

NCCN Digital Booklet of Patient Advocacy Resources



VIRTUAL PATIENT ADVOCACY SUMMIT: Advancements in Precision Medicine and Implications for Quality, Accessible, and Equitable Cancer Care

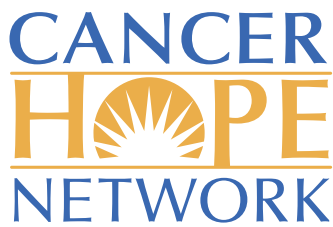
The NCCN Digital Resource Booklet includes information from 14 patient advocacy organizations on programs and resources that aim to enhance access to precision medicine and address related needs for people with cancer.

This Booklet was developed in conjunction with The National Comprehensive Cancer Network's® (NCCN®) Virtual Patient Advocacy Summit: Advancements in Precision Medicine and Implications for Quality, Accessible, and Equitable Cancer Care on December 7, 2021.

To view a broader list of advocacy and support groups on the NCCN website, visit [NCCN.org/patients/support-groups](https://www.nccn.org/patients/support-groups).

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Cancer Hope Network

Cancer Hope Network provides free one-on-one peer support to adult cancer patients and their loved ones. Our 400+ survivor and caregiver volunteers provide support from diagnosis, through treatment and into survivorship. All volunteer and client matches are overseen by a team of nursing/social work and certified tele-health professionals.

Website: cancerhopenetwork.org

One-in-One Peer Support

Resource serves: Adults and older adults facing breast cancer, colorectal cancer, lung cancer, lymphoma, ovarian cancer, pancreatic cancer, prostate cancer, or others cancers, as well as caregivers

When a person is diagnosed with cancer, it is a devastating blow, physically and emotionally. Cancer Hope Network provides support by training individuals who have recovered from cancer, and matching them with patients currently undergoing a similar experience. Our goal is to match patients, caregivers and loved ones with a support volunteer who has been through a similar experience, and in that way, offer hope during a difficult time. Clients are matched with a trained volunteer who has undergone treatment and recovered from a similar cancer experience. Caregivers or family members are either matched with a volunteer who provided care to a loved one with cancer, or a volunteer who is a survivor of the same type of cancer as the patient. Since most matches are facilitated by telephone, our service is readily accessible to patients who may be unable to participate in support groups, and for individuals who do not have other support resources available. Some matches will talk only once. Others prefer to remain in communication throughout their treatment and into survivorship – connecting before or after a major milestone like surgery or a first radiation treatment – or during regularly-scheduled calls.

Website: cancerhopenetwork.org/get-support/support

Phone number: 877.HOPENET (877.467.3638)

Email: info@cancerhopenetwork.org



Cholangiocarcinoma Foundation

Founded in 2006, the Cholangiocarcinoma Foundation is a global 501(c)(3) non-profit organization, our mission is to find a cure and improve the quality of life for those affected by cholangiocarcinoma. We offer a full spectrum of education and advocacy services for patients and families affected by cholangiocarcinoma from mentoring programs, to support groups to access to a clinical trial finder among others.

Website: cholangiocarcinoma.org

Biomarkers Matter

Resource serves: Young adults, adults, and older adults facing breast cancer, colorectal cancer, lung cancer, lymphoma, ovarian cancer, pancreatic cancer, prostate cancer, or cholangiocarcinoma, also known as bile duct cancer

For cancer patients, biomarkers matter! Biomarker testing can open the door to additional, personalized treatment options, including clinical trials. If you've been diagnosed with cancer, it is important that you and your doctor get as much information as possible about your tumor. Knowing your tumor's biomarkers will help you both to make important decisions about your treatment.

Researchers have discovered that different types of cancer are associated with a specific set of biomarkers. Patients with the same type of cancer generally do not all have the same biomarkers.

Knowing which biomarkers are driving your individual tumor can help you and your doctor decide the best way to treat your cancer. It can also open the door to newer drugs and clinical trials that are only available to patients with specific biomarkers.

Biomarker testing is especially important for people with rare cancers or cancers that have few treatment options. If you have a rare cancer with a mutation seen in other cancers, there may be a treatment that could potentially work in your cancer as well.

That's why your biomarkers matter!

Website: biomarkersmatter.org

Phone number: 888.936.6731

Email: info@cholangiocarcinoma.org

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Cholangiocarcinoma Foundation *continued*

Newly Diagnosed/ New to CCF

Resource serves: Young adults, adults, and older adults facing cholangiocarcinoma, also known as bile duct cancer

Hearing the words you have cancer can be overwhelming. If you or a loved one has been diagnosed with cholangiocarcinoma, in addition to your fears, you probably have many questions. You may not know where to turn. The Cholangiocarcinoma Foundation is here to help you navigate your journey forward. Please visit our Newly Diagnosed Webpage, this section of our website is dedicated to providing you a plan for managing your cholangiocarcinoma journey. It focuses on the basics of your cholangiocarcinoma cancer diagnosis, treatment options, biomarker testing options, lifestyle changes, and support and other helpful resources. Included are many resources that can help you find the right team, get a second opinion, get the right tests and more. Please know that you are not alone, Cholangiocarcinoma Foundation is here to help you.

Website: cholangiocarcinoma.org/newly-dx

Phone number: 888.936.6731

Email: info@cholangiocarcinoma.org

Download and print cholangiocarcinoma resources

Resource serves: Young adults, adults, and older adults facing cholangiocarcinoma, also known as bile duct cancer

Request a free 100 Questions & Answers About Cholangiocarcinoma, Gallbladder and Bile Duct Cancers by Dr. Ghassan Abou-Alfa & Dr. Eileen M. O'Reilly E-book that can be downloaded to any computer, iPad, or e-reader device such as kindle or nook. No one with biliary cancer needs to fight this disease alone. 100 Questions & Answers About Cholangiocarcinoma, Gallbladder and Bile Duct Cancers guides patients and their families through diagnosis, treatment, and survivorship. Providing both the doctor's and patient's points of view, this book is a complete guide to understanding treatment options, post-treatment quality of life, sources of support, and much more. Through 100 Questions & Answers About Cholangiocarcinoma, Gallbladder and Bile Duct Cancers, expert authors use their experiences with patients to provide support and hope to those afflicted by biliary cancer. You can also download and print cholangiocarcinoma resources pamphlets including a trifold, infographic and more.

Website: cholangiocarcinoma.org/publications

Phone number: 888.936.6731

Email: info@cholangiocarcinoma.org



Fight Colorectal Cancer

Fight Colorectal Cancer (Fight CRC) is the leading patient empowerment and advocacy organization in the United States, providing balanced and objective information on colon and rectal cancer research, treatment, and policy. We are relentless champions of hope, focused on funding promising, high-impact research endeavors, while equipping advocates to influence legislation and policy for the collective good.

Website: fightcolorectalcaner.org

Biomarked

Resource serves: Young adults, adults, and older adults facing colorectal cancer

Biomarked is a series of educational resources for colon and rectal cancer patients. These resources include webinars, landing pages, fact sheets, and mini-magazines and are meant to inform patients and healthcare providers of the importance and availability of biomarker testing to improve patient treatment outcomes.

Website: fightcolorectalcaner.org/biomarked

Fight CRC Clinical Trial Finder

Resource serves: Young adults, adults, and older adults facing colorectal cancer

This trial finder is a one-stop place to find and learn more about high-impact clinical trials for colorectal cancer patients. The Late Stage MSS-CRC Trial Finder is a place you can search for clinical trials that are open in your geography, and for which you may be eligible based on factors such as one's biomarkers. The current data are limited to MSS (microsatellite-stable) and stage IV CRC patients. The list of trials curated here is sourced from the ClinicalTrials.gov website.

Website: trialfinder.fightcrc.org



GO2 Foundation for Lung Cancer

GO2 Foundation is one of the leading lung cancer patient advocacy organizations in the country aiming to increase survivorship and quality of life for patients through empowerment and access to information.

Website: go2foundation.org

LungMATCH

Resource serves: Adults and older adults facing lung cancer

LungMATCH is an on-demand concierge-style treatment navigation and clinical trial program that helps patients and/or caregivers who call the GO2 Foundation 1-800 HelpLine receive biomarker testing if they need it or explore treatment options based on the results of biomarker testing if they've already received it. Additionally, the LungMATCH program has direct influence in the creation and dissemination of educational materials through our brochures and pamphlets as well as through our quarterly educational newsletter.

Website: go2foundation.org/resources-and-support/general-support/lungmatch

Phone number: 202.742.1898

Email: info@go2foundation.org



ICAN, International Cancer Advocacy Network

ICAN specializes in molecular profiling matching and clinical trials matching for Stage IV cancer patients (in 2021: rare cancers).

Website: askican.org

The Exon 20 Group

Resource serves: Young adults, adults, and older adults; each mutation may be identified in more than 25 separate cancers

The Exon 20 Group, spearheaded by ICAN and chair/co-founder Robert T. Hanlon, PhD, is focusing on converting two challenging rare mutations, EGFR exon 20 insertions and HER2 exon 20 insertions, into chronic and manageable diseases. Founded in 2017, we are 1000 plus members and completely multi-stakeholder: patients, care partners, thoracic oncologists, molecular pathologists and commercial biomarker testing laboratories, industry partners, and cancer biologists/medicinal chemists.

Website: exon20group.org

Phone number: 602.618.0183

Email: exon20@exon20group.org

Precision Medicine Public Advocacy Program

Resource serves: Children, adolescents, young adults, adults, and older adults facing any type of cancer.

Having experience working with Members of Congress and members of State Legislatures since our founding, ICAN's Personalized Medicine Public Advocacy Program focuses on federal and state issues affecting patient access to precision medicine.

Website: askican.org (schedule a call with us)

Phone number: 602.513.9217

Email: PMGovernmentalRelations@askican.org



LUNGevity

LUNGevity is a lung cancer organization focused on accelerating research to patients, empowering patients to be active participants in their treatment decisions, and removing barriers that patients face in accessing the right treatments.

Website: lungevity.org

Take Aim

Resource serves: Anyone and may also be of interest to labs, testing companies, providers, professional societies, and patient advocacy groups

LUNGevity's Take Aim Initiative focuses on ensuring that all people diagnosed with NSCLC have access to timely, high-quality comprehensive biomarker testing—a key component of precision medicine—at diagnosis and progression/recurrence of their disease. Take Aim has three major focuses: Increasing patient/provider awareness about comprehensive biomarker testing; Changing healthcare practice relating to inadequate tissue acquisition; and Changing healthcare practice relating to gaps in preanalytics and improper tissue handling

Website: <https://www.lungevity.org/working-for-you/precision-medicine-initiatives/lungevity%E2%80%99s-take-aim-initiative>

Email: nmartin@lungevity.org

Biomarker testing patient education

Resource serves: Young adults, adults and older adults facing lung cancer, as well as caregivers and family members

LUNGevity has a number of patient education materials on biomarker testing for lung cancer patients and caregivers to learn more about this type of testing to understand the specifics of their type of lung cancer. Examples of materials include biomarker testing booklets in English and Spanish and other related content, as well as updated, real-time detailed information on biomarker testing and the diagnosis experience.

Website: lungevity.org/for-patients-caregivers/get-educational-materials

Phone number: 312.407.6100

Email: info@LUNGevity.org

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Lungevity *continued*

No One Missed Public Education Campaign

Resource serves: Young adults, adults, and older adults facing lung cancer, as well as caregivers and providers

No One Missed is LUNGevity's public education campaign focused on increasing lung cancer survival by driving awareness of biomarker testing. This is a multi-year, integrated campaign to drive comprehensive biomarker testing in non-small cell lung cancer (NSCLC)—the most common type of lung cancer—to help people pursue optimal care. The campaign encourages people diagnosed with NSCLC to follow three steps for biomarker testing: Talk, Test, and Treat. The campaign website provides health literate resources to patients and their caregivers to support their biomarker testing process. NoOneMissed.org includes downloadable resources for patients, including how to talk to your healthcare provider about biomarker testing and a patient bill of rights.

Website: NoOneMissed.org

Phone number: 312.407.6100

Email: info@LUNGevity.org



National Comprehensive Cancer Network® (NCCN®)

NCCN is a not-for-profit alliance of leading cancer centers devoted to patient care, research, and education. NCCN is dedicated to improving and facilitating quality, effective, equitable, and accessible cancer care so all patients can live better lives.

NCCN Biomarkers Compendium®

The NCCN Biomarkers Compendium® contains information designed to support decision-making around the use of biomarker testing in patients with cancer. The NCCN Biomarkers Compendium® is updated in conjunction with the NCCN Guidelines on a continual basis.

The goal of the NCCN Biomarkers Compendium® is to provide essential details for those tests which have been approved by NCCN Guideline Panels and are recommended within the NCCN Guidelines. Tests that measure changes in genes or gene products and which are used for the following are included in the Biomarkers Compendium®:

- Diagnosis
- Screening
- Monitoring
- Surveillance
- Prediction
- Prognostication

General information on appropriate methodologies for biomarker testing is provided, focusing on the biology or abnormality being measured rather than on commercially available tests or test kits.

NCCN anticipates that this compendium may eventually be used by payers in much the same way the NCCN Drugs & Biologics Compendium (NCCN Compendium®) is utilized as a reference for coverage decisions. The NCCN Biomarkers Compendium® aims to ensure that patients have coverage and access to appropriate biomarker testing based on the evaluations and recommendations of NCCN Panel Members.

Clinical professionals should apply independent medical judgment in their decisions about treatment that meets the clinical characteristics and needs of individual patients with cancer.

Website: [NCCN.org/biomarkers](https://www.nccn.org/biomarkers)



Patient Advocate Foundation

Patient Advocate Foundation (PAF) is a national 501 (c)(3) non-profit organization which provides case management services and financial aid to Americans with chronic, life threatening and debilitating illnesses.

Website: patientadvocate.org

Patient Advocate Foundation Personalized Medicine CareLine

Resource serves: All age groups facing any type of cancer

The Personalized Medicine CareLine is a comprehensive patient support resource operated by Patient Advocate Foundation, designed to provide assistance to patients who have completed a genomic test on clinical samples collected during their cancer or other genomics-guided diagnosis, or who are encountering barriers accessing and finalizing that process.

Website: personalizedmedicine.pafcareline.org

Phone number: 866.460.1928

Co-Pay Relief Cancer Genetic and Genomic Testing Fund

Resource serves: All age groups facing any type of cancer

The Cancer Genetic and Genomic Testing fund is intended to cover the cost of physician prescribed Genetic and Genomic tests for cancer. Covered tests are genetic tests to determine the risk of developing cancer based on heredity and genomic testing to diagnose cancer, identify mutation, determine treatment and monitor cancer growth. The fund does not cover procedures to get sample tissues, x-rays, MRIs, or scans/lab work outside of genetic and genomic tests. The fund also does not cover direct to consumer tests not prescribed by a physician. Learn more and apply online at copays.org.

Website: copays.org/funds/cancer-genetic-and-genomic-testing

Phone number: 866.512.3861

Getting the Right Test at the Right Time, A Cancer Patient's Guide to Biomarkers

Resource serves: All age groups facing any type of cancer

Biomarker tests make healthcare more precise and cost-effective resulting in improved health outcomes and targeted treatment options. Written by Patient Advocate Foundation, this guide focuses on the basics of cancer biomarkers and tips on the practical aspects such as access.

Information in English: gateway.on24.com/wcc/eh/1258749/lp/2879137/getting-the-right-test-at-the-right-time

Information in Spanish: gateway.on24.com/wcc/eh/1258749/lp/2927249/getting-the-right-test-at-the-right-time-a-cancer-patients-guide-to-biomarkers-spanish

Phone number: 800.532.5274



Pancreatic Cancer Action Network

PanCAN's vision is to create a world in which all patients with pancreatic cancer will thrive. Our mission is to take bold action to improve the lives of everyone impacted by pancreatic cancer by advancing scientific research, building community, sharing knowledge, and advocating for patients.

Website: pancan.org

Patient Services

Resource serves: Young adults, adults, and older adults facing pancreatic cancer

Patient Services provides free, in-depth and personalized resources and information on pancreatic cancer. Patient Services is the place to contact when facing pancreatic cancer. Our highly trained and compassionate Associates provide free, personalized information about the disease, including our support services.

We can also find resources for any questions you have related to pancreatic cancer. No organization supports pancreatic cancer patients like we do. Through our Patient Services, we provide more resources and speak with more pancreatic cancer patients and caregivers than any other organization in the world. Precision medicine information and personalized biomarker clinical trials searches are two of the many resources we provide.

Website: pancan.org/facing-pancreatic-cancer/patient-services

Phone number: 877.272.6226

Email: patientcentral@pancan.org

Know Your Tumor®

Resource serves: Young adults, adults, and older adults facing pancreatic cancer

PanCAN's Know Your Tumor precision medicine service provides eligible pancreatic cancer patients and their oncologists with information about the patient's biology through tumor tissue biomarker testing. Know Your Tumor gives patients and their healthcare team access to information about treatments – including available clinical trials – that are personalized to the patient. Every pancreatic cancer patient is different. Patients who receive treatment based on their biology can live longer. The Pancreatic Cancer Action Network strongly recommends all pancreatic cancer patients get genetic testing for inherited mutations as soon as possible after diagnosis and biomarker testing of their tumor tissue to help determine the best treatment options. Patients should discuss both tests with their care team. The tests can be available through their treating institution or PanCAN's Know Your Tumor® precision medicine service.

Website: pancan.org/facing-pancreatic-cancer/patient-services/know-your-tumor

Phone number: 877.272.6226

Email: patientcentral@pancan.org



Patient Empowerment Network (PEN)

Patient Empowerment Network's (PEN) mission is to fortify cancer patients and care partners with the knowledge and tools to boost their confidence, put them in control of their healthcare journey, and assist them in receiving the best, most personalized care available to ensure they have the best possible outcome. PEN's programs enhance patient health and digital literacy to enable shared decision-making and provide informational and educational resources to empower patients at every step of their cancer journey.

Website: powerfulpatients.org

Animated video: What You Need to Know Before Choosing a Cancer Treatment

Resource serves: Young adults, adults, and older adults facing any type of cancer

Our approach to helping patients and care partners realize the promise of precision medicine has been to advocate for biomarker testing. To this end, we have developed resources targeted at increasing general oncology knowledge as well as specific disease area knowledge. The animated video (available in English and Spanish): What you Need to Know Before Choosing a Cancer Treatment is aimed at a general cancer patient/care partner audience. The description is as follows: What steps could help a cancer patient and their doctor decide on the best treatment path for their specific cancer? This animated video explains how identification of unique features of a specific cancer through biomarker testing could impact prognosis, treatment decisions and enable patients to get the best, most personalized care.

Website: powerfulpatients.org/2021/03/18/what-you-need-to-know-before-choosing-a-cancer-treatment

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Patient Empowerment Network *continued*

INSIST!

Resource serves: Young adults, adults, and older adults facing breast cancer, lung cancer, prostate cancer, AML, CLL, MPNs, or Myeloma

Building on the success of the program in 2020 and ensuring that we are keeping pace with the most current advances in the quickly evolving field of biomarker testing, the expanded INSIST! Program is designed to give patients and care partners swift and actionable information, empowering them to insist on better care and personalized treatment options. Getting the best treatment involves ensuring a patient gets appropriate tests that inform the most effective treatment option available for their cancer. The program provides patients with supportive information and actionable tools so that they are asking the right questions at the right time at each stage of their disease journey. In keeping with the first iteration of the program which debuted in 2020, there's something for everyone. The information provided through the expanded INSIST! Program gives patients clear information in an accessible and dynamic format. The initiative provides a more in-depth overview of biomarker testing and its impact on care as well as more detailed information for accessing personalized medicine. The expanded program consists of a series of resources for patients and caregivers, including motivating, easy-to-understand videos about disease monitoring and biomarker testing, action-oriented guides to access better care, and curated content intended to educate and inform.

Website: <https://powerfulpatients.org/> (program available by disease area)



Prostate Cancer
Foundation
Curing Together.

The Prostate Cancer Foundation (PCF)

The Prostate Cancer Foundation (PCF) is the world's leading philanthropic organization dedicated to funding life-saving prostate cancer research, including precision medicine.

Website: pcf.org

PCF Prostate Cancer Patient Guide

Resource serves: Adults and older adults facing prostate cancer

This guide is a must-have resource for patients diagnosed with prostate cancer and their families. Compiled with the contributions of top-tier doctors and researchers, it focuses all of the information available about contemporary prostate cancer research, treatment, and lifestyle factors into one consolidated document. The guide identifies how precision medicine can be used in the treatment of both localized and advanced disease, so patients can be informed about their options and prepared to discuss the latest treatments with their healthcare team. Topics covered include: genetic testing for inherited mutations, biomarker testing, and targeted treatments for prostate cancer such as PARP inhibitors and immunotherapy.

Phone number: 310.570.4700

Email: info@pcf.org



Sharsheret

Sharsheret, a national non-profit organization, improves the lives of Jewish women and families living with or at increased genetic risk for breast or ovarian cancer through personalized support and saves lives through educational outreach. While our expertise is in young women and Jewish families as related to breast cancer and ovarian cancer, Sharsheret programs serve all women and men.

Website: sharsheret.org

Genetics for Life Program

Resource serves: Young adults, adults, and older adults facing breast cancer, colorectal cancer, ovarian cancer, pancreatic cancer, or prostate cancer, as well as those at risk of hereditary cancer

1 in 40 Ashkenazi Jews – men and women – carries a BRCA gene mutation, more than 10x the rate of the general population, making Jewish families significantly more susceptible to hereditary cancer, which could include breast, ovarian, pancreatic, prostate, melanoma or male breast cancer. If you or someone in your family has tested BRCA+ or carry another gene mutation (e.g. CHEK2, ATM, PALB2, a Lynch syndrome mutation), whether or not you have been diagnosed with cancer, we can help. Contact our clinical team of trained skilled mental health professionals and genetic counselors to speak privately at any point in your cancer journey. We offer confidential, psychosocial support and information to empower women and families to better understand individual circumstances, cope with unique challenges, and make informed decisions about treatment. Speak one-on-one with our certified genetic counselor about your family history, concerns about cancer risk, and the implications of genetic counseling and testing for you and your family. Our clinical team can connect you to speak with another woman who shares your experience in our national peer support network. Our confidential “Links” connect over the phone and through email and text, and offer invaluable friendship and support.

Website: sharsheret.org/brcagenetics

Phone number: 866.474.2774

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Sharsheret *continued*

Best Face Forward 2.0

Resource serves: Young adults, adults, and older adults facing breast cancer or ovarian cancer, as well as those at risk for hereditary breast and ovarian cancer

Best Face Forward 2.0 provides services and subsidies for eligible individuals for non-medical services that are critical to a woman's quality of life and body image, and that are only partly covered by insurance companies, if at all. Best Face Forward 2.0 services include financial subsidies for wigs (cranial hair prosthesis), cold caps (scalp cooling treatment), and tattooing (three-dimensional micropigmentation of the nipple and areola), tattooing of the eyebrows (microblading), and yoga (where applicable). Additionally there are complementary and holistic offerings such as meditation and yoga. To be eligible for financial subsidy you must: be diagnosed with breast or ovarian cancer, or be considered high risk for breast or ovarian cancer, with documentation to support this from a healthcare provider. A financial application is a necessary part of the process, as subsidies are needs based.

Website: sharsheret.org/resource/best-face-forward-2-0

Phone number: 866.474.2774

Email: info@sharsheret.org

Individual support

Resource serves: Young adults, adults, and older adults facing breast cancer or ovarian cancer, as well as those risk for hereditary breast and ovarian cancer

Contact our clinical team of trained, skilled mental health professionals and genetic counselors to speak privately at any point in the cancer journey. We offer confidential, psychosocial support and information to empower women and families to better understand individual circumstances, cope with unique challenges, and make informed decisions about treatment, and provide specialized support for women living with metastatic or advanced breast cancer and ovarian cancer. We send resources which include packets of information about new diagnosis of either breast or ovarian cancer, genetics information, financial wellness, or caregiver support. We have survivorship kits, best face forward makeup kits, busy box toys and parenting kits, and metastatic breast cancer kits. We have an extensive peer support network to match a caller with someone who has gone through a similar experience. We also have several private Facebook groups that can also provide peer support. All of these services are provided free of charge.

Website: sharsheret.org/what-we-do/speak-with-you-one-on-one

Phone number: 866.474.2774

Email: info@sharsheret.org



The Clarity Foundation

Clarity believes that all women with ovarian cancer deserve the best possible therapies for their unique disease and the best possible emotional support for their unique life challenges. To achieve this, we share the latest information on treatment options, help women access the most useful and comprehensive tests to better understand the molecular profile of their cancer, guide women to clinical trials, where appropriate, and offer professional emotional support and educational resources to women and caregivers.

Website: clarityfoundation.org

Treatment Decision Support

Resource serves: Young adults, adults, and older adults facing ovarian cancer, as well as physicians and caregivers supporting people with the ovarian cancer

Clarity takes a comprehensive, hands-on individualized approach to help women with ovarian cancer identify the treatments that may work best against their unique disease. Assessing their medical history, as well as tumor biomarkers and other diagnostics, Clarity professionals help women and their physicians chart the most advantageous course of treatment.

Website: clarityfoundation.org/treatmentdecisionsupport

Phone number: 858.657.0282

Email: patientsupport@clarityfoundation.org

Tumor Profiling Reports

Resource serves: Young adults, adults, and older adults facing ovarian cancer, as well as physicians and caregivers supporting people with the ovarian cancer

Tumor profiles provide detailed information of a tumor's molecular characteristics. That information can point to therapies that may have the best chances for positive outcomes. These profiles are discovered by testing the tumor for biomarkers such homologous recombination deficiency (HRD), micro-satellite status (MS), and tumor mutation burden (TMB), as well as molecular changes in more than 300 genes. The Clarity Foundation can help women understand the results from the tumor biomarker testing and comprehensive genomic analysis that is ordered by their physicians. We generate our online-accessible interactive report from those results. This Tumor Profiling Report provides information about the drugs that match the tumor profile and the reasons they match – all accessible by a mouse click. The report also provides links to clinical trials for drugs that are a match for the tumor biomarkers. Active trials are regularly updated to ensure timeliness of the information available.

Website: clarityfoundation.org/clarity-tumor-blueprints

Phone number: 858.657.0282

Email: patientsupport@clarityfoundation.org

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The Clarity Foundation *continued*

Clinical Trial Finder

Resource serves: Young adults, adults and older adults facing ovarian cancer, as well as physicians and caregivers supporting people with ovarian cancer

Clarity's Ovarian Cancer Specific Clinical Trial Finder enables searches based on details of the patient's clinical situation (e.g., histology, prior treatments, response to platinum) as well as tumor biomarkers, trial phase of development and location, as well as drug name, category or molecular target. The trials retrieved by the search include reported results for drugs in the trial when they are available and also highlights the trials that are looking promising. New trials are added to the database on a weekly, even daily, basis so that patients will receive the latest options available for their consideration.

Website: forms.clarityfoundation.org/find-clinical-trials

Phone number: 858.264.5124

Email: patientsupport@clarityfoundation.org



The Life Raft Group

The mission of the Life Raft Group is to enhance survival and quality of life for people living with GIST through patient-powered research, education and empowerment, and global advocacy efforts. The LRG vision is to champion patient-powered science and drastically increase long-term survivorship for all cancer patients.

Website: liferaftgroup.org

Biomarker Testing Initiative

Resource serves: Young adults, adults, and older adults facing GIST/ Sarcoma

Our tissue testing collaboration helps to understand the genomic profiles of our patient population. It aims to increase awareness to general GIST community for testing through LRG communication channels. Generate awareness for testing among the medical community.

Website: liferaftgroup.org/mutations-in-gist

Phone number: 973.837.9092

Email: srothschild@liferaftgroup.org



Triage Cancer

Triage Cancer is a national, nonprofit organization that provides education on the practical and legal issues that may impact individuals diagnosed with cancer and their caregivers, through free events, materials, and resources.

Website: tragecancer.org

Triage Cancer Health Insurance Resources

Resource serves: Anyone

Triage Cancer's goal is to ensure that people have access to quality information about health insurance coverage in order to make educated decisions and obtain adequate health insurance options for their needs. Having adequate health insurance coverage is the first step in minimizing the potential financial toxicity of a cancer diagnosis. It is equally important for individuals to understand how to use their health insurance coverage. This resource page contains legal and practical resources to help individuals effectively navigate health insurance after a cancer diagnosis.

Website: tragecancer.org/healthinsurance

Phone number: 424.258.4628

Email: info@tragecancer.org

Quick Guide to Appeals for Employer-Sponsored & Individual Health Insurance

Resource serves: Anyone

At some point during cancer treatment, you may experience a denial of coverage from an insurance company. If your health insurance company denies coverage for precision medicine, the Quick Guide to Appeals for Employer-Sponsored and Individual Health Insurance may help figure out what to do next to appeal that denial.

Website: tragecancer.org/quickguide-appeals

Phone number: 424.258.4628

Email: info@tragecancer.org

CancerFinances.org

Resource serves: Anyone

We know that cancer is expensive. This tool is designed to help guide you through some key topics that may impact your financial situation. Whether you are newly diagnosed or many years past active treatment, this site can help. By answering a few questions, the tool will guide you to information most relevant to you. Check out the new module on Appeals to find information on what to do if a health insurance company denies coverage for precision medicine.

Website: CancerFinances.org

Phone number: 424.258.4628

Email: info@tragecancer.org



For more information on the NCCN Oncology Policy Program,
please visit [NCCN.org/policy](https://www.nccn.org/policy) or contact:

Terrell Johnson
Manager, Policy & Advocacy
Tjohnson@nccn.org