

Support in Finding Clinical Trials

My name is Janet Hunt. I was diagnosed with stage 3 colorectal cancer in 2011 and stage 4 colorectal cancer with metastases to my lungs (and later hilar lymph nodes) in 2012. Like many with colorectal cancer, since I was diagnosed I have undergone a variety of treatments, including 3 surgeries (lower anterior resection and ileostomy, ileostomy reversal and port insertion, and video assisted thoracic surgery on my right lung), “regular” and stereotactic radiation, and chemotherapy (xeloda, xelox, avastin and folfiri). I am getting near to the point where my current chemotherapy regimen will no longer be effective and have begun researching clinical trials as my “plan B.”

I am well educated (undergraduate and law school degrees from ivy league colleges) and had a successful career as a senior attorney for several major corporations yet I needed help with finding the most appropriate clinical trial for me. Finding such a trial is a daunting and complicated task with very high stakes – if I found the right trial, it could add years to my life expectancy. I did not feel that I had the expertise to find the best clinical trial on my own. Not was I confident that a busy oncologist would put the time in to help me select the best trial. The first oncologist I spoke to about helping me find a clinical trial viewed all the legwork for finding a trial as my responsibility and suggested that I contact one of the main cancer centers such as Memorial Sloan Kettering so they would think of me when they had an appropriate trial. I did not think that this was the path to follow since I would not want to limit myself to trials at one institution. The second oncologist I spoke to said he would help me find a trial but that I should also look because I would be more motivated than him to find the best trial. The oncologist I am currently seeing is helping me find a trial.

As I was starting the process of trying to sort through various trials, I saw a posting from Jon Dyne on one of the Facebook colorectal cancer support groups volunteering to help someone with colorectal cancer. I contacted Jon and asked if he would help me sort through clinical trials. Jon agreed to and has provided me with invaluable help, including educating me on cell biology, researching and explaining to me various potential trials and reviewing my medical tests such as my Foundation One genetics study. We usually Skype once a week to go over the materials that Jon has prepared for me. As a result, I have begun to develop the expertise to choose among clinical trials and I have become a much better advocate for myself, including providing information to my oncologists that they did not know about various trials, such as the expansion of the TAS 102 trials to additional sites. When the time comes for me to enroll in a trial, the help I received from Jon has made me far more confident that the trial that I ultimately participate in will be one that gives me the “best shot” at hitting a home run in my battle against colorectal cancer. I don’t think I could have done this without Jon’s assistance. I don’t see how others are able to select which trial may be the best for them without the kind of help that I received. I will be forever grateful for Jon’s help.

Please feel free to contact me if you have any questions.

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