



Patient Report

Behind the Scenes of Cancer Screening

A Report by
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It's time to go behind the scenes of cancer screening. You may be just starting, or you may have been at it for years. Since I've been around the block with various tests and received bad, good and indeterminate test results, I thought I'd share some ideas with you.

If you haven't had regular screening, the hardest obstacle to overcome is probably your own resistance. Perhaps you have had too many medical interventions, too much "being a specimen" in your life. It's not easy being poked and probed as a PJS person. Sensitive people, young or old, carry away scars that are more than skin deep. Perhaps you're afraid of bad news. You plunge into testing with your nose plugged and your eyes closed, hoping for the best, fearing the worst. You just want to get it over with.

Most of us think of tests in true/false, black/white, pass/fail terms. Either you don't have cancer (negative test results) or you do (positive test results). You figure that you'll show up, get the test, get the results and do the right thing for the right outcome. Unfortunately, events seldom unfold this way. In fact, they so seldom unfold this way that I'd like to give newcomers some idea of some of the things that have happened to me and others.

Negatives Your test results are negative, you should party right? Well, I think PJS folks are understandably more paranoid than most. Many of us have gone undiagnosed for years, have had tests that missed obvious problems, perhaps had genetic testing that doesn't show a mutation at chromosome 19. We're just a little dubious about the good news. Then, by the time we finally believe the good news, we realize that we need to come back for the same test next year and the year after until the end of our lives.

False Negatives Your test results are negative, but the test isn't sensitive enough to pick up the problem. If you are asymptomatic and in denial, this is great news. Time to party. But if you are symptomatic, especially with maladies that can't be diagnosed, you may think you are losing your mind. Or perhaps your physician does, you may come away with a script for antidepressants or anti-anxiety drugs rather than treatment. Or you can keep going to different doctors until someone finds the right test to diagnose your problem.

False Positives Your test results are positive, but you don't really have cancer. You find yourself going back for bigger, costlier, more invasive tests. The biopsy, MRI, complete blood panel, CT scan, ERCP. The doctors try to narrow down the problem. At the end of the day you are diagnosed with a malady that is less than life-threatening (a benign tumor, cyst, polyp, disease, abnormality), but an inconvenience. It's easy to think of yourself as damaged goods. You have had many of the hassles of getting cancer, including waiting for pathology results, with not much to show for it. And you still have to go back for more testing next year.

Positives You're told that you have cancer, no doubt about it. You either see the end of your life rushing toward you or you resolve to beat it. But, there is cancer and there is cancer. Sometimes it is contained within one area and can be removed by surgery (this is why most of us screen, not for prevention but for early diagnosis). Sometimes it is a slow growing cancer or in an out of the way place. It's not clear how it will progress, perhaps treatment will cure it or give you a period of remission. Then there are the cancers that have spread and are aggressive and in organs necessary to life. These are much more difficult to beat and the survivors more likely

evidence of miracles than medical competency. Just because there's a diagnosis, doesn't mean there's a cure. It's nice to know that the problem isn't all in your head, but a bummer to know you can't really change it. Sort of like a PJS diagnosis. :-)

Inconclusive results Many members know this one from their genetic testing. One is left betwixt and between, neither a yes nor a no. Maybe it's, "come back in three or six months for a follow-up test". Or "we're sorry, we can see that you're suffering AB and C, but we can't tell you why". Or "it's inconclusive, we'll have to do something really nasty to you to get clear results." Meanwhile you are spending lots of time, money and sleep trying to wrap your mind and heart around what's happening. You have done the right thing, paid for the test and you still don't know what, if anything, is wrong.

And the PJS medical specialists suggest that you do this at least every couple of years. And everybody in your family with PJS should be keeping a similar schedule. And women should be doing more. If you have survived a previous positive diagnosis, you're likely to have more invasive tests more often with more biopsies.

I'm not advising anyone to refuse screening. Most of the guidelines make sense, from a medical point-of-view. But I believe that each one of us has to factor in our own life. How much stress can I take? Do I need to space the tests so that they do or don't all come at once? Do them right before or right after a holiday so I can cope better with possible complications? Take a friend to the appointment to help us listen to what the doctor really is saying? Reschedule tests when other life events are stressing me out? Take up self-hypnosis, meditation, counseling or a spiritual life to help me deal with bad news? Learn to stand up for myself when a doctor suggests that my symptoms and worries are all in my head? Learn to relax into good news?

These are just a few of the stress releases I've worked with over the years. As I said earlier, I've had every type of test result. Each has its own stresses. Managing stress is an important part of living with PJS, since the stress of cancer risk isn't going away. Anyone who's been in this group longer than a day knows that some people with PJS do get cancer. Figuring out who and when and where and how much is impossible. At this point, we are stuck with doing our best to prevent it and coming up with a cancer screening program that works for, not against, each of us.

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