



PARTICIPATING IN RESEARCH: ENGAGING WITH "PHARMA"

With: Tim Turnham, Karen Sachse, and Nancy Lindsey



Engaging with Pharma as a Patient

Karen Sachse:

Just a little bit about my story, I had two years of recurrent urinary tract infections and had blood in my urine, and it was mistaken for a gynecologic issue. Pretty typical for a lot of women that are diagnosed with bladder cancer. I was diagnosed by a community urologist. Then after two courses of BCG and my disease decided it wanted to move up into my lower tract, I moved my care to Johns Hopkins, which of course, as everyone knows, is an NCI designated center.

I was then treated with mitomycin and had three isolated recurrences. Last one was in 2014. As Nancy mentioned, in 2016, shock of all shocks, my husband was diagnosed with muscle invasive bladder cancer and went through chemotherapy, a cystectomy, and then four months after his surgery developed central nervous system metastasis and died from that 15 months after diagnosis.

ABOUT ME

- 10 year survivor of Non-muscle invasive bladder cancer
- After 2 yrs. of recurrent UTIs, blood in urine mistaken for gyn issue
- Diagnosed by community urologist
- After 2 courses of BCG & recurrent disease in lower tract, moved care to Johns Hopkins, NCI designated center
- Treated with mitomycin-C
- 3 isolated recurrences (last 2014)
- 2016 – husband diagnosed with muscle invasive bladder cancer
- Chemo, cystectomy, CNS metastasis 4 mos after surgery
- Roger died 15 mos after diagnosis

My involvement with pharmaceutical industries for BCAN actually started back when I attended the very first BCAN Summit. I attended that with my husband in 2016. He actually had just finished his neoadjuvant chemotherapy and we decided to, since the first meeting then, the one in 2016 up in Baltimore wasn't too far for us. We decided to make the trip and we're so happy that we did. My husband really was very passionate about his mission of BCAN. We both came home very excited about patient advocacy.

At the time, I was employed as a nurse educator for a pharmaceutical company that makes a chemotherapy drug for acute lymphocytic leukemia. I knew that the patient stories are just very powerful from years of setting up orientation and trainings for nurses at the hospital. I could talk all I wanted about side effects from particular chemotherapy drugs. But when a patient got up there and spoke about it, that's when really the nurses keyed in. That's what made them remember the side effects.

Karen Sachse:

Merck, many of you know, is a very large pharmaceutical company. They contacted BCAN looking for volunteers for an unbranded project. By that, it means that the brand of the drug is not spoken about so that it's a very fair and balanced presentation of just generic drugs. Sometimes no drugs are mentioned at all and we're just talking about a disease process.

I had signed up at the summit to volunteer to be contacted. Merck's publish relations company asked me to submit a letter stating that I was writing this letter to somebody that was newly diagnosed. What did I wish I had known at the very beginning of my diagnosis? The program, the project, ended up being called With Love, Me. It was launched in 2019. A collection of stories really from those affected by different types of cancer, patient and caregivers written to their younger self. It involved different, many different types of cancer.

It was an extension of an already established patient site called Your Cancer Game Plan, which featured Jim Kelly, who many of you know is the Buffalo Bills Hall of Fame quarterback. But the

INVOLVEMENT WITH PHARMA

- Attended first BCAN Summit on patient advocacy in 2016
- At time, employed as Nurse Educator for pharmaceutical company that makes chemo drug for ALL
- Knew how powerful patient stories are from setting up trainings for nurses at hospital
- Merck contacted BCAN seeking volunteers for an "unbranded" project
- Had signed up to be contacted at Summit
- Worked with Merck's PR company: submit a letter to someone newly diagnosed on what I wish I had known

MERCK "WITH LOVE, ME"

- Launched in 2019, as extension of already established patient site: Your Cancer Game Plan (features Jim Kelly)
 - Features links to resources on nutrition, education, emotional support
- Collection of heartfelt stories from those affected by different types of cancer, written by patients & caregivers to our younger self
- Topic – what do you wish you had known at diagnosis or caregiving?
- No discussion of specific treatment centers, providers, or drugs
- Videotaped reading letter

really neat thing about this site is that they also have links to other resources. Nutrition, education, emotional support. On the bladder cancer section, BCAN is very prominently linked there.

The topic was very similar to the letter. But as I said, it's writing it to your younger self. There was no discussion of specific treatment centers, providers, or drugs. Then all of us agreed to be videotaped reading our letter. Some things that I was able to talk about, and these were truly the things that I wish that I had known to stay organized, to start a notebook or some type of organization system.

Keep asking questions, find a support group. Cancer can be so lonely. The people that really, really understand are the people that have gone through that journey

with you. At BCAN, I was so excited to be able to talk about the support that I got and that my husband Roger got through BCAN through this whole process. Give yourself permission to ask for help, and let family and friends know what you need.



TOPICS DISCUSSED

- Stay organized & start a notebook
- Keep asking questions
- Find a support group, cancer is lonely
- Give yourself permission to ask for help
- Let family & friends know what you need

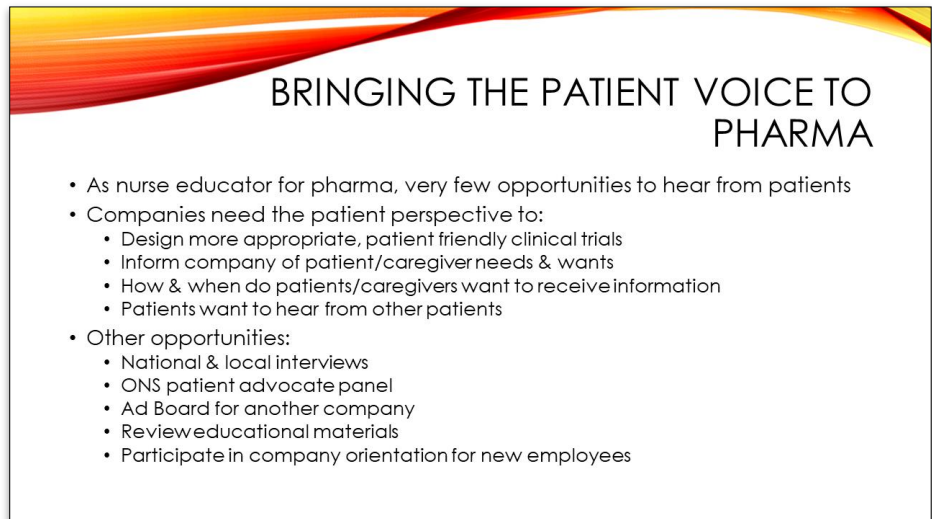
www.withloveme.com

Karen Sachse:

If you want to see what the... an example of the project, just go to withloveme.com. Things that are important about bringing that patient voice on to a pharmaceutical industry. I knew as an educator that they really do have very few opportunities to hear from patients. When companies started asking, I was very excited about participating letting my voice be heard.

They need the

perspective, the patient perspective and many other things that Tim just went over, to design more appropriate patient friendly clinical trials. If blood needs to be given, it needs to be taken twice a day, then that's probably not going to work. And to be able to inform the company of what the patients and caregivers needs and wants, and how and when do you want to receive the information? Patients also, they want to hear from other patients. They don't necessarily want



BRINGING THE PATIENT VOICE TO PHARMA

- As nurse educator for pharma, very few opportunities to hear from patients
- Companies need the patient perspective to:
 - Design more appropriate, patient friendly clinical trials
 - Inform company of patient/caregiver needs & wants
 - How & when do patients/caregivers want to receive information
 - Patients want to hear from other patients
- Other opportunities:
 - National & local interviews
 - ONS patient advocate panel
 - Ad Board for another company
 - Reviewed educational materials
 - Participate in company orientation for new employees

always to hear from their doctor or a company, a drug company. They want to hear from other patients.

Other things that I've been able to do that came out of the With Love, Me project was that I was able to participate in some national and local interviews. Always representing BCAN and women with bladder cancer, and being a survivor and a caregiver, kind of the trifecta. I was able to present on a patient panel to nurses, my fellow colleagues at the Oncology Nursing Society national meeting. I participated on an advisory board for another company, and through that have reviewed educational materials, really looking at them when they were drafted and being able to say, "Maybe put it this way or maybe put it that way," or "Present it in a different light."

Most recently, I have participated with a company in orientation for their new employees. Again, that is something that the new employees don't often get to hear perspectives specifically right from the patients. A couple things that you might want to think about is you have this opportunity. Of course, I would encourage you too if you're interested. One, is there compensation? How will you get to the meeting, the focus group? What are the accommodations?

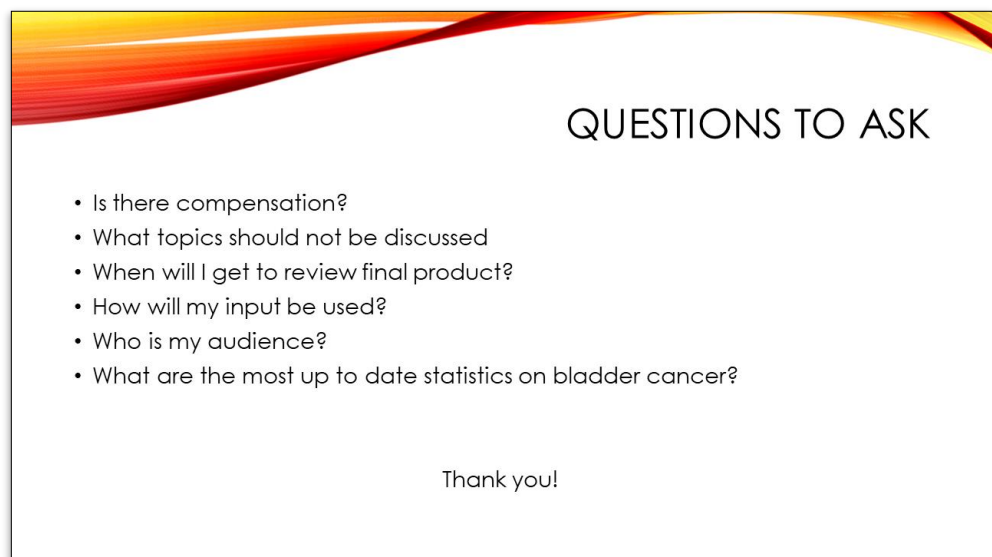
What topics should not be discussed? The pharmaceutical industry is very regulated and there were a couple of times that I had spoken about a particular drug, and that was not something that was allowed. I learned that pretty quickly. When do we get to review the final product? Will you get to look at the product along the way? At what point?

Karen Sachse:

My experience is that everything had been laid out, and they got back to me right away and were able to let me review things before they moved on to the next step. Find out, how will your input be used? Will it be written on a website, in a publication? Will your picture be used? All those things you want to take into consideration, as well as who is your audience?

Then what are the most up to date statistics on bladder cancer? You're out there speaking to the

public, to these pharmaceutical companies. You want to be up on, is bladder cancer the seventh most common in the U.S., or is it the sixth or is it the fifth? BCAN of course can help with that, and they have helped me tremendously. I really enjoyed my experience with the pharmaceutical companies. I have found it to be very rewarding and they have really looked to patient advocates to help them with some of the grassroots projects, so thank you.



Thank you to PCORI for funding this program so that we could really help to engage and develop BCAN research advocates.