

Bladder Cancer Summit For Patient and Families

Saturday, October 10, 2020

1:00 – 5:00 PM EDT



Welcome and Introduction

Stephanie Chisolm: I'd like to welcome everyone to the 2020 Bladder Cancer Summit for Patients and Families. My name is Stephanie Chisolm, and I'm the Director of Education and Research here at BCAN. As you can tell, 2020 has been a bit of a crazy year, and this is our first really large virtual meeting and we're very excited to have you all here. We've had quite a few of our wonderful pharma supporters: EMD Serono Pfizer partnership, Genentech, AstraZeneca, Bristol-Myers Squibb, Merck, Janssen Oncology, the Astellas Seattle Genetics partnership, Urogen, QED, and Photocure. We want to thank them because their support makes this whole thing possible.

Traditionally, we've always talked about bladder cancer as being the elephant in the room. It's something that's there that nobody ever knows about. Nobody ever talks about. And we hear all the time, I hear this as the Director of Education and Research for many, many patients, "I had no idea you could get cancer in your bladder, until the doctor told me that's what I had." We're working really hard as an organization for the last 15 years to change that, so that we can be available to people, so that people know to refer people to us and they can get a lot of answers that they need and support that they need.

And we're working really hard to change the medical dialogue, so that the research is advancing to find new ways to treat this disease.

So I'd like to take a second and introduce our co-founder, Diane Zipursky Quale. Diane, it's a delight to have you here. I've known Diane since the beginning of BCAN and I'm going to turn this over to you. You just let me know when you want me to advance the slides.

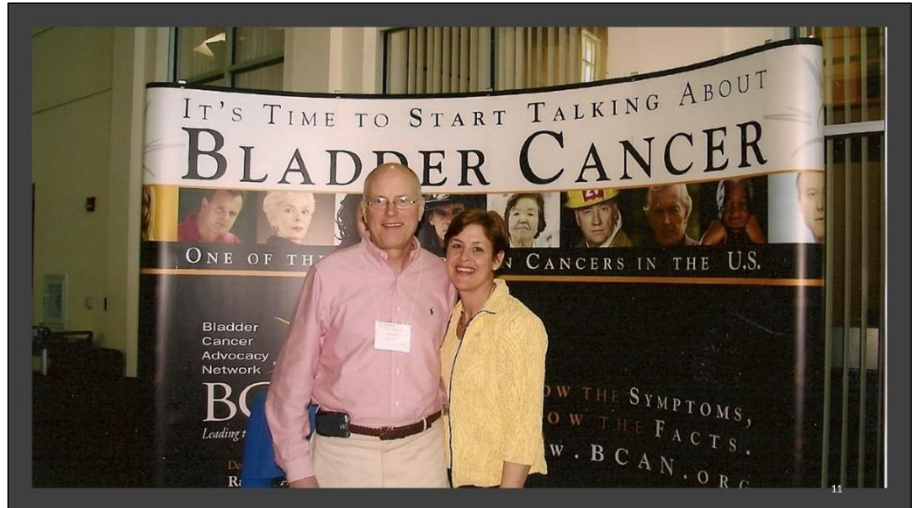
Diane Zipursky Quale: Well, welcome everyone. It's so wonderful to have you all participating. As Stephanie said, it's a really strange year and I'm sorry not to be able to be in person with all of you, but BCAN is nothing if not adaptable. So 2020 is our 15th anniversary and it's been a time of reflection for me, and recognition along with amazement at what we have accomplished.

I've taken some time to look at old photos, old emails, old materials, which has really been a lot of fun. What it's done is it's reinforced for me what I've known from the beginning, BCAN is about people, about family, and about community. So if you'll indulge me for a few minutes, I'd like us to take a walk down memory lane and see the impact we have made over the last 15 years. Next.

Many of you are familiar with the story of how BCAN got started. My late husband, John was diagnosed with bladder cancer initially in 2000 and with metastatic disease in 2001. We created BCAN, because we were frustrated by the lack of awareness of this disease, the lack of information and the lack of treatment options for a disease, which impacts tens of thousands of families every year.

We didn't have a big plan, we just knew there was a big need. We

were very fortunate, because from the very beginning, BCAN got tremendous support from the bladder cancer medical community. And I do mean from the very beginning. I'd like to share with you what I consider to be BCAN's founding document.



It's an email from May 5th, 2005, from me to Mark Schoenberg, who was John's doctor. Mark was then at Johns Hopkins. And I wrote, "Mark, I hope this note finds you well. Based on our experience over the last five years, my husband John and I are exploring the possibility of launching a national advocacy organization for bladder cancer." I ask Mark for his thoughts and his help.

And I said, "I'd love an opportunity to talk with you about it. Perhaps I could set up a time in the next couple of weeks, so that I could get your thoughts and input." Well, Mark delivered. Next, please. And Mark delivered quickly. Because in just a little over two weeks, John and I were in San Antonio, Texas meeting with a group of bladder cancer practitioners at the annual Conference of Urologists.

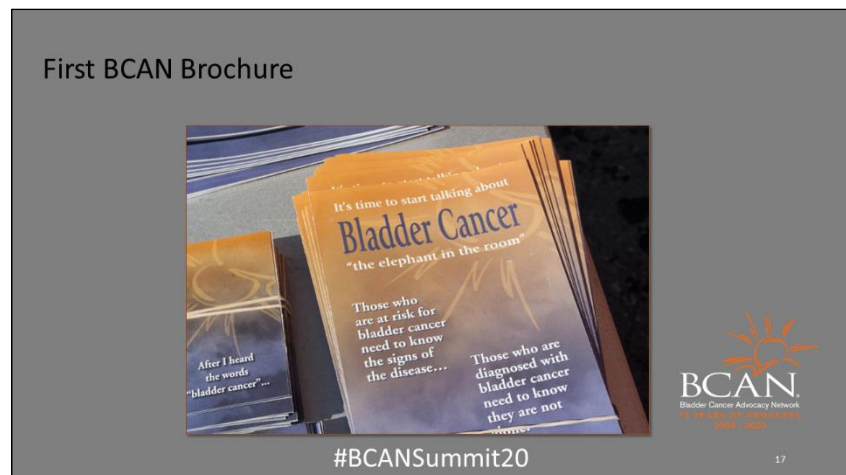
During that 90-minute meeting, John and I were able to share our ideas and our thoughts about creating BCAN. At the end of that meeting, we had a scientific advisory board of 18. Next. Our advisory board now numbers more than 60 people from more than 50 institutions, medical practices and academic institutions, all around the United States and Canada. These members represent all of the different disciplines that address bladder cancer patients.

This group of scientific advisory board has been so instrumental in everything that BCAN does, in all of our programs, our educational programs, our research programs, as well as even our awareness programs. Next. In 2005, in August, we launched our first website. You can see it was a lot more simpler then, than websites are today, but launching the website enabled us to really start our outreach all across the country to find other bladder cancer patients and their families who wanted to join us in raising awareness about bladder cancer.

Our network of volunteers from the very beginning was so instrumental with helping us develop the website, keep it up to date, write articles for the website, put together a quarterly newsletter and do things in their own community, like host BCAN tables at health fairs in their communities. Next. You might recognize two of our long time volunteers, Bob and Karen. They represent many, many of you.

I know that many of you are joining us today who have volunteered for BCAN over the years and are part of this tremendous network. I just want to say, we couldn't have advanced and made the progress that we have made and the impact we've made without your time and effort and energy. So thank you so very much. Next.

In 2006, we published our first brochure. And as you can see, as Stephanie mentioned, we referred to bladder cancer as the elephant in the room, because certainly then nobody wanted to talk about it. Next. In 2008, we published the first edition of our patient's handbook, thanks to the input of our scientific advisory board, and again, our team of volunteers. Our network of volunteers at this time spoke with over 750 urology practices and cancer centers in 32 States to distribute this booklet to over 3,000 physicians.



Currently, the handbook, there are more than a half million copies in print and digital circulation. I think we're now on our fourth edition of Bladder Cancer Basics. This year, we just introduced the new handbook directed at caregivers. Next. All of this has grown into this tremendous offering of resources for patients and their families covering all aspects of bladder cancer information and support, meeting our goal of informing and supporting patients and their families.

You'll hear a little bit more about all of these when Stephanie talks in just a few minutes. Next. We started our bladder cancer awareness site, walk, in 2011 with a handful of sites that year and small, but very passionate groups. We have grown the walks through the years, adding more people and more communities. Next. Now, our walks span across the United States with thousands of people wearing their orange t-shirts, raising awareness of the disease, and raising much needed funds to support all of BCAN's programs.

I want to thank all of you who participated in the 2020 virtual walks, again, something entirely different, but we really appreciate your dedication and your time to help raise much needed funds for us in 2020. We all hope that it will be very soon when we'll be able to do these walks again in person and our orange shirts really making an impact in all of our communities. Those of you who've heard me speak before know how important advancing is to me personally.

When John was being treated for bladder cancer, he had so few options. When his metastatic disease returned six years after we thought he had it beat, there were really no treatments available for him. So

BCAN began funding research and we began with funding people. Next. We started with supporting John Quale Travel Fellows to our annual think tank meeting. This started in 2009. Since that time, we've supported 46 Quale Fellows, almost all of whom continued to be very active with BCAN and have become leaders in the bladder cancer community. Next.

In 2012, along this group, Dr. Armine Smith is now the director of Hopkins Urologic Oncology at Sibley Hospital in DC. Dr. Arjun Balar at NYU is a world renowned expert in immunotherapy and bladder cancer, having led several pivotal clinical trials for drug approval. Both Dr. Balar and Dr. Smith spoke last year at the BCAN patient summit. Dr. Eugene Lee is now Director of Clinical Research at the University of Kansas and recipient of one of BCAN's young investigator awards.

2012 John Quale Travel Fellows



His videos on nutrition and bladder cancer are now featured on our website. There are so many more success stories I could share with you. I am both so proud and also humbled to share the fact that thanks to the generosity of our community, BCAN has now provided more than \$5 million to fund bladder cancer research. Any discussion of BCAN's impact on bladder cancer research must include our annual bladder cancer think tank. I know that many of you who are joining us today have also joined us for this unique and wonderful meeting. Although, of course, our 2020 meeting was virtual. Next.

The think tank started on August 20, 2006, as a group of 35 or so doctors and patients who gathered in Aspen, Colorado to think outside the box to find better ways to collaborate, to find new treatments, to save lives. This meeting really solidified BCAN's role as the facilitator and bringing all interested parties together. My husband, John, shared his story one evening, making it personal for everyone there. That is what continues to make this gathering so unique.

The Think Tank is now the premier scientific bladder cancer meeting in North America with more than 250 participants from all around the world, collaborating to move research forward. Patients continue to be a key focus of this meeting with survivors and family members sharing their experiences and reminding the research community that all of this work is personal. It's about people, it's about families, it's about-

It's about loved ones and improving and saving lives. Next. That brings us back to today, to all of you, many of whom are longtime supporters and advocates, and many of whom are joining us for the very first time. BCAN's existence has always depended on people like you, motivated by the desire and the need to make a difference, not only for yourself, but for the hundreds of thousands of people impacted by bladder cancer. Never doubt that your contributions of time, energy, and financial support are making a tremendous impact. Happy anniversary to all of us.

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