



RACHEL’S STORY

“Clinical trials give me options and hope. They open my eyes to a world of research and science and medicine that I hadn’t witnessed the first time around. Now my health care team and I talk about trials and make decisions together, and think outside of the box. Clinical trials should be considered a first choice and not a last choice approach to treatment. Participating in clinical trials has provided me with a customized approach to treatments based on my specific diagnosis and has allowed me to contribute to the cancer research community.

If you are considered a good candidate by your doctor and you are willing to participate, why not consider cutting-edge science and medicine as a first choice? You don’t have to do it alone. You can rely heavily on your treatment team to help guide you through the process. Clinical trials can contribute to the search for ways to prevent, detect, or treat the disease. I’d like to think that my participation in clinical trials will not only benefit my outcome, but will help those with breast cancer or those who are at high risk.”

- Rachel, diagnosed at age 42

IF YOU ARE AT RISK OR DIAGNOSED WITH BREAST CANCER OR OVARIAN CANCER AT ANY STAGE, WE CAN HELP.

Connect with others who share your experience with clinical trials through our national peer support network.

Discuss genetic concerns related to your family history and cancer risk with our genetic counselor and support staff.

Let us help you help your children through the cancer journey with parenting resources.

Create a survivorship plan tailored to your unique needs.

Learn how to address the cosmetic side effects of cancer treatment.

Join our group of women living with advanced breast cancer or recurrent ovarian cancer.

Call us for resources and with questions from family, caregivers, and friends.

Keep informed about clinical trials by experts in the cancer community on our national webinars, and access transcripts from previous webinars on our website.

To find out more, call 866.474.2774, email info@sharsheret.org, and visit us at www.sharsheret.org.

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Clinical Trials
In A New Age

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WHAT ARE CLINICAL TRIALS?

Clinical trials are research studies to find better ways to screen, prevent, detect, or treat diseases like cancer, and to help find ways to improve cancer care. Whether you are at risk, newly diagnosed, in treatment, or living with advanced cancer, you can consult with your health care team to find a clinical trial that can be right for you. Doctors hope that through clinical trials new interventions that offer better outcomes can be discovered.

When considering a clinical trial, it is important to look at your unique set of characteristics. 1 in 40 individuals of Ashkenazi Jewish descent carries the BRCA gene mutation, which is 10 times higher than those in the general population. In addition to BRCA1 and BRCA2, there are other genes (e.g., ATM, CHEK2 or PALB2) or Lynch Syndrome, any of which may predispose you to a variety of cancers including breast, ovarian, male breast, colon, pancreatic, prostate, uterine, and melanoma. Jewish women and families, particularly those carrying a genetic mutation, may qualify for and benefit from specific clinical trials that focus on these genetic mutations.

CONSIDERING ENROLLING IN A CLINICAL TRIAL?

Questions to ask your doctor:

- What is being studied?
- Why do they think this might work?
- Has this intervention been given to other people before?
- How will we know it is working?
- What are the side effects and benefits?
- What am I required to do?
- How often do I need to come in to the trial?
- How long will the trial last?
- What are the costs of the trial?
- Is there financial assistance for travel and housing?
- Does the trial have follow up?
- Will the trial provide me with results?
- Who is going to be my trial team?
- Can I continue seeing my oncologist?
- Who should be part of my personal support team?

MYTHS AND FACTS

MYTH Clinical trials are a last resort approach to treatment.

FACT Clinical trials offer a customized approach to treatment, at any stage, based on your specific diagnosis and genetic status. What is offered through a clinical trial can be the preferred treatment choice initially, not just as a last resort to treatment. In fact, experts believe that care through a clinical trial can sometimes be better than standard care due to the extra attention that is given to someone participating in a trial.

MYTH On a clinical trial, you get a placebo and therefore are not really being treated for cancer.

FACT In clinical trials, all participants receive standard of care treatment. In addition to the standard of care treatment, some patients will receive the clinical trial drug, while others will receive a placebo in its place. No one receives a placebo in place of appropriate treatments.

MYTH Clinical trials are not safe and you are treated like a guinea pig.

FACT The Institutional Review Board’s mission is to protect the rights and welfare of the individuals who are participating in clinical trials, while data safety monitoring boards look at the data nationally to detect benefits and risks early on. Informed consent ensures that you understand everything that will happen in the study, the reason for the trial, and the risks and benefits.

MYTH If it were right for me, my doctor would have told me about it.

FACT Just because a trial is out there doesn’t mean your doctor knows about it, as your doctor might not be part of a clinical trials network. If your doctor does not have access to clinical trials, or if you wish to participate in a study at another institution, ask about all of your options. You could be referred elsewhere for a study and still maintain a relationship with your own physician.

MYTH Clinical trials only take place at large cancer centers.

FACT Clinical trials take place at cancer centers around the country; at big cancer centers, smaller cancer centers and community oncology practices. Small institutions have relationships with cancer centers and often offer the same clinical trials.

MYTH All costs are covered by the clinical trial.

FACT It is important to understand the financial considerations in a research study. Some medications and services may be covered, while others may not. It is important to explore what the study pays for, what is billed to insurance, and what additional costs you may be responsible for.

MYTH Once you are in a trial, you can’t leave.

FACT If you are not doing well on a trial, it would be unethical for a doctor to keep you

on it. You can drop out of a trial at any time and for any reason without impacting your standard care and ability to receive standard treatment.

MYTH Patients are always notified immediately about the full results of a clinical trial.

FACT Often, individuals are not directly notified about the overall study results, however, are able to review the study’s findings once they are publicly disseminated. Speak with your doctor about how you may receive information throughout the trial as well as after the trial is complete.

MYTH: Participation in a clinical trial is the only way to be involved in research.

FACT: If you are unable or not eligible to participate in a therapeutic clinical trial, there may be other ways that you can participate in clinical research. Sometimes researchers request blood or tissue samples for laboratory studies that will help in understanding mechanisms of disease, genetics of cancer or help in discovering new types of treatment for specific cancers. Speak with your health care provider about how you can participate and contribute to clinical research.

RESOURCES

About Clinical Trials
learnaboutclinicaltrials.org

American Cancer Society
cancer.org

Breast Cancer Trials
breastcancertrials.org

Basser Center for BRCA
basser.org

CancerCare
cancercares.org

Carebox Health
careboxhealth.com

CenterWatch Clinical Trials Listing Service
centerwatch.com

Clinical Trials And Me
clinicaltrialsandme.com

Coalition of Cancer Cooperative Groups
cancertrialshelp.org

Dr. Susan Love Research Foundation
drsusanloverresearch.org
eCancer Trials
cancerconnect.com

FORCE
facingourrisk.org

National Cancer Institute
cancer.gov

National Institutes of Health
clinicaltrials.gov

Search Clinical Trials
searchclinicaltrials.org

Sharsheret
sharsheret.org

Susan G. Komen for the Cure
komen.org