

Prostatepedia¹

¹expert insight + advice



Helping Other Patients

Prostatepedia_June 2019 Volume 4 No. 10

In this issue....

In June, we’re talking about ways in which you as a patient can benefit from and in turn contribute to the prostate cancer community.

What do we mean by that? Chances are, when you were first told that you had prostate cancer, you were afraid. Once that fear passed—if it did—you realized you had some decisions to make. There are a lot of controversies in how the medical profession treats prostate cancer; the path is not always clear. Shared decision-making means that you, as a patient, have to participate and form your own opinion: you can no longer just leave everything up to the discretion of your doctor. This is a good thing, but it does require more effort on your part. Most of you turned to friends and family or began searching online for more information. Some of you joined support groups where you learned from other men with the disease.

The things you learned as you moved through that process are valuable—whether your cancer is under control or not. Your experience will help other men in countless ways.

How can you share that experience with others?

You can join a support group. You can even start a support group if you live in a community without an active group. (Read carefully the conversations with Silicon Valley support group leader Rupen Sheth and Us TOO’s Director of Support Group Services Terri Likowski about how to go about this.) You can even join an online support group if making it out to a monthly in-person meeting isn’t possible.

But what if that type of interaction really doesn’t fit with your personality or lifestyle? You can potentially get involved with clinical research advocacy. We published a conversation with the chair of the Southwest Oncology Group’s patient advocate committee last month, and this month, we feature a conversation with their Patient Advocate Tony Crispino, who works with leaders in prostate cancer research on cutting edge clinical trials.

Or, your cancer itself can contribute to our global prostate cancer community. How? If you’ve got metastatic prostate cancer, your blood or saliva can help researchers build a genomic registry of prostate cancer so that they can learn as much as they can about prostate cancer. Read Dr. Eli Van Allen’s conversation to find out

about how to join and what types of strides his Metastatic Prostate Cancer Project has been making in the past year and a half.

The point is that some greater good can come from your prostate cancer journey. You can contribute to our efforts to eradicate this disease: whether it’s in the form of sharing your story with a friend over a cup of coffee or helping researchers decode the information carried within your blood.

Charles E. Myers, Jr., MD 



The information, products, and media advertised in *Prostatepedia* are advisory only. Individuals pictured are models and are used for illustrative purposes only. Please consult your physician for specific medical or therapeutic advice.

Copyright June 2019. Rivanna Health Publications, Inc. All rights reserved.
ISSN: 2381-4020

Prostatepedia is published in Charlottesville, Virginia by Rivanna Health Publications, Inc.

Contents:

- P4 Mr. Tony Crispino
Patient + Research Advocacy
- P6 Rupen Sheth
Leading a Support Group
- P10 Eliezer Van Allen, MD
How You Can Participate in Genomic Research
- P14 *Become a Patient Ambassador*
- P16 Terri Likowski
Starting and Leading A Support Group

Contributors:

- Editor-in-Chief*
Charles E. Myers, Jr., MD
- Publisher*
Jessica Myers-Schecter
- Copyeditor*
Lito Velazquez
- Proofreader*
Robert M. Protz, MS
- Transcriptionist*
Sarah Mason
- Designer*
Verity Burgess
- Community Outreach*
Corinne Halada
- Sales Consultant*
Rod Schecter
- Business Consultant*
Rose Sgarlat Myers, PT, PhD
- Editorial + Billing Offices*
274 Redwood Shores, #739
Redwood City, CA 94065
(800) 975 6238
- Administrative Offices*
PO Box 655, Earlysville, VA 22936

Mr. Tony Crispino

Patient + Research Advocacy

Mr. Tony Crispino found out that he had prostate cancer at age 44. In the years since his treatment, he has become an outspoken prostate cancer advocate. Today, he runs a support group for other patients in Las Vegas, Nevada and is a Patient Advocate at Southwest Oncology Group (SWOG) where he works with leaders in prostate cancer research on cutting-edge clinical trials.

He spoke with *Prostatepedia* about his own journey as well as ways in which you can get involved in advocacy.

How did you find out that you had prostate cancer?

Mr. Crispino: Like most, I was asymptomatic. I was 44 years old and had no reason to believe that I had cancer. I wasn't even aware that I had a PSA test taken, and I was unaware of what PSA was. It was by chance that I'd had a diagnostic PSA, which was at 20, and then I found out that I had stage IIIB disease.

Which treatment path did you take?

Mr. Crispino: Being diagnosed in 2006, I had fewer options than

patients have today. We didn't have Zytiga (abiraterone), Xtandi (enzalutamide), or Erleada (apalutamide) then. The path I chose was not considered standard-of-care yet, but eventually, it became that for guys with locally advanced disease. I read papers from Harvard, Stanford, UCSF, UCLA, and more, and I decided that a multimodal approach was reasonable. So radiotherapy, hormonal therapy, and participation in research trials were all reasonable. Today, I would likely be offered Zytiga (abiraterone) [per STAMPEDE], six cycles of Taxotere (docetaxel) [per CHAARTED], or both. But I am fortunate to have a good outcome with what I chose. I have not been treated since 2010, and I have a durable remission.

Has the prostate cancer journey changed you in any way?

Mr. Crispino: A cancer diagnosis is a life changing experience for most. Nearly all who are diagnosed and their families have a new reality. My well-known mantra to others diagnosed is to stay positive. I followed that rule, and once I came to understand my condition, it was time to take that lemon and make lemonade. My negatives are obvious, but my positives outweigh

them. I have done well with advanced disease and that helps as there are many who are not as fortunate, and it becomes more difficult for them to stay positive.

I got involved as an advocate, which has been one of the blessings in my life. I have been actively involved in support, mentoring, research, serving on guidelines panels, and lobbying, and I have authored many physician-facing documents. I would have never had those opportunities without that diagnosis, and I would never have dreamed of being a part of them.

How did you first become involved with prostate cancer patient advocacy?

Mr. Crispino: Almost immediately, I was an online surfer like never before trying to regain control of my life. It was through this method that I became educated, a support group leader, and determined to be a part of cancer treatment as more than a patient. But first I had to experience the support I received from all those who paved the way ahead of me.

What do you do with Us TOO and SWOG?

Mr. Crispino: Us TOO is education and support. I am well equipped

to help in these areas, and I have run the Las Vegas chapter for over 10 years.

SWOG is a fantastic experience. There are only four such networks in the National Cancer Institute (NCI) group called the National Clinical Trials Network (NCTN). Being included in clinical trial design and evaluation is a very unique experience that very few patient representatives in this area of research get to participate in. SWOG has led me to my membership in societies like ASCO, participation in guidelines panels for ASCO, AUA, SUO, ASTRO, and being elected to the Prostate Task Force for the NCI.

Why do you continue reaching out to other men with prostate cancer?

Mr. Crispino: I have a great deal of experience across the board. It is not only helpful to the diagnosed patient but rewarding to be able to help others. Reaching out to the patient community allows me to help the physician community and vice versa. It is very fulfilling.

Do you have any advice for other men with prostate cancer?

Mr. Crispino: Get educated. I tell all those I mentor that educated decisions are always better than emotional decisions or passing the decision on to your oncologist. Shared decision making requires that you have some knowledge before a decision.

Beware of bias, as there is plenty of it in the patient and physician communities. Beware of conflicts of interest, as there is plenty of it in the physician community. Even with good intentions, biases and conflicts of interests are common.

Do you have any advice for men with prostate cancer who'd like to get involved with advocacy but aren't sure how to go about it?

Mr. Crispino: Just do it! Many of the positions I hold are elected and have term limits. This means that someone has to grab the baton and move the effort forward when I move on. Being a part of effective advocacy requires many things.

Become educated through peer groups and reading, and by that I mean, listen to all experiences and take notes.

Lose or limit your biases. This is easier said than done. We all think that our decisions are the best and can apply to everyone in the same way. Strong bias might help in the physician and patient communities, but it's not a good trait in research and guidelines panels. It can be harmful in support and education communities.

Define the area in which you think you can be the best advocate. Being an advocate is a broad role. You can lobby and participate in the political side, which I did but I found it wasn't my niche. You can be a research advocate, a support advocate, a patient-physician liaison, or even an online poster.

Partake in physician-patient group meetings. Whether it's attending an ASCO, AUA, ASTRO, or coalition meeting, be there. You will see what it's about and whether it's for you. This is not always easy as these types of group meetings can require travel. If you cannot do that, you can still be an effective support advocate in various ways. For example, you could advocate online or by attending support groups meetings.



Rupen Sheth

Leading a Support Group



Mr. Rupen Sheth leads the Silicon Valley Prostate Cancer Education and Support Group (<https://PCaSupportGroup.org>) in Mountain View, CA.

Prostatepedia spoke with him about his prostate cancer journey and his experiences in running a local support group for fellow patients.

How did you find out that you had prostate cancer? What treatment path did you take?

Mr. Rupen Sheth: After about age 50, I missed my annual physicals for a couple of years. I first had my PSA checked at age 52, and that was the first time my PSA reading was taken, which was detected at 24. That was the first alert, so my situation was fairly sudden.

I had no idea what PSA meant. I saw that it had exceeded the normal amount, but I didn't know anything about the prostate or its function. I just thought it was a reading that's beyond the threshold, just like blood pressure and cholesterol. I thought there were ways to remedy it.

At first, the urologist gave me some medications to see if I had an enlarged prostate. But when

we retested, the readings were about the same. He referred me to a local urologist who did a digital rectal exam (DRE), which came back normal. He suggested doing a biopsy at that time.

“This whole experience has made me a better person in many ways.”

Just like any newbie, I proceeded with what he recommended. He did a random 12-core biopsy. It was only later that I learned about scans and doing an MRI-guided biopsy, which would have been better. Five out of twelve cores were positive, with one at Gleason 4+5.

It was only then that I started researching and tried to get an understanding of what all this meant. I had CT and bone scans, which came back negative. After some initial research, I realized that I needed to work with some better doctors, oncologists, and institutions than the ones the urologist referred me to. My experience with that urologist was not positive. I sought

out folks at Stanford University in Palo Alto and had discussions with a number of people there.

I was almost on a path for getting surgery, but I learned more about long-term outcomes of other treatment options versus surgery and decided to change my course of care.

Instead of getting surgery, I opted for a tri-modal treatment at Stanford, which included two sessions of high dose-rate (HDR) brachytherapy, with five weeks of intensity-modulated radiation therapy (IMRT), followed by androgen deprivation therapy (ADT), which I stayed on for about 18 months. After discussions with my oncologist, we stopped my Lupron (leuprolide) after 18 months. I'm at a point now when we're monitoring it on a periodic basis.

How has the prostate cancer journey changed you?

Mr. Sheth: There have been a lot of positives from this, despite the initial shock that you typically go through. We have access to a lot of information, which is both good and bad. It can be overwhelming. There is a lot of garbage out there too. You have to be able to filter through that. That requires you

to have people who can coach or guide you.

I lean on support groups a lot because there are a lot of people who have been through this journey and have made mistakes. I learn a lot from the missteps that others have taken.

Ultimately, you've got to be able to take all of this information and come up with your own road map. I've come to realize that you've got to take action and control what needs to be done. Others can serve as a guide, but this is about you. That realization has been a positive.

This whole experience has made me a better person in many ways. I'm more conscious of diet and exercise than before. I'm more tolerant and sympathetic. It's given me a chance to pause and reflect, to determine what is truly important. Those are all good things. Despite 18 months of roller-coaster times, it's been a good experience.

How did you first become involved with the support group?

Mr. Sheth: As I was trying to determine my treatment options, I looked to speaking to others who had been through this journey. I got some referrals for local support groups. But interestingly enough, it was quite difficult to find out which local prostate cancer support groups were operating. The information online was not current, so it took me a few weeks to get in touch with the individuals who ran the local support groups.

I attended a couple of these. When I attended, I presented the treatment course I thought I would take based on everything that I had researched. It was reassuring to get

some validation that the plan that I had chosen seemed to be the right one.

I continued to attend the meeting because I was learning a lot. I found out that the more you know, the more you know you don't know. I was committed to prostate cancer, so I wanted to know as much as I could about it. There was a wealth of knowledge among the folks who had been through it. I was just observing and learning. It was also an opportunity for me to know enough so that, if by chance there is recurrence, I'll be better prepared. As I attended, I got more actively involved.

And now you lead the group?

Mr. Sheth: Right. I felt that the group had given me so much and now I had an opportunity to give back.

Our support group has a ton of books and DVDs. A gentleman, Dean Andrus had been our librarian for over a decade. He used to carry all of the material to all of the meetings to facilitate people who wanted to check stuff out.

I started off by taking ownership of the library from him and looked for ways to improve and optimize it. I worked with the El Camino Hospital. They have two library facilities, so we got all of our materials checked in there and set up online so that people can search the catalog, request materials, and check them out.

At first when the previous group leader had retired, the steering committee talked me into leading the group. And again, because of all the support I had gotten from a lot of great members, I felt it was one of the ways for me to do my little community service.

How do you develop programming for and organize the group? Do you have guest speakers? A newsletter?

Mr. Sheth: Our group meets monthly. We also run an advanced prostate cancer group, led by Walter D'Ardenne that meets just prior to ours. A lot of the members from the advanced group participate in my group as well. They serve as a sort of advisory panel because they have a lot of experience and knowledge.

I am a part of the steering committee. We meet more often per month. We talk about how things are going and discuss ideas, topics, and speakers. There's a good mix of people who are new to this and others who have a number of years' experience. So, we try to get a mix of relevant topics and some of the new, emerging topics as well. Because there's a lot of research being done, we try to get others who are doing clinical trials in this space to stay current.

We attend conferences and relevant cancer symposiums. We bring back information on what we learned and discuss it in our meetings. We try to promote and propagate that information through our newsletters and our website.

I took it upon myself to build the website, get the whole layout structure in place, administer it, and host it for the three local support groups.

You're doing quite a lot.

Mr. Sheth: Yes, but because there are already so many websites, I didn't want to create yet another one. For us, it was mostly about promoting the resource gems, the topics that are important,



useful nuggets, and other things that we discuss in our meetings. Mostly, it's a collection of references to other sites. We're not creating new content. We're merely cataloging and curating other relevant sources.

How many people do you have in these three groups? How many people do you have in your email list?

Mr. Sheth: My email distribution list is about 350. Because I always look for ways to reduce the amount of work that I have to do, especially repetitive work, I didn't want to manage our list manually. There are a lot of good, free services available, so I chose MailChimp for the newsletter. It allows folks to opt in and out on their own, which keeps it easy. Generally, about 40 members come to each meeting.

Do you get the same 40 people each time, or do you have a core group that comes every time and then newbies?

Mr. Sheth: There are about ten people who are always there. They're part of the steering committee. There could be a few more who are regulars. And then another 10 to 15 who frequent our meetings but who are not regulars. They try to come to as many meetings as possible. There are about two to five new members. If we have a speaker or a topic of great interest, then there could be more people who attend.

What is it about helping other men with prostate cancer that you find rewarding?

Mr. Sheth: I've found that this particular area is more confusing for folks. A lot of the responsibility has been given to the patient because there is no clear choice. I've seen

folks make decisions prematurely. Everything that I've learned from others provides a way for me to guide folks, to help them get out of their fear that leads them to not make those hasty decisions. I try to get them to understand that they're not alone and that this is a slowly progressing disease. You have time. You can research, gather the information, and make the right decision.

For me, providing that type of coaching, mentoring, and guidance to others is very fulfilling because a few people did that for me, and it helped a great deal. I've seen people who didn't have that, and I want to make sure that we're doing all we can to make that available to everybody who needs it.

Do you have any advice for men who want to run their own support group or who are running a support group?

Mr. Sheth: See if other existing national groups or organizations have the framework, resources, and guidance that you could take advantage of so that you don't need to figure everything out on your own. Organizations like the California Prostate Cancer Coalition (CPCC), Us TOO, and the American Cancer Society have affiliations or chapters that you could create. See if you can associate with one of those national organizations because it will help guide you through that process.

Then get other volunteers. Don't try to do everything yourself. There are plenty of people, and you can delegate and rely on others so that you can do this as a team.

Do you have any thoughts for men with prostate cancer?


Dr. Sheth: Take your time to understand, research, and learn what you have, where it is, what the treatment options are available, and what the side effects are. The fact is that this is generally a slow-progressing disease, so don't rush to make any decisions. Know all of your details. A lot of people don't.

After the test, doctors don't necessarily communicate all of the information, so a lot of patients don't know all of their details. Make sure you ask for them, if you don't have them, and make sure you know those details.

Know your PSA history. It's not just the number, but also the rate of change or doubling time that's important. Know your prostate size because PSA density is important. Know your Gleason score.

Get a second or a third opinion. It's surprising how many tests are done, yet it's not about the tests or scans. Reading and interpreting the tests is generally an art and not a science. Yours could have been misinterpreted, so it's better to get a second or a third opinion. Question your oncologist. Don't just take their word for it. Use leading doctors and centers.

Attend support group meetings and other support structures that are there to help you through the process.

You've got to take control and ask questions. No one knows everything. Even a lot of the doctors are just too busy. They can't keep up with everything that's going on in this field. You've got to do your own research. 

Eliezer Van Allen, MD

How You Can Participate in Genomic Research



Dr. Eliezer Van Allen, Assistant Professor of Medicine at Harvard Medical School, a clinician at Dana-Farber/Partners Cancer Care, and an Associate Member at the Broad Institute of MIT and Harvard, focuses on computational cancer genomics, using new technology in precision medicine, and resistance to targeted prostate cancer therapies.

Prostatepedia spoke with him about how even those of you in remote areas can participate in nationwide genomic research study for men with advanced or metastatic prostate cancer.

What is it about medicine and caring for patients that keeps you interested and engaged?

Dr. Eliezer Van Allen: There are two answers to that question. One, the scientific answer, is that it's been so remarkable to see how quickly advances that we've learned from studying patients with cancer have immediately translated into the clinic and have impacted my patients' lives. It's impacted people I don't know, and that cycle of innovation is becoming quicker. It's so exciting. It's a privilege to be part of that from a professional level.

The other answer is more of a humanistic thing. I went into medicine because of my experiences at Camp Kesem, which is a camp for kids whose parents had cancer. It was a life-changing experience to be involved with that and to help drive it from the beginning. Whether or not any individual therapy works for any of my advanced cancer patients, there's a human element to this job that's very profound. That is also a privilege, to be involved with that day-to-day, no matter what.

+
"We give patients an opportunity to share information about themselves and share their tumor specimens for us to do genetic testing."

Camp Kesem is still around, right?

Dr. Van Allen: Yes, it's growing amazingly. There are over 100 camps now around the country, and thousands of families are involved. It's wonderful.

Have you had any patients who changed either how you view the art of medicine or your own role?

Dr. Van Allen: Absolutely. At some level, every single patient both challenges and reinforces aspects of what it means to be a doctor and deliver care. Each in their own way has changed the way I think about things. There are obviously some stories that stand out and some experiences.

Some of the patients who've had the most catastrophic outcomes and succumbed to the disease in rapid form have taught me the most about what it means to live your life to the fullest, whatever that means to you. I have a lot of respect for them.

It's a special thing to care for people at the particular moment, when they face big life questions.

Dr. Van Allen: About eight or nine years ago, I wrote a piece for the *Journal of Clinical Oncology's Art of Oncology* series. It was about this one patient I had as a first-year fellow who had this positive thinking attitude in the wake of the most potentially catastrophic scenarios up until he passed away. It was such a surreal thing. In that

case, it was rare, but I think it teaches you a lot about what it means to be human and how hard this disease is.

What is the goal of the Metastatic Prostate Cancer Project?

Dr. Van Allen: The Metastatic Prostate Cancer Project is a patient-driven research project whereby, rather than expecting the patients to come to us to join and participate in advanced research, we bring the project to their doorstep, and we engage with patients in new ways. We give patients an opportunity to share information about themselves and share their tumor specimens for us to do genetic testing. The goal is building the largest genomic registry of prostate cancer that we can learn from, and in so doing, accelerate that discovery to translation cycle even more.

Can you give us some updates on how the project has been going since you launched?

Dr. Van Allen: We launched this project in January 2018 in a patient population that is known not to talk about their disease in any venue, under any circumstances, to anyone. There's no social media presence for this disease space, or at least on the surface, and frankly, we would've been thrilled had ten people signed up. Our sister project, the Metastatic Breast Cancer Project, has a loud and overt presence of women taking selfies with their saliva kits, so we weren't sure how this was going to work.

We're a little past a year from launch and over 700 men have engaged in research, given us consent to access their samples, filled out the patient-reported survey, and joined this *Count Me In* movement. It's remarkable, but not

only have these 700 men signed up, we're already at the other end of the cycle of this project now, and we've generated complete data sets for the initial wave of these men. By complete data set, I mean genetic, clinical, and patient-reported data, and we've put that data out to the entire community in the research setting to learn from.

+
"Over 700 men have engaged in research, given us consent to access their samples, filled out the patient-reported survey, and joined this Count Me In movement."

This proves the principle that we mean what we say when we're generating data for the community. We're not trying to build a silo here. This is patient-demanded, and therefore patient-driven, from day one. From every aspect across the board, it's been remarkable and exciting to see how we've done so far.

We are 150% absolutely still looking for patients. We'll always be looking for patients. Anyone who's interested should feel comfortable to go to MPCProject.org and click *Count Me In*.

What kinds of patients should join? Anyone with prostate cancer?

Dr. Van Allen: This project is for advanced or metastatic prostate cancer, which means prostate cancer that's left the gland. That could be folks with local, regional prostate cancer involved

in the lymph nodes, folks with biochemical recurrence only (only PSA detected in the blood), and all the way to patients with heavily pretreated, advanced disease that's spread to bone, liver, or wherever. Anyone in that spectrum is considered advanced or metastatic from our perspective.

The project is basically unending, right?

Dr. Van Allen: That's the goal, releasing it as fast as we can.

Do you just release the data, or are you also forming collaborations with other institutions or projects?

Dr. Van Allen: We'll release the data. We're obviously going to try to learn from it ourselves and use it to come up with perhaps new drug targets, biomarkers, and whatnot, but also we would like to connect with other efforts that are spiritually aligned in any way that's feasible.

One of the best outcomes would be that some researcher who is in no way affiliated with our project finds our data useful and uses it for their research to inform what they do. We're already starting to see that happen with our sister projects where there are scientists and labs that we are not affiliated with who are using the data to inform how they think about their research and their projects. All of those outcomes are on the table, and we're excited to pursue all of them.

Is there anything else you want patients to know about how the project is doing, about further studies you're doing, or other studies you think people may find interesting?

Dr. Van Allen: This is a patient-driven project. Some of the patients who've given us feedback on their experiences

so far have also prompted questions that we can ask that we, in our little academic bubble, probably would've never thought of. That's how we're starting to dive into things that are driven by patient experiences or that we're observing in the patients who have signed up, down to questions that might seem curious but are illuminating, ones that we hadn't intended initially.

For example, in the first patient data release, when asked if they had surgery for their prostate, almost half the patients marked: "unknown." We can compare that to their medical record and sort that out, but it provides a window into something that wasn't the initial intent of the project. That feedback opened up a lot of interesting questions and opportunities for research that we hadn't necessarily anticipated up to that point.

Men didn't know if they'd had prostate cancer surgery or not?

Dr. Van Allen: It may have been the way we asked the question. It may have been that patients were interpreting what they were supposed to answer. We don't know. The point is that this is not something we initially set out to do, but it is an early example of how patients can guide where the research needs to go.

I just presented this project at the American Urologic Association meeting, and a gentleman came up to me afterwards. He's had metastatic prostate cancer for four years and a complete response to cancer immunotherapy, and he wanted to know if he was eligible for this project. Not only is he eligible, but he's an extraordinary case. We want to understand why. This patient is not within 500 miles



of an academic medical center, and he would otherwise never be approachable or available to engage in research. We exchanged information, and he's going to sign up.

Patients may not realize: they have the power to drive this field forward in this unique way. It's not something that medicine is used to doing. We want to get the message out that this is all starting with patients and their ability to contribute. That will determine how far this goes.

It's easy for them to participate: go to the website, fill out the forms, and give a blood sample?

Dr. Van Allen: Yes. You don't even have to do the blood sample if you don't want to. It's exactly what you described. Go to the website, click a few buttons. There's a very simple online consent form. We'll send you a saliva kit and a blood biopsy kit and take it from there.

Can you still participate even if you're in a remote area?

Dr. Van Allen: Yes, anywhere in the United States and Canada. For the blood biopsy, we send you a kit, and you bring it to your next lab draw, PSA test, or whatever, and there are instructions in the kit for the phlebotomist. In some cases, phlebotomists have not been willing or able to participate, so we can provide vouchers to patients to do it at a Quest Diagnostics lab or somewhere convenient to them. The intent here is that the patient bears no financial burden in participating. ^{PP}

For more information ...

Visit <https://mpcproject.org>

Become A Patient Ambassador

INFORMED HEALTH CONSULTING (IHC) co-founders Merel Nissenberg and Tom Kirk recognized that for many patients, a recommendation by a physician for a test, treatment or product is not sufficient unless they can hear about the experience from other patients. So IHC developed a unique means to engage certain patients as Ambassador(s) for those tests, therapies, or products for which they would like to provide peer-to-peer personalized reviews and descriptions.

IHC identifies and recruits some of those patients and looks for diversity in age, geography, ethnicity and socio-economic status. As one can imagine, this is not an easy task and can take months to find the best Ambassador(s), who are then invited to an Ambassador training weekend. This weekend combines a meeting at company headquarters for the product in question; holding dinner and breakfast sessions with introductions, self-identification and bonding; listening to company presentations; touring the company in areas that pertain to the product in question; and finally working with a videographer and public relations expert to prepare the Ambassadors to speak at support groups, service

groups and civic organizations about their personal experiences with that test, treatment or product. Each Ambassador is taped, and following their presentation, a detailed analysis and critique is provided to help them feel more confident in speaking to others. This is not a marketing or sales demonstration. These Patient Ambassadors are learning how to share their personal experiences in order to give others the patient viewpoint, not that of the physician. Patient Ambassadors are comprised of patients (and sometimes their wives) who really just want to be of help and are willing to speak publicly or by phone with a patient.

All materials for the training weekend are prepared by IHC with input from the company in question, and each Ambassador Trainee receives a packet of materials that IHC has prepared on the Ambassador Training Program and on how to speak on a personal, peer-to-peer basis to introduce and describe the product to their fellow patients.

IHC then arranges for at least one speaking engagement for each Patient Ambassador to allow the Ambassador to tell others about personal experiences. Sometimes



the patient's wife becomes the Ambassador, not the patient. But these are all people who just want to share their firsthand knowledge and experience.

IHC maintains a current telephone list of the Patient Ambassadors so that people can contact an Ambassador and schedule a one-on-one conversation to discuss the Ambassador's personal experience with the subject subject test, treatment, or product. IHC helps with logistical efforts to make the match, despite geographic limitations. IHC maintains the Ambassador List for one year unless the company wants to extend the arrangement. We call this a list of *On-Call Ambassadors*.

If you have any questions...

Please contact [Merel Nissenberg](#) or [Tom Kirk](#) at 424-253-1169 or e-mail them: merel@informedhealthconsulting.com or tom@informedhealthconsulting.com



Terri Likowski

Starting and Leading a Support Group



Ms. Terri Likowski is the Program Director of Support Group Services for Us TOO International Prostate Cancer Education and Support Network, a nonprofit dedicated to providing comprehensive educational materials and support group services to men with prostate cancer.

Prostatepedia spoke with her about starting and running a prostate cancer support group.

What is it about prostate cancer advocacy that has been meaningful to you?

Ms. Terri Likowski: The people I have met through the Us TOO organization are just so inspiring. To get a cancer diagnosis is frightening, and it can be especially difficult for men with prostate cancer. With so many treatment options available, it can be an overwhelming experience. There is also a strong possibility that these men could be facing some major quality of life issues after treatment, such as erectile dysfunction (ED) and incontinence. I meet a lot of men and families who handle their situations with dignity and grace. They are not ashamed or embarrassed to talk about some of their fears and concerns about what the future could hold. They open up

to me about possible side effects they could be facing, or express concern on whether or not their treatments would work. I started to build strong relationships by being there to listen and learn from their personal stories and experiences. They are my mentors and I am close to these men and their family members. I admire them so much for the way they turned a cancer diagnosis into something meaningful in their lives. It is just something really special, and I feel lucky to be a part of it. I have to thank all of our support group leaders; past, present and future. We could not provide our support services without you.

What is your role now?

Ms. Likowski: I started out in 2005 as the Executive Assistant to the CEO. I then quickly became a Program Manager for the Minority and Underserved Populations Program. We had a five-year grant through the Centers for Disease Control (CDC), so I was engaged immediately in the nonprofit cancer world. I did a lot of traveling, attended many conferences and met amazing, brilliant people—doctors and advocates. Because the African American community is at increased risk for prostate cancer, I especially loved getting out into these communities

and educating men and their families about the disease. I learned that you had to build up a lot of trust before Us TOO could really start to make a difference in these underserved areas. We were able to provide some excellent educational materials and created a “train the trainer” program so that we could empower men and women, and provide them with the tools to be able to go out and educate others in their local areas and spread awareness about prostate cancer. After a few years in that role, I was respected and greeted with open arms because I think they knew that I really did care. I made a lot of connections that helped to strengthen our network, once that trust was established. I was promoted to Program Director in 2016 and serve as the point person to establish, maintain and expand the Us TOO network of volunteer-led prostate cancer support groups throughout the U.S. and abroad.

How many support groups does Us TOO have? Where are they located?

Ms. Likowski: Right now we have 210 Us TOO support groups throughout the country and in most states. We have four support groups in the Bahamas who are doing an amazing job educating men and their families and spreading

awareness about prostate cancer. We also have groups in Spain, Australia, and Canada.

How large are these groups?

Ms. Likowski: The groups can be anywhere from 5 people to 85 people. I would say the average support group is between 20 and 25 people, but attendance tends to ebb and flow. Newly diagnosed men sometimes come in and might only attend a few meetings. Then they'll make their treatment decision and they won't come back. I've had a lot of discussion with my support group leaders about this. Sometimes the leaders feel that if a man comes to the group and then doesn't come back that they've failed him somehow. But I say that it's exactly the opposite. They haven't failed the men. The attendees found what they needed and now want to move on with life and put their prostate cancer behind them. Typically, a handful of people are the stronghold of the group. These are the ones who always come back, and some have been going to the group for years. They find it rewarding to be able to mentor newly diagnosed men, to help them through those beginning stages, and to help them to make informed decisions on what treatment options are best for them.

Do you have groups for caregivers?

Ms. Likowski: Our groups are open to patients and caregivers. However, two years ago, we started a platform called “A Forum for Her”. This is a call-in support group specifically for women with a partner who has prostate cancer. That group is going extremely well. We have two to three calls per month, every month, which are led by volunteers. We try to keep those calls to six or seven ladies on each call. This creates an intimate setting, where they are more open to share

things with each other. We have had very positive feedback about these calls from a large number of participants, and our group list continues to grow. I'm also thrilled to announce that we just launched a forum specifically for gay men and their partners. It's already branching out into the LGBT community. “A Prostate Cancer Forum for Gay Men and Their Partners” is a new, ongoing conference call series, which provides gay men and their partners with important peer-to-peer support. Usually, both the man living with prostate cancer and his husband or partner are deeply impacted, and each is subject to his own physical and emotional concerns. It can be helpful to address these concerns by speaking with others in a similar situation.

This is a phone-call based group?

Ms. Likowski: Yes. This group and “A Forum for Her” are phone-call-based.

I wonder if that's easier for people to join than an in-person group. It must feel a bit more anonymous.

Ms. Likowski: It is. Most participants just share their first name. We don't record the calls and we want to be very respectful of everyone's privacy. I would always recommend, whenever possible, face-to-face groups because I think that you can really bond and open up more in person. But if there is no support group in the area, or if there are issues with transportation, I think a call-in group is a really great option. Some people just do not like to meet in person and feel more comfortable on a phone conversation.

The forums are bringing people from the cities together, and often they will meet for coffee or

dinner once that relationship is formed. It's really fulfilling to see these relationships grow. They are supporting each other and making a difference for each other in very meaningful ways!

Do you help these support groups develop programming? Do you offer guidance as to how to run a support group?

Ms. Likowski: We help facilitate, provide educational materials, and offer guidance. We don't control the group, but we help them and support them the best we can. In addition to our monthly newsletter, the Hot SHEET, our website is a great educational resource. We provide free educational materials for leaders to hand out at meetings. We have a support group leader resource page on our website that is for support group leaders only; they can share some information offered there with anyone engaged with their group.

We've worked really hard to provide support for leaders in the beginning stages. For those starting a new group, we offer suggestions on possible venues to hold their groups and how to get the word out into their communities about the new groups. We provide some basic templates for meeting flyers, business cards, and we now have a new brochure specifically for support groups that they can hand out in their communities.

We provide input on topics and videos from our recent Prostate Cancer Pathways educational event series, which were recorded last year. In these videos, we offer links to short segments on very specific topics, including: all stages of disease, from newly diagnosed to advanced stage; sex and intimacy; psychosocial issues such as anxiety and depression; and much more. These videos offer

an excellent resource that support group leaders can show at their meetings if they don't have a speaker scheduled.

I'm sure finding a speaker can be difficult for people in more remote areas.

Ms. Likowski: That can be a real struggle, so having these up-to-date educational resources can really be helpful in those situations. Another thing that we've been doing over the last couple of years that has been extremely successful is our monthly support group leader phone calls. I generally have anywhere between 18 and 35 support group leaders from all over the country on a call. Those calls have really helped build camaraderie. The leaders learn from each other about different cultures throughout the country. The beauty of the calls is that new leaders connect with peers and mentors in the group, some of whom have been leading groups for 20 to 25 years. They share their best practices with the new leaders, including how to grow the group or how to get the word out to newly diagnosed patients. We're also working with an advocate from a pharmaceutical company who is going to teach a series of five webinars, one per month, on things such as listening skills, presentation skills, and questioning skills in order to enable dialogues at meetings and help leaders understand behavioral styles. We're really excited about that.

It sounds like you provide quite a lot of guidance and support as men start these groups. If a man reading this is in a community that doesn't have a support group and thinks he might want to start one, what should he do?

Ms. Likowski: Contact me at terril@ustoo.org or 336-842-3578. I like

to first have an initial talk. We like to build communication with leaders right from the beginning and that initial conversation is great first step. If you're even just thinking about starting a group, start talking about it. Talk about it out loud. You'd be surprised at the number of people you might meet who are affected by prostate cancer. It might be your neighbor or somebody that attends your church group. Find others who can help you manage the support group in the beginning stages; let others take some ownership of that group. It will help you to build a much better group in the long run.

When you need to find a location to meet, talk to your urologist, your oncologist, or your own personal doctor. See if they're interested in helping to promote the group. Maybe your hospital would be willing to host a meeting. Other options are local cancer centers, community centers, libraries, or VFW halls. Those are all really great places to host monthly meetings where there won't be any associated cost.

Do you give the men advice about how to get the word out about these groups?

Ms. Likowski: We're putting the finishing touches on a brochure that specifically talks about our support groups. Each support group can put their own information on the front of the brochure. That will make a really great handout. These can be left at urologist offices, community centers, and hospitals. We recommend to always reach out to the partners of the men affected by prostate cancer. Generally, women tend to talk to each and open up more than men, so it's a good idea to get the women engaged right away. Sometimes they might help take the reins and get the group moving forward. We have several groups now that are led by couples.



For prostate cancer support...

Visit www.ustoo.org
or email ustoo@ustoo.org,
or call 800-808-7866.

I'm sure women will feel more comfortable joining the group if there's a female leader involved.

Ms. Likowski: Yes. There are a lot of situations when the men might be in denial or they just don't want to talk about their prostate cancer. Sometimes their partner will attend the support group on their own. Then eventually, they can hopefully convince him to come.

Often when people hear that they have cancer, they get really scared. And fear can paralyze you, if you let it.

Ms. Likowski: Absolutely. You hear that over and over again. Especially when they're newly diagnosed. They hear those words "you have cancer" and that's all they hear. After that, it's just a big blank. We suggest bringing somebody else with you when you go to talk to your doctor. That person can record the conversation or take notes for you.

Another pair of ears is always useful.


Ms. Likowski: Definitely!

Do you have any advice for men with prostate cancer?

Ms. Likowski: I think the most important thing is to educate yourself. Take an active role in making informed decisions regarding your treatment choices. Do your research. Knowledge is power and the more you know about your situation and your specific options, the better equipped you're going to be to make a decision. You've got to ask about possible side effects. Quality of life issues sideswipe many men after treatment because they didn't really talk about those side effects with their doctors before treatment. Make sure you're doing your research and talking

to other people. It's really helpful to talk to somebody else who's been in your shoes. Get involved in a local support group. If you don't want to go to a support group, we can connect you to a phone group. We can connect you with virtual support groups or one-on-one conversations with someone else. You don't have to feel like you're on your own. Even though every man's prostate cancer is different, talking to other people will really help. Also, make sure you have a strong relationship with your doctor. Having a strong relationship with your doctor who helps you talk through treatment decisions can be really empowering. It helps you feel like you've made the right choice and then you can move forward. There is so much confusion with prostate cancer, because there are so many options out there. You really do have to do your homework and educate yourself.

There is nothing like talking to somebody else who's going through something similar to what you're going through. It makes you feel less alone.

Ms. Likowski: It does. One of my favorite leaders, who passed away from his prostate cancer four years ago, used to share with me that there's nothing better than when somebody walks into your group afraid and then, two hours later, leaves feeling hopeful. You have had a good day when you can really change somebody's outlook like that, and you've made a difference in their life in a positive way. That's really a powerful feeling. It makes you feel good about yourself and that you have found purpose in your own life. There is not a day that goes by in my role with Us TOO that I don't hear those words in my head, and it makes me smile. 

274 Redwood Shores, #739
Redwood City, CA 94065
(800) 975 6238
info@prostatepedia.net
www.prostatepedia.net

Coming Up!

*July:
Genomics*