Clinical Trials

Discover how one woman dedicated her life to advancing cancer treatments even as she battled stage IV cancer.

BROWSE more stories online, including one on how eClinical platforms provide benefits to clinical researchers.

LEARN about the movement encouraging cancer patients to discover the best clinical trials for their needs.
How Everyday Heroes Are Changing Medical Research

Medical heroes are those who selflessly choose to participate in clinical trials, allowing for medical innovations that have the power to change lives.

During the past decade, powerful and productive medical innovations have delivered more than 4,000 experimental drugs and interventions into active clinical trials around the world. But the success of these innovations – ultimately measured by improvements in the quality of patients' lives and by the availability of new treatments and cures for unmet medical needs – depends entirely on the millions of people who participate in clinical trials each year. We call these brave individuals medical heroes.

Everyday heroes
Medical heroes are mothers, fathers, siblings, children, friends, and colleagues who have chosen to give the extraordinary gift of participation in clinical research. Their decision is a selfless act because participation always carries risk but is unlikely to bring any direct personal benefit. While it is true that participation may bring hope to patients and their loved ones, ultimately it is future generations who are the direct recipients of the benefits of clinical trials. Medical heroes profoundly contribute to our society’s collective knowledge about the nature of disease, its progression and possible treatments.

Raising awareness
Sixteen years ago, the Center for Information and Study on Clinical Research Participation (CISCRP) was founded to provide outreach and education to those individuals considering participation in clinical trials. Based in the Boston area but with global reach, this nonprofit organization focuses its energy and resources on raising general awareness, educating patients and the public, and on enhancing study volunteer experiences during and after clinical trial participation.

It is CISCRP's ongoing mission to raise public awareness about the importance of clinical research and to increase public recognition of the millions of study volunteers and clinical research professionals who, together, help advance medical knowledge.

Medical heroes are at the very heart of life-saving research innovation. We owe them our deepest appreciation for their profound gift of participation.
A Doctor's Perspective on the Benefits of Clinical Trials

Clinical trials offer the most effective treatments available, as well as the opportunity to help future patients.

As a doctor who talks to patients living with cancer every day, I am often asked about clinical trials, including what happens during a trial and if a patient should consider participating in one.

Clinical trials are extremely important in making progress for cancer patients. Some clinical trials try to determine if a new type of therapy is both safe and effective. Many large clinical trials compare a standard treatment with a more novel treatment that cancer experts think could possibly lead to changes in how patients will be treated in the future.

**Discovering new treatments**

Patients today have benefited from the thousands of courageous individuals who participated in past clinical trials to help make progress in advanced treatment options. In fact, most standard cancer treatments are based on the results of previous clinical trials. For example, trials in the 1970s compared outcomes for patients who received a mastectomy to those who received a lumpectomy with radiation for their early-stage breast cancer. The results showed the less invasive lumpectomy and radiation approach was equivalent to having a mastectomy. This trial dramatically changed the standard of care today.

There are several reasons why a cancer patient might consider joining a clinical trial. These studies offer the most effective treatments available, including the current standard of care. In some cases, a new therapy may only be available through a clinical trial. If your doctor advises looking into a certain trial, she or he likely considers the unique characteristics of your cancer to be a good fit.

**Upcoming advancements**

Ongoing clinical trials are testing new and powerful ways to combine different types of cancer treatments, similar to the example of combining radiation with surgery for early-stage breast cancer. One approach that is generating significant excitement in the research world is the use of radiation therapy to boost the impact of immunotherapy drugs. Radiation has been shown to make immunotherapies more effective, but more clinical trials are necessary for doctors and scientists to better understand how this interaction occurs and design the best approaches to combine these treatments.

Clinical trials are available everywhere—not just in major cities, university centers or large hospitals. Most cancer centers and doctors who treat cancer patients can guide their patients to a trial that could fit their situation. In addition, patients frequently find support from networks of cancer patients who have been through trials themselves and can provide helpful first-hand knowledge and advice.

Patients who join clinical trials make a valuable contribution to science and help improve the lives of future cancer patients. Talk to your doctor if you are looking for available clinical trials to treat your cancer.

By Catherine Park, M.D., American Society for Radiation Oncology Science Council
To Conquer Cancer, Our Nation Must Continue to Invest in Research

For many cancer patients, clinical trials offer new hope. Therefore, government funding is a necessity in bettering the chance to cure cancer once and for all.

When I began my oncology career nearly 30 years ago, the possibility of conquering cancer would have seemed an implausible pipe dream. Now, with the tremendous progress being made in understanding and treating cancer, I believe that dream is firmly within our grasp.

Nearly every American is affected in some way by cancer, and many of us know first-hand how a cancer diagnosis can disrupt the lives of patients and their families. As a surgical oncologist, cancer researcher, and the President of the American Society of Clinical Oncology (ASCO), I’m honored to have a front row seat in today’s cancer revolution and to directly contribute — in a role that is amplified by the strength of ASCO’s oncologists and the patients that we serve — to advances in cancer prevention, diagnosis and treatment.

Providing hope
During my career, I have seen how cancer research can help patients live longer with better quality of life, and how many patients can be cured. The National Cancer Institute (NCI) has an essential role in this progress, with federal research unlocking answers to questions about preventing cancer or identifying treatments that cause the fewest side effects. Research supported by NCI has spurred innovation, including most recently the first immunotherapies for cancer. This new treatment approach has produced dramatic improvement in outcomes for some patients with previously difficult-to-treat cancers. We are driven by this success to further unlock the secrets that will make this result achievable for all patients with cancer.

The need for funding
With all this good news, it’s hard to see 88 percent of qualified research go unfunded. I’m thankful that Congress has marshalled bipartisan support for the NCI, providing funding increases that aim to reverse nearly a decade of flat funding. However, even with these recent investments, the decline in purchasing power means that NCI can only fund 12 percent of qualified research applications. That is less than half of the 27 percent of research proposals funded in 2003. And support for our publicly funded National Clinical Trial Network continues to decline in real dollars.

For some of my patients, a clinical trial is the best option. We need to make it easier for patients to participate in important research that not only affords them state of the art cancer treatment, but also helps others who face a cancer diagnosis.

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By Monica Bertagnoli, M.D., FASCO, President, American Society of Clinical Oncology
Debunking the Myths Surrounding Cancer Trials and Research

In order to further our knowledge of cancer diagnoses and treatments, a greater number of diverse clinical trial participants are needed.

Getting a cancer diagnosis can be frightening, and picking a course of treatment may feel overwhelming. But new innovations in research are changing the way cancer is being treated, and clinical trials are providing cutting-edge new treatments that may improve future diagnoses. The goal of clinical trials is to find treatments that are better than what’s currently available. Virtually every therapy approved to treat cancer has been made possible by those who agree to participate in clinical trials.

There are currently over 22,000 active cancer clinical trials in the US that are enrolling patients or preparing to recruit participants. However, very few adult cancer patients join a trial, and one-in-five cancer clinical trials aren’t completed due to a lack of participants. Without enough patient data, a promising treatment might never get approved.

**Debunking myths**

In addition to the lack of awareness of the necessity of clinical trials, there are many misunderstandings and myths that need to be addressed. For example, clinical trials are not just a last hope for patients for whom the traditional standard of care has failed; many cancer trials enroll patients who have not received prior treatment. There is also a misunderstanding concerning the use of placebos, which are rarely used. Most clinical trials provide either the experimental treatment or the treatment that is the most current “standard of care.”

Another issue to consider is that members of minority communities are too often underrepresented in clinical trials. According to the FDA’s Drug Trials Snapshots, in 2017, nearly 75 percent of the participants in cancer clinical trials leading to drug approval were white, whereas only 12 percent were Black or African-American, four percent were Hispanic, and 12 percent were Asian.

**Public awareness**

Seeking to increase the public's awareness of clinical trials, Stand Up To Cancer (SU2C) has launched an extensive public service awareness campaign encouraging patients to ask their doctors which clinical trial may be right for them. The campaign features Stand Up To Cancer Ambassador Sonequa Martin-Green, as well as diverse cancer patients, and the online resources available in both English and Spanish aim to include people from all ethnicities and backgrounds.

Visitors to StandUpToCancer.org/ClinicalTrials (and StandUpToCancer.org/es/ensayosclínicos) will find content that is easy to understand, including short videos explaining clinical trials and different types of treatment, the terms one may hear when discussing trials, the benefits of participating, and what to expect if you or a loved one participates in a clinical trial. The website also provides a list of questions that can be printed for reference during discussions with your healthcare provider. Additionally, Stand Up To Cancer provides a free and confidential Clinical Trial Finder service through EmergingMed that allows patients or caregivers interested in finding an appropriate clinical trial to submit an online form or call a toll-free number to begin the process.

Since launching this campaign in February, SU2C has engaged dozens of advocacy organizations to increase the reach of these assets. As we collectively increase awareness, and more diverse cancer patients participate in clinical trials, researchers will learn about new treatments that may be more effective in fighting cancer.
How Cancer Patients Can Participate in Clinical Trials from Home

Gail Adinamis
Founder and CEO, GlobalCare Clinical Trials

Many patients are deterred from signing up for clinical trials due to an inability to leave their homes. GlobalCare is a patient-centric service that brings the trial right to the patient’s door.

There has been a lot of focus recently on patient-centered clinical trials. However, the basic model of conducting trials is slow to change. Sites are still tasked with enrolling patients, and patients must return to the site for their study procedures. GlobalCare Clinical Trials, LLC provides a patient-centric model where selected clinical study visits are conducted at patients’ homes, workplaces or alternate settings.

Benefits of home trials
CEO Gail Adinamis states, “Our patient-centric service model provides faster patient recruitment, better protocol compliance and higher retention rates, while decreasing development time. Our model was built on the simple premise that if you make study participation convenient and comfortable, more patients will be willing and able to participate.” Adinamis founded and pioneered this service model that she introduced 25 years ago, and GlobalCare has since supported over 450 Phase I-IV trials across a variety of therapeutic areas. A 50 percent reduction in subject recruitment time and an increase in subject retention rate of more than 95 percent are among the results that have marked GlobalCare’s growth.

“Oncology, rare diseases, and neurologic disorders are among the therapeutic areas most demanding of these services,” said Adinamis. “In addition to study drug administration, blood draws and clinical assessments at home,” Adinamis continued, “we also provide travel companion services to assist patients to the site, as well as a variety of on-site support services to ease the burden on the investigative staff.”

Providing comfort
GlobalCare is a niche service provider to the world’s pharmaceutical, biopharmaceutical, biotechnology and medical device companies engaged in product development. GlobalCare’s model enables patients to participate in clinical trials regardless of study duration, frequency of visits, disease state, distance to site, family, work and community commitments by conducting study visits in a location convenient to them.

Services include global project management, study drug administration, blood and other biologic sample collection, clinical assessments, patient training and education, device management, source documentation and data collection. In addition, the company offers global pharmacy services including storage and distribution, compounding and dispensing, cold chain logistics and sourcing of commercial products and devices.

Remembering Rachel Minnick: Passionate Clinical Trial Volunteer and Advocate

Rachel Minnick dedicated much of her life as a medical hero. We honor and remember her legacy.

Diagnosed with stage 2 breast cancer in 2013, the wife and mother of two fought back fiercely against the disease with a double mastectomy, chemotherapy and radiation. She participated in a clinical trial. And she worked tirelessly to educate others about their treatment options and the clinical research process.

“Rachel was always pro research, pro clinical trials,” says her husband, Pete Minnick. “She always had that mindset ‘we’re on the cutting edge of medical breakthroughs and technology,’ and she wanted to be on that cutting edge.”

Her cancer was in remission from 2014 to early 2017, until she began experiencing pain in her back and neck. It was at this time that her doctors informed her that the cancer was back and had spread to her bones. “That was a huge blow to us,” Pete says, noting it was stage 4 cancer. “She knew she wasn’t going to be cured.”

In early 2018, the cancer spread to Minnick’s lungs and liver. She was actively looking for her next clinical trial when she passed away this past April, at age 39, but her legacy lives on.

Meaningful work
Prior to her cancer spreading, Minnick took a position as a Senior Manager of Marketing and Patient Engagement Alliances at The Center for Information and Study on Clinical Research Participation (CISCRP), a non-profit dedicated to educating the public and patients about clinical research.

She was passionate about her job for many reasons not only was there a focus on the patient community but it also allowed her to work from her Philadelphia-area home which gave her the opportunity to continue her medical care as well as spend time with the couple’s children, Emily and Sam, now ages 9 and 7.

Being a part of CISCRP was more than a job for her.

“She felt like she was helping the entire clinical trial community as well as doing something she liked,” says her husband.

CISCRP gave her the opportunity to offer hope to other people who were in her same situation.

Personal experience
“Rachel had direct experience which gave her such an inside perspective,” says her former boss, CISCRP founder, Ken Getz. “It fed her compassion and helped her understand, even more deeply, what so many patients are going through.” Getz says Minnick’s legacy lives on through her work; the panels she moderated, the clinical trial awareness initiatives that she spearheaded, her collaborative projects, and the enduring educational brochures, newsletters and other patient communications that she wrote during her time with CISCRP.

“Her passing was truly a shock to me,” says Pete Koerner, a pharmaceutical industry colleague, who worked with Rachel and the CISCRP team for two years.

He described Minnick as someone who was always enthusiastic, passionate and dedicated to her family, her staff and her work.

“She was invested in clinical research,” says Koerner, explaining Minnick was proud to be the patient voice and wanted to advance the techniques and technologies in the clinical trials process.

“She felt like she was helping the entire clinical trial community.” Getz reflects on Minnick’s lasting impression, “Her compassion combined with her professionalism and the passion that she brought to CISCRP has inspired so many people — those who reported to her, those who she mentored, and those with whom she collaborated. That will stay with us forever. She truly helped to define our culture and evolve it in such meaningful ways.”
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To all clinical research volunteers, thank you.

A sincere thank you to all of the men and women who take part in clinical research studies each year. By volunteering today, you become a medical hero forever. For more information about clinical research, please visit CISCRP.org.