatly over the years, but most symptoms have stabilized.</li> <li>5) I worry that all of the symptoms I am already experiencing are going to worsen by a tenfold. I also worry that my life expectancy isn't going to be as long.</li> <li>6) I could be doing more (like exercising and taking my vitamins), but admittedly I often lose interest in taking care of myself properly due to mental/emotional obstacles.</li> <li>7) Yoga and hiking has always helped me the most in the past--both mentally and physically, when I am consistent with a daily or near-daily routine.</li> <li>8) Lack of libido and decreased motivation are two of the most significant downsides of Letrozole/menopause. I have lost a lot of interest in things that previously brought me joy, and I have lost a lot of intimacy in my relationship with my partner.</li> <li>9) My biggest concern is a proper screening test because even though I am currently considered NED, I still am not confident that my radiologists know how to detect low-grade cells.</li> </ol>

<p>Kate</p>	<p>The fatigue is what impacts my life the most. It's made it difficult to keep up the pace needed for my job and will sometimes force me to cancel plans with friends and family.</p> <p>Best days – I'm able to live life without having any physical or mental impact from LGSOC. This means doing all the things I want to do and not have concerns about my future. Worst days – there is an exhaustion that no amount of rest or sleep can relieve. Physically I feel pain in my joints, sharp pains in my pelvis / abdomen, and constant tension headaches. Mentally I struggle with the fact that my life will be significantly shorter than my friends and I will most likely never have a romantic relationship again.</p> <p>I don't let my LGSOC stop me from any activities that I want to do. I may take longer to do them but if there is something I want to do, I will find a way to do it!</p> <p>My symptoms have stayed consistent over the past 4 years since diagnosed. I accept them as my new "normal" and monitor to ensure if there's any change from "normal", I speak to my doctor.</p> <p>Being single and having to manage life on my own. I have many friends and family; however, I hesitate to ask for help and I don't want to be a burden on others. I wonder what life will be like when I can't take care of myself fully.</p> <p>Drugs to manage side effects of joint pain, resting, meditating, diet, counseling.</p> <p>Treatments manage symptoms fairly well.</p> <p>I'm not able to work at the level I was at and have taken a step back from my career. Ensure there is a holistic approach to the disease – physical care and mental health care.</p>
<p>Elizabeth</p>	<p>I was diagnosed with LGSOC on my 58th birthday in 2018. Since then, I have had 4 surgeries. I live with a colostomy bag, and at one point had my colostomy, two nephrostomy tubes/bags, and catheter bag- had a little wheeled box cart to drag them around so I could move. This year I have had three bowel blockages, and a few weeks ago was told I would need a gastric depression tube and would have 3-4 weeks to live. That was my lowest point, seeking help and having a doctor tell me there was no more help, prepare to die. Thankfully, instead, I have been on Verastem's latest clinical trial and am hoping my tumor shrinks enough so I can get off a liquid diet. Before this trial, I was on Doxil for 23 months. Unfortunately, my oncologist was not looking at my CT scans, which I have every 3 months, and somehow missed the 3" tumor that is blocking my bowel. What frustrates me most is my hard work- full-time job of seeking the best medical care I can find, and then having those doctors not pay attention. Not looking at my scans, even!! I have been to MSK, Johns Hopkins, NOVA, Yale, UVA, WVU and other Institutions in search of just ONE doctor who cares enough to help me on this journey- and that is, I believe, the only reason I am still alive. Because I keep trying, not them. I have had to give up my business as a glass artist after 38 years because it is a full-time job just trying to stay alive. The downside of my current treatment is that I have to travel - an 8-hour drive, or very expensive flight, and am not poor enough for assistance nor rich enough to afford the travel and hotel expenses. But I have no choice. There is a clinical trial closer to me but after my last bowel blockage, they</p>

	<p>stopped talking to me about transferring me to that closer study.</p> <p>I'd be thrilled if these pills shrunk my tumors enough so I can eat again, and hope for the next thing that comes along that will actually kill all the cancer cells.</p>
Susan	<p>I would suggest next time that they have some older patients speak. I am 72 and did not have anybody close to my age to relate to.</p>
Chasisty	<p>I was diagnosed with LGSOC in 2017 at 41. I had a 4-year-old daughter at the time. I'd previously had my ovaries removed in 2002-03 due to borderline tumors. Due to the way in which my LGSOC presented itself, I have not had as difficult a time as many have as it has only impacted one area. However, my tumor was inoperable, which meant lots of chemo to try and shrink it as much as possible. The chemo and subsequent maintenance drugs helped me to be stable for nearly five years. However, I've recently had a recurrence and had to go through chemo again during a time when there was a carboplatin shortage.</p> <p>For me, the worst part of this diagnosis has been the treatment and the side effects. I now deal with chronic joint and muscle pain, blurry vision, and tinnitus daily. Not everyone is as fortunate as I was, and chemo does not work for everyone. We desperately need other treatment options, as well as a screening test.</p> <p>The most frustrating things about my condition are the concern over if/when it will return and whether I will live to see my daughter into adulthood.</p>
Janna	<p>Letrozole causes severe, daily bone and joint pain. It has also caused severe osteoporosis that I was diagnosed with at 36. I now have to take daily injections of Forteo. I've also broken both of my wrists in multiple places (5 breaks to the left and 2 breaks to the right) that resulted in my left wrist being fused. I've also broken my tailbone twice. Finally, I have to get bilateral hip injections quarterly due to daily pain.</p>
Debbie	<p>Low-grade ovarian cancer has many unanswered questions. We have lost so many to this disease. Thank you to everyone working towards a cure. We need it.</p>
Jan	<p>I have started treatment at MD Anderson so I can get a targeted therapy (CDK 4/6) for LGSOC. Unfortunately, it is off-label use and insurance is denying it. My local gynecologic oncologist refuses to prescribe it, yet is happy to offer chemotherapy. I now drive 6 hours round-trip to be treated by Dr. Gershenson, who has concentrated years of research into LGSOC and how it is different from HGSOC.</p> <p>As a woman with LGSOC, I would like access to some of the breast cancer drugs that have been effectively stopping or slowing LGSOC. Like breast cancer, my cancer cells have tested ER+ and also respond well to a class of drugs called aromatase inhibitors (used in conjunction with the CDK4/6 mentioned above).</p> <p>I have had many years of stable disease taking AI drugs. I need some more new weapons in my arsenal and prefer not to take the traditional chemo drugs I've used in the past.</p> <p>I am blessed to have survived many years and have always had excellent medical care. I would like to see changes in how LGSOC receives newer therapy drug approval. As a rare subtype of an already rare disease, low-grade ovarian cancer does not generate big studies and resulting data. I find out what other women are taking by the sharing through an online forum. We listen to the experts, share our experiences, and are</p>

	<p>willing to try new therapies. It is important to me that more targeted drugs become available to women with LGSOC so we have what we need, when we need it, and close to home.</p>
<p>Fazilah</p>	<p>Flatulence and bowel movements have the biggest impact as can be awkward and embarrassing in public. This despite being careful with my diet and using docusate when required. Not a daily occurrence but often enough to make life difficult.</p> <p>What I fear most is progression. In the 4.5 years since diagnosis at Stage 4, I have been on Letrozole (didn't work), standard 6-cycle carbo-taxol (partial response, lasted 7 months), Tamoxifen (2 months), and Trametinib (severe immune reaction). I am currently on Olaparib (I am BRCA2+), which shrank my tumours initially and is now keeping me stable. Clinical trials are not an option in New Zealand. I worry that I don't have any real options if/when this treatment stops working.</p> <p>I am currently on Olaparib. Started in July 2022. I am tolerating it really well and have no symptoms other than moderate fatigue, flatulence and bowel issues, which have all been present in varying degrees since primary debulking surgery. Fatigue is more noticeable now but I am not sure if it is due to Olaparib or the cumulative effect of all the treatments.</p> <p>The ideal treatment would be easy to take anywhere (pill or capsule), have mild side-effects, shrink tumours or keep tumours stable for a long period, and be relatively inexpensive. (It takes years for treatments to be funded in New Zealand. For example, Avastin is still not funded.)</p>

Claire	<ol style="list-style-type: none"> <li>1. Fatigue and constantly being uncomfortable since debulking surgery.</li> <li>2. Best days I get showered, dressed and makeup on and go out. Worst days I don't shower or get dressed and I stay in bed.</li> <li>3. Exercise and being active. I miss being spontaneous.</li> <li>4. Symptoms of LGSC haven't changed much since surgery I'm just living with the new me, not able to do what I used to but just glad to be here.</li> <li>5. Not being here to watch my children get married and have their family.</li> <li>6. Letrozole and paracetamol.</li> <li>7. CA 125 is rising again, so waiting on next CT scan to know what's next and I just have to live with the stiff joints and aches and pains from surgery.</li> <li>8. Wish there were more holistic therapies to help with the effects like aches and pains and other side effects of menopause, sleep problems and fatigue.</li> <li>9. Testing bloods with CA 125- like smear tests.</li> </ol>
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### **Pre-Meeting**

- I am a physician-scientist of 30 years studying the molecular features of cancer. Using functional organoid testing with a CLIA-certified test we developed, we had several success stories in LGSOC. Here, I like to share a case we just published in *Nature Precision Oncology* where a patient who was in hospice care with bowel obstruction, inoperable, achieved a complete clinical remission from ECOG status of 1 to ECOG of 3 using a personalized targeted therapy identified by organoid testing. She lived for 2.5 years with a good quality of life. Other cases are in preparation. For all LGSOC that we tested, targeted therapies were identified indicating some common drug sensitivities, that could not be clearly related to single mutations. Link to Publication: <https://www.nature.com/articles/s41698-023-00379-8>

**Pre-Meeting Survey Topic 1 Results**

First name	<p><b>1. Of all the symptoms of LGSOC, which 1- 3 symptoms have the most significant impact on your or your loved one's life?</b>  <b>1a) Which symptoms most affect you or your loved one now?</b>  <b>1b) Which symptoms were the most significant at other times in your or your loved one's life?</b>  <b>1c) What were the first symptoms that you detected (where you suspected something was off, or when looking back after diagnosis you now believe to be related to LGSOC)?</b></p>	<p><b>2) How does LGSOC affect you or your loved one on best and on worst days? Describe your best days and your worst days.</b></p>	<p><b>3) How have your or your loved one's symptoms changed over time? How has the ability to cope with the symptoms changed over time?</b></p>	<p><b>4) Are there specific activities that are important to you or your loved one that you or they cannot do at all or as fully as you or they would like because of LGSOC?</b>  <b>4a) How does LGSOC affect you or your loved one? What are the challenges you/they face?</b>  <b>4b) How does LGSOC affect life activities (school/work, learning abilities, self-sufficiency, living situation, activities, etc.)?</b>  <b>4c) If you or your loved one could do one activity that you or your loved one currently is unable to, what would it be?</b></p>	<p><b>5) What do you fear the most as you or your loved one gets older? What worries you most about your or your loved one's condition?</b>  <b>5a) What capabilities are you most concerned about you or your loved one potentially losing while growing older?</b>  <b>5b) What frustrates you most about your or your loved one's condition?</b></p>
<p>Laura</p>	<p>Bloated abdomen; fatigue; digestion</p> <p>Lymphedema; fatigue</p> <p>Bloating; nausea; inability to eat a full meal</p> <p>Couldn't eat much full quickly; stomach hard and bloated; diarrhea; nausea</p>	<p>Best days I have energy and can do the things I love like walk my dog and make dinner.</p> <p>Worst days I have to elevate my leg and rest can't do too much or I will be set back</p>	<p>It's a slow process. Now with no treatment options that would even work for me or tolerable I am on Hospice and just enjoying whatever time I have left.</p> <p>It's sad but it is my journey. God has blessed me with more time.</p>	<p>Yes, traveling is difficult and can't go see my grandkids without having my leg worse or days of exhaustion afterwards.</p> <p>Looking into a van or something to help with travel It is a daily struggle to manage the fatigue and lymphedema but I am determined to keep fighting until there is a cure!</p> <p>I am on disability. Had to leave my nursing job and is something I miss terribly. I also miss bike riding, camping, and going out to dinner. I'm too tired to go out in the evening so we have lunch out sometimes.</p> <p>Travel; dinner</p>	<p>Leaving my family behind</p> <p>Movement; self-care</p> <p>That there isn't anything I can do about it!</p>
<p>Lindsey</p>	<p>Side effects of letrozole and sensory pain caused by extensive surgery and adhesions compounded by low estrogen sensitizing pain threshold. But low estrogen is needed to hold residual disease in check so it's not possible to stop taking the AI so it's a vicious circle. All that's on offer is codeine oramorph.</p> <p>Pain; bowel spasms; hot flashes relentless; I'm 28 I've had it for three years it gets no better</p> <p>Grief at loss of fertility; fear being told I have cancer in my twenties</p> <p>IBS / bladder pain was treated for three years for this and my ascites was treated with omeprazole as gastritis. Because I'm young no ca125 blood test was allowed in NHS. Finally young GP who had done gyn specialty did it and it was 3000. By then it was stage 3b and game over.</p>	<p>Continual fog of opiates, bone pain, now immobile, can't work, can't walk, spine disc collapsing, weight gain, depression. There are no good days</p>	<p>No change. Pain worse because of letrozole</p> <p>I'd like to work as when diagnosed I'd just got a good job as a biomedical scientist. After university I was going in to do a PhD. The medication that keeps me stable makes me unable to do this. I now exist.</p>	<p>Walking my children ( 3 Labradors)</p> <p>I'm angry, depressed, suicidal and totally without hope as I know how tricky drug research is. I feel no one cares because it's rare and no money for pharma in these niche markets .</p> <p>Surgical mp is horrific</p> <p>Life is just over. I've lost everything and young women seem to get this a disproportionate amount and no one cares. Had to move home leave my life</p> <p>Walk and work</p>	<p>I'm going to die slowly and it's taken my future and my beauty at a young age and deprived me of children. I'm an only child, just me and mum. The end of the line. It's lonely.</p> <p>Independence, intellect, physicality</p> <p>There's no hope and no treatment. Blind leading the blind in U.K. Treated like high-grade; clinicians do not understand it. Pathology diagnosis is inept and no transparency over how they diagnose from borderline malignant etc</p>

Brittany	<p>Infertility, menopause, internal abdominal scarring.</p> <p>Menopause and internal abdominal scarring causing gastrointestinal issues.</p> <p>Menopause, gastrointestinal issues from scarring.</p> <p>Pain when touching abdomen, distended abdomen, pain during intercourse, lower back pain, extreme fatigue.</p>	<p>On a daily basis I am in fear of the cancer returning so the emotional impact is always present even on my best days. On my good days I have energy, don't have extreme gastrointestinal problems and menopause symptoms are under control. My worst days are when the fear of reoccurrence is very high, dealing with bad abdominal issues, managing fatigue and hormonal imbalances.</p>	<p>My gastrointestinal, hormonal symptom and emotional symptoms have improved over time. In 2019 I started seeing a functional doctor. The functional Dr. acknowledged and helped treat my symptoms whereas my regular gynecologist and PCP didn't offer any alternative options. I am extremely aware of my body since my diagnosis in 2010. I pay attention to any changes and have doctors investigate symptoms. I got emotional support through different forms of cognitive therapy.</p>	<p>Not presently.</p> <p>The emotional effect of living in fear of reoccurrence is the worst and the reality I could no longer have children at age 36. The extreme menopause symptoms at such a young age was also awful and trying to balance my hormones today is a constant struggle. I also have a lot of internal abdominal scarring from the 3 surgeries I needed, this has caused many ongoing gastrointestinal complications.</p> <p>My physical symptoms before being diagnosed affected everything, I was exhausted, had extreme inflammation, abdominal pain and nobody knew what was wrong so I felt crazy too. After diagnosis the 3 surgeries affected my ability to be physically active, be an active mom for around 6 months and my ability to work. I was a single mom and needed help, it was a very difficult situation.</p> <p>I can do everything I need to do now.</p>	<p>Reoccurrence.</p> <p>Survival if the cancer comes back.</p> <p>No doctors believed there was anything wrong at the time, I had to force doctors to keep texting me. They said it was probably IBS, or fibroids or maybe endometriosis, I knew I had never even had these issues before.</p> <p>Why don't doctors monitor CA125 levels in young women if this is an indication of ovarian cancer? I felt like nobody knew anything about low-grade ovarian cancer in 2010, not even doctors, and I had no real resources for long-term support.</p> <p>I had symptoms for years before any Dr really investigated my situation and listened to me when I said this isn't how my body normally is, I don't feel right, I'm in pain and something is wrong! I had 4 ultrasounds because I kept saying they have to be missing something and they were.</p>
Catherine	<p>I really had no initial symptoms. I went to urgent care for some abdominal pain, thinking it could've been potentially a kidney stone or something and the scans showed a mass once that discomfort subsided I really didn't have much. The most significant impact was the surgical intervention in the recovery process that went along with that piece. I have not yet started treatment, but I'm sure that will affect certain things in my life as well.</p> <p>Now looking back, I was diagnosed with hyper thyroidism and then a few months later experienced some abdominal pain. I had never had any health issues, so the hyperthyroidism was obviously triggered by something, i.e the cancer that they found later on.</p>	<p>Right now a lot of the effects are emotional, because of the unknown whether the treatment will work or not work given its tendency to be chemo resistant. I feel as if I have a great Medical team, so I have faith that we will make progress but still it's not an easy process.</p>	<p>The unknown is my biggest fear. I am young with 3 children- it's hard not knowing treatment will be successful for us. I will be dealing with this very very little or short time if the treatment is not successful.</p>		
Bobbi	<p>Not knowing if I am cancer free now that I'm NED for almost 3 years or if and when the cancer will come back.</p> <p>I am "lucky" in that I am only on Letrozole so there is no chemo side effects. I really can't complain but I do feel older and less able to take as active of a part in my life than I believe I would have if not for this disease.</p> <p>I had no "symptoms" at all. My Doctor felt the tiny cyst. I am very fortunate.</p> <p>None</p>	<p>Best day is some knee soreness and more tired than usual. My worst days are very sore old feeling body, fatigue and low energy.</p>	<p>Symptoms seem to come and go. I am 68 so I never know if it is the cancer med or my age. But before this I wasn't fatigued and had no body pain. I don't have it bad but it is wearing</p> <p>No. I just wear out sooner than I'd like</p> <p>Just the unknown. I believe many cancers either are treated and the cancer either keeps on growing or is killed. With this slow-growing cancer I might think it is gone but it is slowly moving about my body without my knowledge. Worrying about that every day though would certainly ruin my quality of life so I don't.</p> <p>It doesn't much, thankfully</p>	<p>Will it come back? Should I be preparing for a time when it will?</p> <p>Going about my normal life without needing caregiving</p> <p>The unknown.</p>	

Sharron	<p>For me, the most impactful symptoms are those that have been a result of the debulking surgery and chemotherapy- to include colon complications linked to the removal of over 18 inches of my large colon, the peripheral neuropathy that impacts my hands and ability to type and so my job on a daily basis and my ability to sleep which affects my overall disposition.</p> <p>While my peripheral neuropathy has been numbed so to speak - it has not been removed and has resorted in multiple falls in my home and overall weekends and an inability to regain a strength needed to engage with my family in the day to day adventures once enjoyed.</p> <p>I had noticeable abdominal pain that I associated with some type of appendicitis or kidney issue but this started during the pandemic and as a single mother of a young child, I was not in a position to venture to the emergency room with my child in tow and risk exposure for a "maybe" issue. Every day that passed made me think it was just a non-issue.</p>	<p>I have to get up each day and put my symptoms and diagnosis in a box in order to carry on and get the day started. I am single mother of a 7 year old girl and currently two years into my LGSOC diagnosis and I know that I'm playing the odds game. If I focus too much time on the reality of my condition, it is not helpful. I have to just keep pushing forward regardless of the pain, fatigue or absolute exhaustion that comes with it.</p>		<p>I am no longer able to exercise the way I used to or engage with my young daughter the way I used to. I was diagnosed at 42 and was always active with my daughter. We hiked and traveled and did "all the things" together. Now I am more of the "couch potato" type. My body gets so tired so quickly and is no longer cooperative or as strong as I want or used to be.</p> <p>I move much slower and need assistance more for the little things, like closing zip lock baggies. I also have to rely upon greater accommodations at work to assist with typing because my fingers/ hands no longer work the way they used to. My memory is also fogged from the chemo and my ability to actively pursue any type of athletic adventures is not much of an option.</p> <p>I honestly feel disabled by my diagnosis, surgeries and treatments. I want so badly to be strong again but I feel like my body defies me at every turn. I know some people come back and run marathons, etc, but I would emphasize that not everyone responds the same and unfortunately, I have not been one of the lucky ones to date.</p> <p>I would love to be able to run again. I used to be a runner. I ran track all through high school, college and in my adult years- I did run 5ks, 10ks and marathons! I used to work out two hours a day pre surgery and was winning 5k races right up until my surgery and diagnosis. I can't even get through 15 minutes on a spin bike currently and would love to be able to just jog or go for a fun run.</p>	<p>I fear leaving my daughter an orphan at a very young age.</p> <p>The ability to be able to function enough to do my job. I cannot afford to go on disability.</p> <p>The ability to access care. There is no access to care in my state and the advancements in LGSOC are underwhelming. The lack of funding, research and medical treatments for this disease are what make the statistics so unbearable to read, live and die if you are a patient. It's a terrible prospect to be given such a diagnosis- google and find the limited amount of work that has been done.</p>
Betty	<p>After debulking and treatments still dealing with bowel, bladder, and bloating issues that come and go. Excessive fatigue. All of the above. Bloating, abdominal pain, fatigue and weakness Bowel issues "IBS" (?), chronic fatigue IBS symptoms after 60 years of regularity. Urinary inconvenience, retention and UTIs</p>	<p>Best days of improvement: more energy. Worst days: depression, fatigue, restless nights, abdominal and back pain</p>	<p>From never showing on scans (found during bowel blockage surgery) to progression now showing on scans. Fear of what the future holds. Minimal treatments for ER/PR positive with no other mutations. Stopped anastrozole in January due to severe osteoporosis and fractures. Increased anxiety</p>	<p>Yes. Housework. Shopping. Cooking. Depression, anxiety. Physically, emotionally and mentally exhausted. Difficulty focusing on tasks. Walk further and no more vertebral fractures</p>	<p>Dying from progression of my LGSC PPC IV. Independence Weakness, depression and not having a day I don't think about cancer.</p>
Lacey	<p>Fatigue and back pain Infertility Fatigue and back pain The fatigue and back pain, plus I had a period that lasted for 90 days about 6 months prior to discovery of my tumors</p>	<p>Honestly nowadays the mental part of a cancer diagnosis in my early 30s is the hardest part. We were hoping to grow our family and now it's not an option. These two things are the hardest parts on good and bad days.</p>	<p>With tumor removal I don't deal with cancer symptoms anymore. It's the side effects of treatment that are the worst part.</p>	<p>Involuntary surgical infertility and the inability to afford a surrogate are huge things for us. We don't get the option for more kids; we have our son but we wanted 2-3 more. Paying for treatment is a huge detriment to us financially. I worry constantly about how paying for treatment for the rest of my life will impact us. More kids!</p>	<p>I know the likelihood that I recur increases every year - I've defined it as both a count up and a countdown. I fear when treatment stops working. I just worry about an early death. I was diagnosed young so I worry about what it means for longevity. The impact it has on my family - emotionally, financially, etc.</p>



Tracey	<p>The uncertainty of this disease</p> <p>The side effects of Letrozole</p> <p>Fear of return</p> <p>Fatigue... I could not make it through a day without a 3-4 hour nap every afternoon.</p> <p>Frequent urination, bloating, bowel changes, fatigue, protruding lump in my stomach, which I thought was a hernia. As I look back now knowing what I now know, the symptoms were all there.</p>	<p>Best days are when I'm full of energy and can participate and get things done. Worst days are when I hurt from head to toe.</p>	<p>Knowledge is power. I'm one of those people that like to know options. Though I'm NED now I want to be aware of what I could do should ever needed to fight again. It empowers me.</p>	<p>Planning. I have a hard time looking too far into the future anymore. I'm aware that things could change on a dime for me.</p> <p>The side effects of Letrozole.</p> <p>I seem to suffer from "brain fog" and I don't have the energy I did pre cancer, surgery and chemo.</p> <p>Go hiking. I love the outdoors and I miss going for long walks.</p>	<p>The fear of return and potentially have more surgery and/or chemo.</p> <p>Being able to get around comfortably.</p> <p>The loss of the energy I once had. Once again, uncertainly. I wish it was: "we got it all, you're good, it will never come back." But sadly no one can say that with 100% certainty.</p>
Kelly	<p>Fatigue, blood clots, neuropathy, joint pain in my fingers</p> <p>All four</p> <p>Fatigue</p> <p>The tumor that developed under my arm after my second covid shot. When I was diagnosed, all the fatigued made sense. It's thought my chronic fatigue was activated again.</p>	<p>Best days are when I'm productive, walk many miles.</p> <p>Worse day is the exhaustion and needing more than a short nap.</p>	<p>I'm not as productive as I used to be.</p> <p>I think I cope pretty well with all this. Don't like it, sad when I hear progression, but continue to live each day.</p>	<p>Scuba diving due to the blood clots that formed.</p> <p>Running is too exhausting, so I walk.</p> <p>Feeling like we live PET scan to PET scan. Not feeling like we can plan too far in advance.</p> <p>Fortunately I'm retired. After chemo I don't feel like I have the comprehension like I used to.</p> <p>Scuba diving</p>	<p>I don't fear it. I'm a woman of faith, and from day one my phrase I live by is "I'm in a win-win situation". So I live every day here on earth well until I go see Jesus.</p> <p>Walking.</p> <p>How can I have had this so long without detection. Why are we not getting CA125 tests as a part of our annual routines.</p> <p>Yes, there are false positive results; however, that should give a warning to have other tests done.</p>
Not provided	<p>Lengthy periods of bleeding, cramping, stomach pain, nausea, diarrhea.</p>	<p>Worst days are comforting her when she is losing hope that she will ever get help with her symptoms.</p>	<p>Symptoms continue and get stronger some days than others. Frustration has increased exponentially over time. Seeing doctor after doctor and getting sent in circles to other doctors yet receiving no actual help for her symptoms has been extremely frustrating for both of us. It is time-consuming, disappointing, expensive, scary... a never-ending cycle while she is suffering with her symptoms.</p>	<p>Yes! My daughter cannot do many physical activities like she used to. She loves to hike, travel, camp, kayak etc. Even things like shopping can be too hard some days. Many times we get concert tickets, thinking she can at least enjoy seeing her favorite bands, but often feels too sick to go, or stay long. Things like attending/ getting to class can be too hard for her some days. We have also canceled or shortened trips because she feels too unwell.</p> <p>It is very hard trying to support and comfort a loved one who constantly feels unwell and is not getting treatment for her symptoms. I don't always know what to say or do to help her, and often feel helpless myself.</p> <p>She has so many challenges. She is living an isolated life because she doesn't have the energy to spend time with friends. She has lost many jobs in the past because of all of her doctor appointments, to the point I was doubtful she could ever live on her own (she is in her 20s).</p> <p>Travel more without having to worry about symptoms affecting the enjoyment of the trip.</p>	<p>That she will continue to get sicker without help and be unable to continue doing what she is doing now on her good days.</p> <p>Ability to support and care for herself.</p> <p>No help from the endless line of doctors.</p>

<p>Ingrid</p>	<p>Fatigue Mental fatigue from long-term living Abdominal pain from multiple surgeries Fatigue and abdominal pain Fatigue. Mental health from being fatigued sexual function from so many surgeries and lack of estrogen, plus the fatigue.</p> <p>The fatigue makes it so you can never forget that you have cancer. It is literally always at the top of your head. So then we get Ativan that just puts us to sleep and erases our short-term memory. Make a drug that doesn't include being tired. Make it an upper. I did not have any symptoms</p>	<p>On the best days, I am not tired and on the worst days, I am so tired that I cry. I have a daughter with cerebral palsy that needs a lot of care. There are days that I have to have her count my steps while I am holding her, so that I can get her upstairs for baths. She counts and tries to stay still in my arms. We basically hold our breaths. This didn't happen before cancer. I have had 5 surgeries and two treatments for it. I am currently going to radiate my abdomen, so we can count that too. My pelvis is dead. This makes it hard to help my daughter.</p> <p>My best days I can love all the people in my family with the energy that they each deserve. I can be present for all of my daughters and my partner too. My worst days, I can't love any of them. Including myself. I am too tired.</p>	<p>Over time, the mental toll of having to research this cancer, because the doctors that you run into have never seen it and they are just dead wrong in their treatment ideas has come full force. I can't cope with having to explain and re-explain to so many people that this is different. Of course, over time if you never get to NED, you get more sad. You know every treatment is shit and that none of them are worth the side effect. You will still go right in the hole. You become cynical and then you just ignore the "new" shows promise treatment. I understand genetics and clinical trials at a level I never wanted. I can understand this cancer is an arms race and that each institution who studies it is only interested in their research, not everyone's collectively. I also have seen lots of my friends die. There is grief that deep. Over time you become more of an expert. My ability to cope with all of this gets less each day. When better treatments take decades to get to. even though functional testing is available, a large group of women on Facebook is at your disposal for surveying, and then you ultimately find yourself begging insurance companies to just give you the treatment off-label because you have tried them all; well, it gets hard.</p>	<p>I need to take care of my daughters. I'm tired of being tired. I would like to eat normally again. I would like to have sex, like the vixen I was again. My husband doesn't have the wife he once had. I look like her, but because of the above-mentioned things, life has changed. He will be a widow. This makes him sad and detached.</p> <p>My daughters think I am strong. They don't understand how serious this is, because we try so hard to make life normal. We have therapists. It is hard to think of the future. We don't. We live by my doctor's schedule. 3 months at a time. None of these have been affected for me. I have figured out how to do them. It's just the fatigue and pain from so many surgeries that has been a nuisance. Eat. I wish I could eat like I did before.</p> <p>Sex. I wish I could have sex like before.</p>	<p>I am going to die. I just wish I had a clearer timeline. I hate leaving my family behind. My daughters are only 10 and 13. I think that I have lost the bulk of them. The only thing left is not being able to walk and needing hygiene care. My tumors are taking over all the areas of the pelvis. I suppose I could have a hard time breathing too, if it goes to my lungs, but I think I have already lots all of it. That you want to use the same medication for every patient. That you know chemo doesn't work, yet it's your go-to. That you won't use functional testing for a data-driven approach to treatment and that the treatments pound the person to death. I wish I had breast cancer.</p>
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**Pre-Meeting Survey Topic 2 Results**

First name	1. What are you currently doing to manage your or your loved one's LGSOC symptoms? 1a) Which specific LGSOC symptoms do the treatments address? 1b) How has this treatment regime changed over time and why?	2. How well do these treatments treat the most significant symptoms of LGSOC? 2a) How well do these treatments improve the ability to do specific activities that are important in daily life?	3. What are the most significant downsides to your or your loved one's current treatments and how do they affect daily life? (Examples of downsides may include bothersome side effects, going to the hospital for treatment, etc.)	4. Short of a complete cure, what specific things would you look for in an ideal treatment for LGSOC?
Laura	<p>Hospice</p> <p>No treatment did anything but make me feel worse</p> <p>The Fulvestrant injections made me more fatigued and lost weight and loss of appetite was awful</p>	<p>Didn't treat anything at all</p> <p>None</p>	<p>Treatment doesn't help</p>	<p>A better treatment</p>
Lindsey	<p>Letrozole codeine oramorph and venlafaxine, amitriptyline buscopan, etoclopramide</p> <p>Re growth of cancer pain hot flashes gut spasms</p> <p>No change apart from pain meds have increased to cope with side effects of low estrogen</p>	<p>Not very good pain control Letrozole so far is keeping residual disease in check</p> <p>Incapacitated most of time</p>	<p>Pain stress of regular CA125 Living with regular scans</p>	<p>Pain control that doesn't involve opiates</p>
Brittany	<p>I take bio-identical hormones, work with functional doctors to get a bigger picture of my health, and do extensive bloodwork. I had full genetic analysis done, eat healthy, focus on reducing inflammation, low-impact exercise, strength train, regular physical and gynecologist exams, yearly mammograms, yearly pelvis and abdomen CT scans, meditate, go to talk therapy.</p> <p>All of them.</p> <p>It has become increasingly necessary to manage my physical and mental health as I age. It took me years and years of investigating doctors and resources that could help deal with early surgical menopause and the psychological and physical effects associated with it and having cancer.</p>	<p>Very well.</p> <p>Very well so I can feel physically and mentally capable of doing my daily activities.</p>	<p>Financial implications, it's very expensive to see doctors and try alternative treatments. I also have to see many different doctors when I have a new symptom to rule out any reoccurrence. The time it takes to find help due to a lack of knowledge, research and resources for people with low-grade ovarian cancer.</p>	<p>Awareness!!</p> <p>Resources and information on the physical and mental impacts of LGSOC.</p> <p>Earlier detection and some evaluation or symptom checkers for very young women.</p> <p>Additional long-term support and resources from doctors on how to manage life with LGSOC.</p>

Bobbi	<p>Letrozole along with other supplements. I did a 2-year course of off-label meds with Care Oncology and I am hoping that was helpful also. All sorts of things to help myself like eating better, keeping a stress-free life as much as possible, keeping my body healthy. Oxygen isn't cancer's friend so I try to do as much activity each day that gets my heart pumping. Jane's book "How to Starve Cancer"..... has been very helpful. The Facebook Group on LGSOC has been so helpful with all the suggestions etc...</p> <p>Keeping the cancer cells from reproducing. Keep my stress levels down.</p> <p>Just all things known to stop reoccurrence and keep it at bay. Stayed mostly the same</p>	I don't really know since I haven't stopped doing them to see how I would do without them.		<p>I hear terrible side effects some women have on some of the meds/treatments they have and I wish they weren't so hard on us. An ideal treatment would be taken by those who will reoccur without treatment. It would be nice to know how that can take place.</p> <p>I am glad you are giving this survey; however, it is very long and fatigue has set in so my answers to the past questions are not as good (or absent) as I would have liked to present. But thanks for asking and please give those of us who need better treatments a chance for them.</p>
Sharron	<p>I am seeing my gynecological oncologist regularly and also seeing a palliative care doctor to assist in managing the pain and symptoms. I also see a rheumatologist to assist with some of the side effects for my letrozole. I also get CA 125 blood work done and occasional CT scans. I also see a gastroenterologist to assist with colon regulation. I also see a nutritionist to assist with weight gain.</p> <p>Significant Peripheral Neuropathy- major hand and feet swelling, dizziness, nauseous, colon issues- diarrhea and constipation. Weight gain.</p> <p>Mostly stayed the same- I personally chose to reduce some of the gabapentin over time (with my doctor in agreement). Just to assist with some of the level of medication I had on-board</p>	<p>Ok- need more help With the neuropathy and upset the help With weight gain not covered even though it was chemically induced</p> <p>Somewhat allows me to be way more functional than I would be without</p>	Amount of meds- if I miss a dose- I'm in severe pain and non-functional	Reduction in symptoms and coverage by insurance of any treatments that were to reduce symptoms developed as a result of side effects of treatment
Betty	<p>No treatment at the moment. Meds for anxiety and pain. Doctor considering CDK 4/6 inhibitor and fluvestrant. I'm afraid of taking meds that could cause more back fractures.</p> <p>ER positive</p> <p>Yes. Frontline chemo, Avastin, letrozole, tamoxifen (recurred), 8 months RAMP 201 (progression), anastrozole (stopped Jan 2023 due to fractures)</p>	<p>They haven't</p> <p>They don't.</p>	Side effects	Estrogen blocker/treatment that doesn't affect bone health.
Lacey	<p>I'm on anxiety meds and see a therapist. My family members also had to start therapy, including my 12-year-old. It's a lot.</p> <p>Anxiety</p>	Like I've said, these aren't symptoms of LGSOC but the after-effects. If we knew more about LGSOC and more research was being done, it would help curb some of that.	Being one of the youngest people at the cancer center sucks. Scanxiety sucks. Living with a well-built idea of my mortality sucks. I shouldn't have to think about death as much as I do.	Longevity. Minimal side effects. High quality of life.
Tracey	I have no symptoms from LGSC. I'm just managing symptoms of Letrozole.			Control. Being able to stop the cancer in its tracks and not allow it to progress any further.

Kelly	<p>Organic plant-based diet. On a blood thinner and an estrogen inhibitor that just quit working.</p> <p>Progression. However, I have progression; that's why we know it has quit working.</p> <p>Three different estrogen blockers this year. Each quit working. Now they want to try Ibrance. Too many side effects for me for the amount of time it could give. Not a good lifestyle for me.</p>	<p>They add to the symptoms, but worth it when the progression was stopped this past year.</p> <p>No effect.</p>		<p>One without the harsh side effects.</p>
Not provided	<p>Still see doctors regularly. She takes nausea meds, sometimes pain meds (sometimes doesn't because says it doesn't help), sleeps a lot, heating pad....spends a lot of time in the house alone.</p> <p>She initially had surgical removal of tumors and now just gets scanned. We see changes in the scans but doctors who seem unfamiliar with this disease, keep suggesting to continue watching.</p>	<p>They don't.</p>	<p>No real treatment. Causes major fear for her of the disease progressing to a point where it "will be too late" for her to get help.</p>	<p>Help her live a normal life for someone in her 20s, doing things she can enjoy.</p>
Ingrid	<p>I am in palliative care and I take pain medication for my abdomen. I am going to do radiation and immunotherapy to see if we can reduce the size of two tumors that are sticking to my ribs. I rest a lot. I am in Dignity Therapy. I spend time with my family. I take lots of baths and I work out like crazy.</p> <p>My treatments address pain and fatigue.</p> <p>Treatments get more hard-core and less effective over time. I haven't done the standard of care because I had functional testing and I just had my one medication that shrunk my tumors lose its efficacy totally over the summer. I am pivoting to radiation and immunotherapy and then will be back to a drug from my list of medications.</p>	<p>Pain meds work well and my treatment that I was on was great. I am just now experiencing symptoms of the cancer. All my pains have been from the side effects of medication. I am not sure how well the radiation will work yet. It starts Friday.</p> <p>I can do my daily life. I just do it with pain.</p>	<p>The treatments are time consuming. The at-home treatment pills are alright. You just need to make time to sleep in the day.</p>	<p>High efficacy Minimal side effect Specific to your own tumor</p>