Clinical Trials Need Cancer Patients

By STAN COLLENDER  JUNE 19, 2015

I HAVE a very rare and aggressive type of skin cancer — Merkel cell carcinoma — for which there is no approved cure, and I’m participating in a clinical trial to deal with it. If successful, the trial will show that the drug I’m being given at least manages what is now an often fatal disease.

Unfortunately, participation in clinical trials by cancer patients is, like my disease, extremely rare. Only roughly 3 percent of all cancer patients in the United States ever agree to join a trial. Among women and many minorities, the participation rates are even lower.

This is not a (excuse the term) benign problem. Clinical trials are the way promising new drugs are tested and progress against cancer is made. The paucity of participants also significantly increases the time it takes for new medications and treatments to be approved because the trials take so much longer to complete. And that means that many people who would benefit from these drugs won’t get them in time.

There are many reasons participation is so low.

In some cases, a patient’s doctor may not know about the trial or may not want to lose the patient. Or the doctor may be unwilling to spend the time it takes to enroll the patient in a trial, especially because physicians aren’t always paid to do so.
In others cases, patients may not know what a clinical trial is or whether one exists for their disease. They may be concerned about what the new drug will or won’t do. They may fear losing control of their treatment or be unwilling or unable to make multiple trips to a hospital. Or they may not want to change doctors.

I had many of these same concerns. My first question was one many patients ask: What will happen to me if I’m in the “control group” — the patients who don’t receive the experimental drug?

My doctor explained to me that I had absolutely no chance of getting the new treatment if I wasn’t in the trial, but at worst a 50 percent chance of getting it if I participated. I later discovered that in my particular trial, everyone would be getting the new drug.

In other trials, some patients get the test drug while the others receive standard treatment, so the two can be compared. According the National Cancer Institute, placebos are almost never used in cancer treatment trials.

As for other patient problems that reduce participation rates, the good news is that there are fixes for them. For example, informing patients about clinical trials could be made a part of the standard of care by doctors and, as such, insurers could be required to pay for the physician’s time.

The National Cancer Institute’s website, which lists clinical trials planned or underway, could be revised so that patients and not just health care professionals could understand it.

And the big fear of patients about not wanting to be used for experimental purposes should be addressed directly.

On hearing that I was in a clinical trial, one colleague actually told me that he would rather take his chances with no treatment than be used as “a lab rat.”

I am not a lab rat.

What I am is a patient who needs and is receiving treatment. I’m being seen by
one of the world’s foremost experts on my disease. He has studied my cancer far more extensively than any other doctor I have seen (and there have been many) in the past two years. In fact, my other doctors used his research to advise me on options. I am ecstatic about working with him directly.

I’m also very much in control of my treatment. I was the one who decided that my previous treatment wasn’t adequate. Once I was told about this clinical trial, I was the one who decided to join it. If the time comes, it will be my decision to stop participating in it.

I am also a collaborator. No, I won’t be presenting the results at a medical conference or writing a paper for a peer-reviewed journal, but my physical and emotional reactions to the drug are being monitored and recorded, and that data will contribute to the results and conclusions. I’m also actively and enthusiastically reporting my responses to help improve the way the trial is conducted.

One of my doctors called me a pioneer. I am, after all, a member of the team helping to develop a drug for my cancer, and one of the first people to use it for that purpose.

But I really like to think of myself as the equivalent of a test pilot like Chuck Yeager and the early astronauts. The difference is that, instead of testing aircraft and aerospace vehicles, I’m testing the efficacy of a drug that may cure my cancer, or at least prolong my life and the lives of others.

Being a test pilot is a far more romantic, daring and audacious notion than being a lab rat.

In the fight against cancer, it’s also more accurate.

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