

Expert says participation in adult cancer clinical trials needs to rise

May 21 2015, by Toni Kay Mangskau

Toni Kay Mangskau has worked at the Mayo Clinic for the past 28 years. Her current position of clinical trials referral coordinator for the Mayo Clinic Cancer Center was created in 2005 after a need was identified for providing clinical trial information and resources to internal and external patients, family members, and referring health care providers. Mangskau oversees the clinical trials referral office for the Mayo Clinic Cancer Center's sites in Arizona, Florida, and Minnesota. Nationally, Mangskau has served as a steering committee member for the Summit Series on Cancer Clinical Trials, and was co-chair of the infrastructure/funding subcommittee to develop a nationwide training program for research staff on communicating with patients about clinical trials. Mangskau's prior work experiences include the Mayo Clinic Nicotine Research Program, various community mental health and corrections programs, state legislative analyst, and a volunteer caseworker for a local immigrant and refugee agency.

My brother-in-law Bruce was diagnosed with [cancer](#) 10 years ago and died a short time after receiving the diagnosis. My sister was left a widow with two young children. My heart still aches when I think back on this time.

Those of us who interact with cancer [patients](#) continue to hear stories very similar to this one. The medical community needs to take steps forward to advance research so fewer families suffer through this type of experience. So what needs to happen?

Participation in adult cancer [clinical trials](#) in the United States is about 3 percent. For women and minorities, the percentage is even lower. Our goal should be to increase these numbers significantly. With well-designed studies available around the country, [health care providers](#) need to feel more comfortable incorporating the topic of clinical trials into their conversations with patients. In a 2013 poll from Research America, patients report 70 percent of doctors have not talked with them about medical research and 8 percent were not sure.

From the time a cancer patient is newly diagnosed to the time a patient has exhausted standard treatments, patients need to be hearing about clinical trial opportunities.

A common saying is "the clinical trials of today are the treatments of tomorrow." In order to provide more treatments, we need to debunk some of the myths. There is still the misconception of being a "guinea pig" while participating in a study. In studies related to treatment, patients will receive either the treatment being studied or the standard of care. Placebos are used only when there isn't a known approach (standard treatment) for a particular type of cancer. New agents are studied many years in the lab for safety and effectiveness before they are available to people. Study participants are monitored closely by their medical team. Without clinical trial participation, we are unable to answer critical questions our patients are asking.

Mayo Clinic recently redesigned its public [clinical trials website](#). Our [cancer center](#) has implemented a universal phone number and web form for clinical trial inquiries. We are streamlining the process for patients, family members, and referring providers to contact us for clinical trial information.

As the clinical trials referral coordinator for our cancer center, I talk with thousands of individuals each year. It is my hope that our improved

clinical trial website and streamlined process will continue to improve our clinical trial participation rates.

My brother-in-law would have traveled anywhere in the world to participate in a clinical trial that would have possibly given him more quality time with his family. Unfortunately, he was unable to locate a study. It is time to examine current systems and look for ways to make the information readily available. We all need to make improved clinical trial participation rates a priority.

Simply put: clinical trials need to be part of the conversation with our patients. This simple act can and will help move science forward.

Provided by American Association for Cancer Research

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