Hepatitis C Clinical Trials: Tips from a Nurse

June 3, 2014 By Lucinda K. Porter RN

I was a clinical trial nurse at Stanford for many years. In addition to coordinating the hepatitis C studies, I also participated in a clinical trial after I left Stanford. I love clinical trials. As a nurse, I felt I could spend more time with patients. As a subject, I felt I was less likely to slip through the cracks. Between the additional appointments, labs, and questionnaires, I was well monitored. I also like the feeling of contributing to science. The price was right too, because I didn't have to pay for any of my medical costs. I did have to travel, so it wasn't completely free, but it was still a good deal since at the time I was uninsurable.

I am now free of hepatitis C, and although I am no longer working as a clinical trials nurse, I highly recommend studies if you have any near where you live. Clinical trials often fill up quickly, so here are some tips that may help give you an edge:

- Look for clinical trials through reputable sources. Avoid clinical trial organizations that are looking for participants but don't provide specific clinical trial information. They are basically head hunters and their practices are questionable. Reputable trials can be found at: ClinicalTrials.gov, CenterWatch, or on medical center websites.
- Call as soon as you can, and don't put off calling about a study. The first study I called about received hundreds of calls in the first hour for only ten slots.
- After you call, find out everything you can about the study so you are sure you meet the minimum requirements. For instance, if the study is only accepting patients who have genotype 1, be sure you have a copy of your genotype.
- Getting in to a study can be very competitive. The people who are more likely to get called back are the ones that are as organized and ready to go. Have your medical history, labs, copy of biopsy, medication list, and any other relevant paperwork on hand. Ask for a number where you can fax your information to, and request a consent form to be emailed to you. I wish I could say

that patients are called first come, first serve, but sometimes the calls are taken by multiple people. The patients who are going to be called back first are the ones who are the most prepared. For instance, if the study requires a liver biopsy as part of the enrollment criteria, then those with recent liver biopsy results can be enrolled more quickly.

- Be gently proactive. The polite, persistent, squeaky wheel helps you get attention. If you don't hear back in a few days, email or call every few days until you get a response. Ask if they might know when they are starting, and if there is anything they need from you to help secure a spot in the trial.
- Thank them even if they say no. If you don't get into a trial, ask to be put on a waiting list. Tell them you can step in at any time. Despite having worked at Stanford, I was denied a spot because they were full. Someone was disqualified at the last minute and the next day I was in the study.
- Keep trying. Keep checking for clinical trials at the medical centers near where you live. If they don't post trials, call once a month and leave a friendly message letting the coordinator know you are still looking for a clinical trial.

There is much more to clinical trial participation than this, so if you are interested, check out Hep's Clinical Trial information.

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