



SEA Stories

*A Personal Experience
from Horst Elendt,
Prostate Cancer Warrior*

Twenty-Three Years of Active Surveillance, and Going Strong!

Horst Elendt is a regular, long-time participant in the SEA Blue Chicago Prostate Cancer Walk and Run. He is also someone who has directly experienced the positive impact of an Us TOO support group. Twenty-three years ago, he was prepared to undergo a radical prostatectomy to treat his prostate cancer. Through his attendance at the Bill Blair/Russ Gould Us TOO group in Inverness, IL, he learned about active surveillance as a possible treatment option for his situation. Twenty-three years later, we are pleased to have Horst and his family joining us once again at SEA Blue. Following is a bit more about his story:

You have been on active surveillance for a long time. Can you tell more about that?

I have been on active surveillance for the last 23 years. When diagnosed with prostate cancer, I was told by my urologist to have a prostatectomy or I was going to die. A second opinion confirmed I needed a prostatectomy.

How did you choose active surveillance as a treatment option?

After attending several Us TOO support group meetings, I learned that, with a PSA of 1.0 and a Gleason score of 6.0, there was plenty of time to have a radical prostatectomy, if needed. After a few years, I had a color Doppler ultrasound done near Detroit, Michigan, which confirmed that I could go on active surveillance.

What other options were you considering?

None.

What initially brought you to Us TOO?

A friend told me about the US TOO support group.

What are the positive and negative aspects of active surveillance?

It was positive not to need to undergo a radical prostatectomy. A negative would be not knowing, with certainty, if it was the right decision in the long run. My feeling of uncertainty is very much reduced by digital exams, MRI and the encouragement of my urologist.

What are the most important things to know about active surveillance of prostate cancer?

A person on active surveillance must have regular digital rectal exams, PSA tests and occasional biopsies to make sure the Gleason score has not increased. One cannot just sit and wait; one has to monitor the condition.

What Us TOO services/resources have you accessed and how helpful were they?

The Us TOO support group with men sharing their experiences, the lectures by professionals and the literature that is available.

Some men who are diagnosed think they can eliminate prostate cancer from their lives if they have a procedure – “get it out and move on.” But they may not fully consider that they’re still going to need to get PSA tests periodically for the rest of their lives. They’ll never be rid of the specter of PCa. Did you have any considerations such as these when deciding to go on active surveillance?

I did not. I first wanted to know all about my options and the problems with prostatectomy or radiation, like incontinence and impotency.

What guidance would you offer someone recently diagnosed with prostate cancer?

Request genomic testing of the biopsied tissue to help determine if the cancer is more likely to be aggressive or benign. Know everything you can about your Gleason score. If your Gleason score is 3+3, take your time to decide what to do. Active surveillance is most likely a good option. If your Gleason score is 3+4, active surveillance may or may not be a good option. The higher the Gleason score, the more urgent it is to eliminate the cancer.