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### **Stephanie Chisolm:**

Welcome to Quality Care in the Community Setting. This is the patient insight webinar from the Bladder Cancer Advocacy Network. We're very thankful to our sponsor, the EMD Serono / Pfizer Alliance for helping to support the patient insight webinars. I'd like to just give you a little bit of background about our speaker, Dr. Suzanne Merrill. When you think about it, bladder cancer is the sixth, most common cancer that's diagnosed in America yet. Very few people know anybody else who might have it. Because the disease requires an expert to treat it, finding the right doctor, whether it's a urologist or a medical oncologist, or perhaps a team with both is very important because you'll probably be seeing that physician for a really long time.

That's because there's a high rate of possible recurrence and a need for surveillance to make sure that that cancer doesn't come back. So we do know that as many as 70 to 80% of the more than 81,000 people who are going to be diagnosed in America this year alone will receive their healthcare in their local communities.

So BCAN is delighted to welcome urologic oncologist, Dr. Suzanne Merrill from Colorado Urology. Dr. Merrill is going to explain what type of care is delivered in the community. In addition to being a urologist who specializes in bladder cancer and other urologic cancers, Dr. Merrill is also involved in some clinical trials and when she needs to can work very closely with colleagues at large teaching hospitals to ensure she's delivering the best care for her patients. So welcome Dr. Merrill. We're really looking forward to learning more about how patients are treated in the community and how they can be more involved in their care. So I am going to stop sharing my screen and let you take over.

### **Dr. Suzanne Merrill:**

Okay. Thank you so much, Stephanie, for that introduction.

Well, I'm Suzanne Merrill and I am a urologic oncologist working with Colorado Urology, which is out of Denver, Colorado. We're actually a part of a larger national group called United Urology that has different locations across the country. So I'm going to be speaking again, as Stephanie mentioned, about quality bladder cancer care in the community. I have no disclosures. So we're first going to talk about should all bladder cancer be treated at a university or academic center. Then we'll dive in into how we created a community bladder cancer program of quality out in the community and how we ensure in this program that we're able to deliver quality control to our patients and practice standard of care, guideline care for bladder cancer. We'll show you how we feel that such a program does improve access

to our patients in Colorado and provide them with a wide spectrum of resources, which you would think that would only be available maybe at a university or academic setting.

We'll then look at the clinical trial options that we are able to provide out in our community program and compare that to what may be seen in an academic center and how actually the two different options are complementary for our patients that we serve. Then hopefully I will disprove that there may not be any great collaboration between us and the community with our university and the academic centers of the state.

### Dr. Suzanne Merrill:

So here we go. So should all bladder cancer care be delivered at a university or hospital setting? So truly this is not feasible. There really are just too many patients with bladder cancer that need care. As it's already been alluded to in 2022, we're estimated to see over 81,000 people in the US newly diagnosed with bladder cancer. Really this translates to almost about 223 people per day hearing the words, "You have bladder cancer." We're again, estimated to see over 17,000 deaths attributed in 2022 to bladder cancer. Now, another way to put this is that there are actually about over 700,000 people in the US living with bladder cancer. So those who are being newly diagnosed and existing with bladder cancer. That's more people than in the state of Wyoming.

In Colorado, we're estimated to see in 2022, over 1200 new cases. Interestingly, and we're unique in this way, Colorado really only has one university hospital system. Now, yes, they have multiple affiliate hospitals about 10. But really there's only one true large university academic hospital that really does all those complex bladder cancer cases. So really this is just too few of options for our bladder cancer population in Colorado. Our patients need and deserve to have more options where they can feel good about receiving their bladder cancer care. So, kind of juxtaposed to this problem of trying to funnel bladder cancer patients to a single or a couple specialized centers in one state is that we do see that there is benefits actually in doing so. Certainly for our invasive bladder cancer patients, where they're looking at coming up to undergoing a big complex surgery called a radical cystectomy.

### All Bladder Cancer → University Hospital

*Not feasible...too many patients need care*

Over **81,000** people in the U.S. were diagnosed with **bladder cancer**



**~223 people per day** heard the words "You have **bladder cancer**"

**17,100 deaths** attributed to bladder cancer

### All Bladder Cancer → University Hospital

In Colorado....**1,220 new cases** in 2022

**Only 1 University Hospital System**

- UC Health

*Patients need more options*



## Dr. Suzanne Merrill:

So we see in such patients that when radical cystectomy procedures are performed in high volume hospitals, those patients actually have decreased complications and improved overall survival. Really what this means is that at these high volume centers, you have a surgeon that is highly qualified, performing these surgeries very frequently. You have staff that understand these procedures and are routinely taking care of such complex patients and procedures, and are able to get these patients through such situations very seamlessly. Now, unfortunately there are disadvantages to regionalizing,

okay, invasive bladder cancer care, and they're as follows. It can exacerbate existing health disparities. What I mean by that is it can worsen patients that are more socially or economically disadvantaged. If they have to travel to a specialized center where they might not have the means of transportation or the money to do so. Funneling care to a specialized center can also risk delay in treatment due to poor accessibility, and certainly increase the cost of burden if patients are having to have a hotel stay when they're seen and doing these consultations and undergoing surgeries.

So we know that the majority of care actually occurs in the community for bladder cancer, about 70 to 80% of non muscle and muscle invasive disease is cared for in the community. We actually saw that when we pulled all of you who registered for today's webinar, that of those who are receiving bladder cancer care about over 70% are today receiving it in the community. Now we know bladder cancer is truly a very burdensome disease for a number of reasons. One, it disproportionately affects older adults where the median age is around 73 for diagnosis. When we're elderly, we're going to have more medical ailments. We have mobility issues. Often there is a lack of a

## Regionalization of Invasive BC Care

- **Benefits:**
  - Radical cystectomy in high volume hospitals →
    - Decreased risk of complications
    - Improved overall survival
- **Disadvantages:**
  - Exacerbation of existing health disparities
  - Risk of delay in treatment
    - Poor accessibility
  - Increased cost burden



Herrera JC et al. Clinical Genitourinary Cancer 2020 Ryan S et al. J Urol 2018; Nielsen ME et al. BJU Int 2014; Hollenbeck BK et al. J Urol 2005

## The Reality of BC Care

Majority of care occurs in the community

- **70-80% of non-muscle and muscle invasive**

Bladder Cancer = **burdensome disease**

- Disproportionally affects older adults:
  - **Median of 8 chronic conditions**
  - **Mobility issues**
  - **Lack a "physically" capable support system**



**Muscle invasive disease:**

- Multiple visits and providers (med/onc + urologist)
  - Procedures, Imaging, Chemotherapy, Labs, Operative prep

physically capable support system where the partner of a bladder cancer patient may not drive anymore. Maybe they're also used in some assisted devices.

**Dr. Suzanne Merrill:**

Now for our muscle invasive disease, they're confronted when they have that diagnosis of undergoing multiple visits and seeing multiple providers. Doing procedures, imaging for full staging, maybe chemotherapy is part of their treatment, labs to follow up on and even preoperative prep appointments with their surgeons. We certainly know that our superficial bladder cancer or non muscle invasive bladder cancer patients have a burdensome chronic condition. So although there typically is a low risk of death and mortality with this disease, there certainly is a high risk of recurrence where we need to follow these patients with frequent surveillance to cystoscopy appointments. Due to that high risk of recurrence, there can be frequent ambulatory anesthetic surgeries. This table here outlines that, according to the risk that a superficial bladder cancer patient may be categorized as during that first year after diagnosis, you can see if a patient is categorized as high risk, they could be realizing up to 19 visits with your urologist. This really even excludes when they have to undergo surgical appointments, pre-op appointments, path reviews. So these are really just receiving the cystoscopies for surveillance and intravesical treatments. So this is a lot.

So when we were thinking about how we can come up with a community bladder cancer program that can deliver the quality of care that is needed for this patient population, improve access for more patients and deliver the resources which we expect, and that is seen in the university center, we feel that it needs a three-pronged infrastructure to do so. So one is to have a large urology group practice. Colorado Urology here out in Denver has actually 11 office locations spread out from really central and even the top parts of our Southern part of the state, all the way through the Northern

### Superficial Bladder Cancer: Burdensome Chronic Condition

- High risk of recurrence (30-70%) and low risk of death
- Need for frequent cystoscopies
- Frequent ambulatory anesthetic surgeries

	Low Risk (T <sub>a</sub> low grade)	Intermediate Risk (T <sub>a</sub> high grade)	High Risk (T <sub>1</sub> high grade, CIS)
Cystoscopy visits in 1 yr	2	4	4
Intravesical therapy	N/A	6x induction	6x induction 3x maintenance #1 3x maintenance #2 3x maintenance #3
<b>Total Visits for Bladder Cancer in 1 yr*</b>	<b>2</b>	<b>10</b>	<b>19</b>

\*Excluding recurrences, surgery, preop appointments, path discussions, etc.


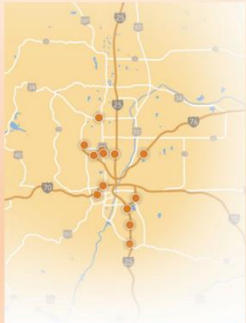
AUA/SUO NMIBC and NCCN Bladder Cancer Guidelines

### The Infrastructure: Community Bladder Cancer Program

**Large Urology Group Practice**

- 11 Office locations
- 23 Urologists
- 13 APPs

**Wide catchment of patients**

region. We comprise 23 urologists and have 13 advanced practice providers. So have an ability to have a large footprint and provide access to a large catchment of patients.

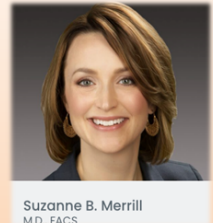
Now, next to this, as we definitely agree with the regionalization of these high acuity procedures and for complex procedures and complex care for bladder cancer, we need a hospital system that has a track record of having being capable with treating complex patients and procedures. Sky Ridge Medical Center out in Lone Tree, Colorado certainly fits this bill and being a high acuity care hospital that has a focus on providing their patients with leading edge technology. Importantly, also it has an integrated cancer Institute. So Sarah Cannon is the National Cancer Institute for the HealthOne HCA system, which Sky Ridge is a part of. This allows our bladder cancer program to have access to a lot of important resources, which cancer programs need.

Then finally, part of this infrastructure requires a specialist who is willing to take the charge and develop bladder cancer protocols, be aware and appraised of all the changes of this ever changing bladder cancer landscape these days of the new drugs and technology that are coming down the pipeline. So really has a passion for this disease and the expertise also to carry out these complex procedures in a safe and efficient manner. So, typically bladder cancer champions are going to be urologic oncologist in nature who have a specialized training, even beyond just being a urologist. Of course, like I said, has a passion for bladder cancer.

### **Dr. Suzanne Merrill:**

So, really the infrastructure to create a community bladder cancer program that can deliver quality of care is this three-prong partnership between a larger urology group practice that has access to wide footprint of patients, a hospital system that has the capability to provide high acuity care and perform complex procedures safely and has access to leading edge technology. Then, you have a bladder cancer champion.

## The Infrastructure: Community Bladder Cancer Program



- High acuity care hospital
- Focus on leading edge technology
- Integrated Sarah Cannon Cancer Institute
- Urologic Oncologist fellowship trained
- Passion for bladder cancer
- Career + Leadership experience

Now the algorithm by which to be able to deliver quality of care to bladder cancer patients incorporates multiple key components. These are listed here and we're going to go over actually each one of these, which are very important to be able to deliver that quality of care out in the community. So one is instituting recurring education to the people involved in this program. So I take it upon myself to educate all of our 23 urologists and 13 advanced practice providers, outfitting all of those 11 clinic locations to ensure that they're aware of the best practice guidelines in bladder cancer, which are again constantly changing and being updated as new drugs and technology come out and ensuring they are aware of the new treatments out there and what the pathways are for standard of care for bladder cancer.

Additionally, it's important to educate our hospital staff who takes care of these patients and our clinic nurses and medical assistants. So they're familiar with bladder cancer specific procedures, and they can triage common complaints and complications that might come to them. Then importantly, down at Sky Ridge Medical Center, we have rolled out a number of bladder cancer, advanced recovery pathways to follow so that when we do perform these complex radical cystectomy procedures down there or other bladder cancer procedures, we are all on the same page of how to care for these patients, both intraoperatively and postoperatively. So their care can be efficient and safe and they can get out of hospital within around five days for a radical cystectomy. So we're recurring education is an important piece to the quality control within our program.

Secondly, is central review. What I mean by that is that there is an overseer, which is myself, and one of our advanced practice providers to review what is going on granularly at these clinic locations. So of course, all bladder cancer patients can't come to the one or two locations that I serve. They have to be able to increase access to our Colorado population with bladder cancer. We have to allow, of course, other urologists and advanced practice providers to provide that care. But we feel that there should be oversight on the care that is delivered to ensure that it's correct and safe and the standard of care. So to do this for our non muscle invasive bladder cancer patients, we've come up with what we call a BCG stewardship program.

## The Algorithm: Quality Community BC Program

1. Education
2. Central review
3. Distribution of leading edge technology
4. Centralization of high acuity procedures
5. Key Personnel
6. Comprehensive patient resources
7. Access to clinical trials
8. Collaboration with *The University*



### Dr. Suzanne Merrill:

This is that we review all BCG treatment requests. This was an important piece to put in place. Initially when we were all realizing a BCG shortage and some of us still are this ensures appropriate allocation of this important drug and the correct treatment usage. It also allowed me the opportunity to spread to our treating neurologists and APPs, whether patients could be eligible also for a clinical trial. So it provides also more options and reminds urologists of more options. Now, hopefully in the future with our Colorado Urology and Sky Ridge Bladder Cancer Program, we hope to incorporate this for all intravesical treatment request. This of course will allow me a better appraisal of the treatments and the planned treatment course that is being enacted out in our wide program. So a central review again, enables us a quality control aspect.

Now for our muscle invasive bladder cancer patients for all new diagnoses, we do require such patients to consult with me to review the diagnosis, ensure appropriate staging has been done to provide the right counseling on options. However, we do allow both in person and virtual appointments, and this helps to take off some of the burden when we're treating those patients in our Northern region of our state, which requires sometimes to get down to me, which I'm more in the central part of the state, almost two hours. So certainly a lot of this can initially be done virtually.

We also have a multidisciplinary genitourinary tumor board, where myself is a part of this, another urologist who performs high acuity procedures, who could comment from a surgical perspective. On that board is also of course, a medical oncologist who specializes in bladder cancer, a radiation oncologist, a pathologist to review the tissue diagnosis and a radiologist to review the staging imaging and through the review of all invasive bladder cancer cases, we ensure and provide the patients with a consensus treatment plan. Again, this helps us to ensure a quality control with the care that we're delivering in this community program.

### Dr. Suzanne Merrill:

## The Algorithm: Central Review

### ***Non-muscle invasive bladder cancer:***

- BCG Stewardship program
  - Review of all BCG treatment requests
    - Ensure appropriate allocation + correct tx usage
    - Opportunity to spread awareness of clinical trials
- Expand program for All Intravesical Tx Requests (*planned*)

**Central Review = Quality Control**

## The Algorithm: Central Review

### ***Muscle Invasive Bladder cancer:***

- New diagnosis → required consultation with bladder cancer champion
  - In-person or Virtual initial appointments
- Multi-disciplinary Genitourinary Tumor Board
  - Review of all Invasive BC cases

**Central Review = Quality Control**

Now, thirdly, which is important is ensuring that we're able to distribute leading edge technology to all these outreach clinic locations, 11 clinic locations. So I ensure at each of these clinic locations that our urologists and APPs have knowledge and access to key bladder cancer, diagnostics. URO17, and Cxbladder listed here are urinary studies often used for follow up of non muscle invasive bladder cancer, sometimes upon even new diagnoses. Then also to treatments such as Jelmyto. This is a trade name for a gel mitomycin chemotherapeutic delivered to the upper urinary tract for upper urothelial cancer, as well as gemcitabine and docetaxel, which are intravesical chemotherapeutic agents, which can be critical in the need when our patients have become BCG unresponsive.

### **Dr. Suzanne Merrill:**

We're also, not listed here, currently underway of getting set up to be able to deliver immunotherapy as well, pembrolizumab for our non muscle invasive bladder cancer, again, that has become BCG unresponsive and has carcinoma on site too. We're just in the beginning phases of kind of outfitting our locations with blue light cystoscopy and cysview, which is a great diagnostic to help pick up kind inconspicuous recurrences for non muscle invasive bladder cancer. At Sky Ridge Medical Center, we're a little bit further along in getting set up with blue light cystoscopy and cysview in the hospital for anesthetic procedures. Again, an important technology which can help us ensure that all cancer is resected and that we're not missing any during those important procedures. Then, as well Sky Ridge Medical Center has a great robotic center. Over five robots at this institution, and they're very much savvy in performing robotic surgeries. So, here I'm able to perform both robotic and open cystectomies with the patient's preferred urinary diversion.

So ensuring that our program is able to distribute leading edge technology and staying up to date on this with the knowledge of use, certainly improves access to good resources for our patients in Colorado. So again, because we definitely believe in the data that there is benefit to centralizing or regionalizing high acuity procedures such as high tumor volume to RVTs, radical cystectomies. For patients that have multiple comorbidities and might be very ill and need more complex medical support around their procedures, we do request our treating urologists in this program to refer down to myself and Sky Ridge Medical Center. So we can capably and safely and effectively take care of such patients that are going through these procedures. So again, centralization of these high acuity procedures is certainly important to ensure quality care delivery in our community program.

## The Algorithm: Centralization of high acuity procedures

### ***Referral to BC Champion:***

- High tumor volume TURBT
- Radical cystectomy
- Patients with multiple comorbidities



***All such procedures performed at  
Sky Ridge Medical Center***

**Centralization of high acuity procedures =  
Quality Control**



Now, of course, our program wouldn't be without a core team and key personnel. So from the Sky Ridge Medical Center side of things, we have our bladder cancer nurse navigator. Her name is Amy Gillman, and she is absolutely essential to our program. What she does is she really helps to work with each of our complex bladder cancer patients and identify really and reduce care barriers, help to reduce this burden of this cancer journey for them. So what she does is she ensures that the patient is aware and

understanding of the next steps in their treatment plan, helps to more seamlessly ensure imaging gets done and that care appointments get consolidated so the travel might be not so burdensome for the patient and really individualizes assistance through the cancer care continuum from diagnosis, all the way to survivorship. We certainly would not be a quality program without her.

Secondly, from the Sky Ridge team is the leadership. So Sky Ridge medical center has been nothing but great support for this program and ensuring that we have internally in the hospital, a good quality care that's delivered from operating room all the way up to our floor nursing. They're helping us to facilitate growth of the program and ensuring access to leading edge technology that we see as necessary to deliver optimal bladder cancer care. From our Colorado Urology team, we have a group called physician liaisons, and they're really unique position in that they actually help us establish community working relationships with medical oncologists, radiation oncologists, and even primary care. What this allows me to do is to keep patients at home, locally to get that chemotherapy or radiation treatment and not, again, have to always funnel down to only one center to receive their care.

What's nice about this is through these relationships, everybody has everybody's cell phone number. So instead of having the laborious facts of my ClinicNote, or trying, leaving a message with clinic staff, I'm able to text these medical oncologists, "Oh patient so-and-so, we had to delay their surgery because of X." Maybe it's the medical oncologist saying, "Oh, we have low blood count. We're having to delay cycle three." So we're able to more stay up to date in real time with our patients on what's going on. So we're able to just seamlessly move things along rather than delays occurring because of lack of communication or delay in communication.

## The Algorithm: Key Personnel

### Sky Ridge Medical Center Team:

#### 1. *Bladder Cancer Nurse Navigator:*

- Identify and reduce care barriers
- Individualized assistance through cancer care continuum: diagnosis → survivorship



Amy Gilman, RN

#### 2. *Hospital Leadership:*

- Support and ensure internal quality care
- Facilitate growth and access to leading edge technology

## Dr. Suzanne Merrill:

These physician liaisons also help spread awareness over bladder cancer community program in Colorado here. Both to establish patients so they can reach out if they're interested. Again, does that regional outreach to primary care physicians. Our Colorado Urology leadership is also integral to this program and they helped to establish that those leading edge technology pieces that are so important to delivering up to date care for our bladder cancer patients, to all of our 11 clinic locations, they help me to facilitate the necessary recurring educational updates to all our staff and to kind of funnel Q and A sessions as needed. They really help support adherence to the bladder cancer program protocols that I've rolled out to ensure that people are following, again, these standard of cares that we know are needed for this disease state.

Our program would not be one of quality without having some great comprehensive patient resources. So we've developed a specific bladder cancer educational and care navigation packet for our patients. We have multiple oncology prehab and rehab resources that span, again across the region. So again, patients do not have to only funnel down to one location. Certainly, we have a great rehabilitation center at Sky Ridge Medical Center when our patients are hospitalized. But definitely have outpatient resources for those patients who may need or, and, or be interested in going through what we call prehab before undergoing their major surgery, getting some good muscle strengthening exercises or pelvic floor physical therapy done and before they have to face a big surgery. We provide nutritional support, both through educational handouts, as well as have a great inpatient at Sky Ridge support team to provide those patients who, after a complex, radical cystectomy and many times new adjuvant chemotherapy need help ramping up their nutrition.

We have a great wound ostomy clinic at Sky Ridge medical center who sees our patients both before surgery, educates them about ostomy care. We even have a wound ostomy patient support group at Sky

## The Algorithm: Key Personnel



### Colorado Urology Team:

#### 1. Physician Liaison:

- Establish community working relationships:
  - Medical oncology, Radiation oncology
- Spread awareness of BC community program
  - Established patients
  - Regional outreach

#### 2. Organization Leadership:

- Integration of leading edge technology into clinic locations
- Facilitate educational updates
- Support adherence to BC program protocols

## The Algorithm: Comprehensive Patient Resources

1. BC educational and care navigation clinic packet
2. Oncology pre-habilitation + rehabilitation (outpatient + inpatient)
  - Strength training, balance exercises, pelvic floor PT
  - Outpatient + inpatient teams
3. Nutritional support (education + inpatient support team)
4. Wound ostomy clinic
  - Pre-surgery visit + inpatient RN team + outpatient services (in-clinic + virtual)
5. Smoking cessation counseling/navigation
6. Mental health support (outpatient)
7. Survivorship support (*in development*)
  - Patient support group
  - Sexual function rehabilitation
  - Awareness of cancer follow-up components/time line

Ridge Medical Center, and our nurses see our radical cystectomy patients, of course, in the hospital, make sure that they're getting the education and experience they need with their ostomy and how to change things, how to triage issues. Then they have an outpatient services clinic where they even hold virtual appointments again, to improve access for patients who may be far away to, again, learn tips and tricks and triage issues that might come up.

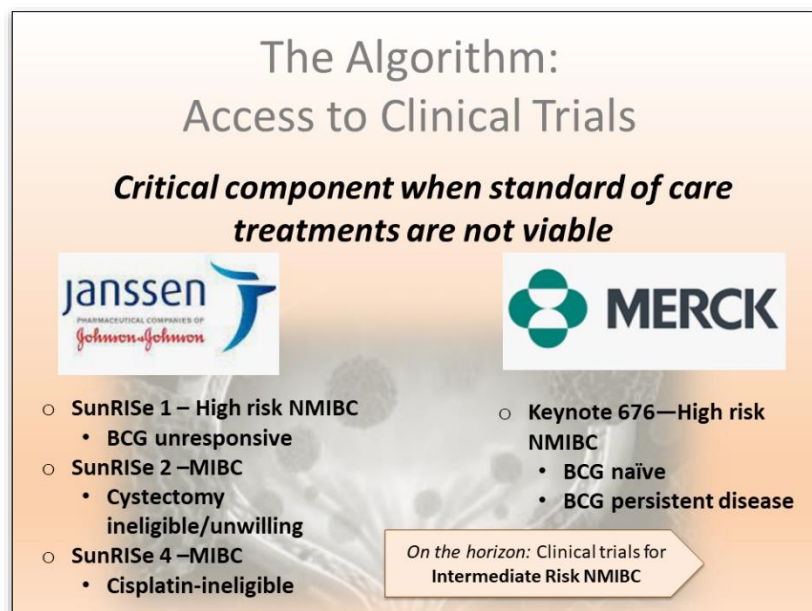
We have smoking cessation counseling, which is a very important aspect. We know with this disease state, we have mental health support, and we're just in the development of kind of expanding our survivorship arm of our community program, where we hope, in the 2023 to roll out a Colorado patient support group for bladder cancer. We have a sexual function rehabilitation, a clinic as part of Colorado Urology that can help those patients who are interested in regaining back at this part of their life. We're working to better help patients be aware of the cancer follow up components that they're going to now face after they've gone through, again, their treatment. They might be on just now that surveillance arm of their cancer continuum, making sure that they understand what that follow up looks like, what components that should be done. So they can also be their own advocate.

### Dr. Suzanne Merrill:

Now, certainly a very important component piece in our community program is to have our patients have access to clinical trials. Clinical trials are a definite critical, critical component when standard peer treatments are not Bible, right? This provides us the next step. Okay, next option, if you will. Maybe the new frontier to tell you the truth. So in our program here with Colorado urology, we have multiple different clinical trials. They're all industry sponsored clinical trials. I'll go into this in a little bit, a little bit later here. But we feel it's necessary to have options for both are non muscle invasive bladder cancer patients, of course, who have become BCG unresponsive. For example, again, failed standard of care, but as well as to have options, as more trials are rolling out in this space where we're combining standard of care with new novel drugs or combinations.

So we have both options available right now in our program for non muscle invasive bladder cancer. Then for our muscle invasive bladder cancer patients, we have options for when patients are not interested and undergoing cystectomy or may be too ill. Then we also have options for patients who may be ineligible for standard of care of receiving neoadjuvant chemotherapy due to hearing loss, peripheral neuropathy, already from other chronic conditions and chronic kidney disease. We hope in the future, and this is near on the horizon to get clinical trials for our intermediate risk, non muscle invasive bladder cancer patients. We really feel that this is an area that is much in need of extension of treatment options. There's certainly more trials starting to come online that are in this space.

Now, as I mentioned before, the options that are available in community programs are going to be more industry or pharmaceutical sponsored. This is because really there is less red tape to get industry sponsored trials up and running in the community as compared to university and academic centers. Now



this is not always the case, but often it is. Certainly we can help these industries get patients enrolled. Many times for these trials, they're already later phase trials, phase three trials, for example, and they need large patient numbers to be able to understand if these drug combinations can prove efficacious in terms of cancer control. So we can help these companies get to that understanding so that we may be closer to another FDA approved drug for bladder cancer.

### Dr. Suzanne Merrill:

Now, whereas what we see in the academic center are unique more what we call investigator initiated clinical trials. These are novel studies that typically either the investigator by themselves, who is a treating provider at that institution has come up with and so they may be not drug trials. They may be survey style survey studies, trials looking at quality of life. What is a preferred surgical option, et cetera, or urinary diversion, for example, but they also, maybe investigator initiated, combined with a drug or industry sponsored drug. So this can be a combination as well, trial that we see taking place in academia.

Additionally, in academia, which is unique is they have what's called collaborative trials. So, you'll see multiple universities coming together and working together on one kind of large, usually randomized trial. One of which is going on right now, looking at immunonutrition both before and after radical cystectomy. So these unique collaborative trials are something more beholden in the academia setting. So, as you can see the difference in trial options between community programs and academia actually can be very complementary to providing a wealth of opportunity for the patients with bladder cancer in one state.

So hopefully to disprove the misnomer, that there may not be any collaboration with the university, I will tell you, we truly are all in this together. So one, the people who are running these community programs like myself and the people who are in the university setting, we're all urologic oncologists. This is truly a niche group and a small group of specialized urologists who typically are very passionate and nerdy about their bladder cancer. So we routinely interact both professionally and personally, many times have each other's cell phone numbers. Certainly when we see each other at meetings, the communication is truly bidirectional. We're collaborating on challenging cases. How would you have handled this, surgical techniques and technology. What do you think of this technology? How do you perform this in the OR? Do you use this device or that we talk about the clinical care pathways that we've set up in our program? What has worked, what is not as well as what our thoughts are about new drug therapies.

We all really have a patient-centric focus. So we really want to ensure patients are getting the treatment they need and desire. So I will tell you these points here, I wish we could do a little bit better on. So, you'll see typically more out in the community. We are offering up kind of second opinion consultations,

## Collaboration with *The University*

*We are all in this together!*

1. Niche group of urologic oncologists
  - *Passionate about bladder cancer*
  - Routinely interact: professionally + personally
    - Communication is **bidirectional**
    - Collaboration on:
      - *Challenging cases*
      - *Surgical technique & technology*
      - *Clinical care pathways*
      - *New drug therapies*



or are just more used to kind of setting up again, other consultations typically with the university for our more complex cases that we see. Hopefully in the future, as more of these community bladder cancer programs, get set up across the country and get well established, our university colleagues will become more aware of us and see more of us as a partnership that if a patient is having trouble with resources and funneling down to their specialized center, they may consider referring to our community program.

Additionally, we are aware of each other's clinical trials, like I mentioned, but this is an ever changing landscape to tell you the truth. I do hope that we can set up a platform that can help us to be better aware of each other's clinical trials so that we may have this in our armamentarium when we're reviewing options with our patients in real time that, maybe they'd be better at the university with X clinical trial, for example, or vice versa. So again, I think this is an aspect that we are aware and we do collaborate on, but we probably could do a bit better with.

### **Dr. Suzanne Merrill:**

Now a unique situation, certainly for us in Colorado and certainly afflicts other states is, for example, we border some states which do not have a great university academic center of excellence for bladder cancer nor community program. So recently we ran into this issue where here in Colorado Urology, in Sky Ridge Medical Center, we received a referral from one of our out-of-state locations of a patient with no medical insurance, with muscle invasive bladder cancer. As our university setting received state funding for patients who are kind of self pay, we were able to facilitate that patient, getting down to our university colleagues to be better served with. So truly there is a pretty good collegial relationship between us in the community and the university.

So I'd like to end with about how you as patients can be more involved in your care, whether it's at the community setting or at the university setting. Really it's just important. I know you all have heard this, that it's important to be your own advocate, but these are some of the questions that I find could be helpful that aren't often asked. Many times it is such a challenge during these consultations to get in all your questions. I know this is something that we could all do better on, but here we go.

So one question is, "Is my case atypical or complicated?" I think this gets at, really, when you ask, "Are there aspects of my case that may make you more concerned than usual," it asks the provider is what you're telling me, a deviation from the common care pathway. I think this is an important point for patients to understand. Is what my provider's telling me, the common way everybody goes, or is this something different? This kind of also opens the door if you find yourself being confronted that your diagnosis is somewhat atypical or unique or complicated if a second opinion consultation could be helpful here. Sometimes this is a hesitant ask of your provider for a second opinion consultation, or if

## Collaboration with *The University*

### 2. Patient centric focus

- *Ensuring patients are getting the treatment they need & desire*
  - **Second opinion consultations**
  - **Awareness of clinical trial options**
  - **"Out of state" or lack of insurance cases**
    - State specific funding for "self-pay" situations



**University** ↔ **Community** =  
**Collegial Relationship**



this could be helpful. So going about it in this direction might open the door for a more easy conversation here.

### **Dr. Suzanne Merrill:**

Secondly, "Are there alternative treatment paths to consider?" Often again, due to time constraints, the provider is leading the patient down one avenue of recommended treatment. So, I think it's important for the patient to put themselves out there and ask, "Is there anything else that we should be thinking about here? Are there less invasive options? And what are the implications if I choose this?" This also opens the door to, are there any clinical trial options for my state right now.

Thirdly, and I think a very important one is what else can I be doing to improve my cancer and health outcomes. This offers up to the provider for you, what other resources should you be tapping into. I think this helps you to understand what that bladder cancer program has available. I think it's very important as we are, of course, during these initial consultations really just focused on treatment. That's where everybody's minds are. But we really have to in today's day and ages, we're becoming more holistic multimodal that we need to be starting these conversations earlier. Certainly we all believe that we can be improving health outcomes if we start these conversations earlier and get you, the patients tapped into a lot of these other resources from prehabilitation, nutrition, smoking cessation, et cetera.

Then fourthly, "Are there similar patients who may be willing to speak with me?" So this opens up, are there local patient support groups that you could tap into both for bladder cancer, maybe for just in general ostomies. Then if there's not, I bet you, your provider has patients who they've even asked if they would be willing to be kind of a sponsor and a person who would be willing to talk to new patients, maybe going through such experiences. I think this really helps patients to lower levels of anxiety to speak to other patients about what is going to be expected.

### **Dr. Suzanne Merrill:**

## How Can **You** Be More Involved in **Your Care?**

***Don't hesitate...be your own advocate!***

### Starter questions:

1. Is my case atypical or complicated?  
*(Are there aspects about my case that make you more concerned than usual?)*
  - Needed deviation from common care pathway?
  - Second opinion consultation helpful?
2. Are there alternative treatment pathways to consider?
  - Less invasive options...implications?
  - Clinical trial participation

## How Can **You** Be More Involved in **Your Care?**

***Don't hesitate...be your own advocate!***

3. What else can I be doing to improve my cancer/health outcome?
  - What **other resources** should I be tapping into?
4. Are there similar patients whom may be willing to speak with me?
  - Local patient support groups/advocates
5. What does this next year look like for me?
  - Follow up visits, procedures, extra treatments etc?



Finally, asking the question, "What does this next year look like for me?" Again, I think responsibility of the provider that often is kind of left maybe to the very end or never really gets to until after that treatment is delivered and we're now in the follow up phases. But I think, again, this is important to set expectations, to understand what the future might hold for you to be aware of what again, do these next year look like, follow up visits, procedures, extra treatments, et cetera.

All right, well, I will stop there. Thank you so much for allowing me to share our program out here in Colorado with Colorado Urology and Sky Ridge Medical Center. Thanks so much to the bladder cancer advocacy network for letting me to share this.

### **Stephanie Chisolm:**

Oh, thank you so much, Dr. Merrill. This was so informative and you made so many really amazing points. I think that your presentation was so comprehensive and I'm sure that there are quite a few people that are like, "How far is it to Colorado? Could I get there for 19 visits a year because we should go there," because it seems like you have a really comprehensive program. I think that that's very exceptional. You made some really amazing points about access to care and going to a large academic hospital might really be a big burden for people to do.

So, I want to go back to some of the questions that have come in and then some questions I just came up with on my own in listening to your talk. What do you think the percentage of community based practices have similar programs? You are considered one of the large urology group practices, part of a much bigger organization. There are still smaller practices out there. So do most doctors have a nurse practitioner or a nurse navigator who's able to help out their patients or perhaps a physician liaison who's able to make those community connections to other services that patients should have. What do you estimate is a percentage of community based practices that do that?

### **Dr. Suzanne Merrill:**

Yeah, no, I think that's a really good question. I, unfortunately, do not think it is a very large percentage. So I think there is still a large, relatively large portion of smaller community urology practices who are performing these high complex procedures, probably more out of need, to tell you the truth than want. That is to try to help best serve the patients that they're seeing, knowing that these patients may not be able to go to, again, that specialized center of excellence in the university or academics. But I think, yes, our kind of program is pretty unique in knowing that we need this large neurology practice footprint and then the high acuity hospital and all those components to make it run with quality care, standard of care and have those resources. So I think you're only going to find something like ours, where you have that three prong kind of infrastructure in place that can have those resources within it to be that comprehensive program unfortunately.

I hope though, I will tell you definitely the kind of future of these independent urology practices. Most of them are coming together to be these large urology group practices. We're realizing as large urology group practices, we need to have disease specific programs to deliver that quality of care well. So I think, to tell you the truth, the future is going to be brighter in this arena, that we're going to see more of these community bladder cancer programs pop up in the future in these states because everybody's kind of joining together these days rather than the olden days of everybody's kind of this independent practice.

### **Stephanie Chisolm:**

I think that collectively people can bring in those additional services. Unfortunately, if you're not in a community right now that has done that, you're going to have a little bit of time before that happens.

**Dr. Suzanne Merrill:**

Yes.

**Stephanie Chisolm:**

So do you have any suggestions then for some of our listeners that might not be in a community that has a few urologists that come together. How would they work to bridge that gap and be able to connect, to say a medical oncologist when you are going to perhaps suggest that somebody have their bladder removed? If you suggest neoadjuvant chemotherapy prior to that radical cystectomy, because that's the best treatment for that individual, how would you help them find medical oncologist that's going to deliver that chemotherapy? Is that usually something that the local community urologist said, "Well, here call Dr. Smith because they treat all of my patients," or do they have to do that on their own? How do patients address or deal with that burden, that extra step?

**Dr. Suzanne Merrill:**

Yeah, that's a good question. Typically, I will say, even outside a community bladder cancer program, if you're just working with a kind of more smaller urology practice and going through this, that urology practice actually has typically these physician liaisons. So they've established working relationships with community providers, whether it's the physical therapist or whether it's the medical oncologist. So it is more common for that urologist to know certain providers throughout their region that would be good with providing X. So, I would say it's more typical that it's going to be the urologist kind of leading the charge in making that connection and having that connection for that patient.

It's very interesting as I came from academics to the community, and this was a very unique kind of position, this physician liaison that I had not come across before. They are definitely instrumental with making sure that everybody is aware of everybody and the community and that we really worked together and use community resources, which was really refreshing to again, make it as burdensomeless, less burdensome for the patient. So they're not having to just, "Yep, no, you can only come to this one hospital to get all your care."

**Stephanie Chisolm:**

Okay. That's great. Again, it's really a challenge because not every institution, every practice is as wonderfully integrated as yours is. So I think this is excellent. So there was a question here about whether or not you have a nutritionist on staff as part of your team, or do you refer out if people have questions specifically about what they should or shouldn't be eating either with or without a cystectomy. Should there be any concerns that they might have? Who do they contact? Is there somebody there?

**Dr. Suzanne Merrill:**

Yeah. So what we've done is we've actually worked with our Sky Ridge Medical Center nutritionist to find out what they recommend when our patients have muscle invasive bladder cancer and who may be going through chemotherapy. So often this type of cancer can be at times very hypermetabolic. So you need extra calories and protein intake to get you through the chemotherapeutic part, as well as the surgery. So they've helped us to come up with some nutrition educational handouts for our patients to help get them started. Then once they're in the hospital with us for their radical cystectomy, they see these patients while in the hospital, provide further education, kind of triage, any kind of, again, questions that might have, and then send them home with further education.

**Stephanie Chisolm:**

Okay, great. Well, I hate to do this, but we do have another program coming up at seven that needs to use this Zoom. So Dr. Merrill, I'm going to thank you.

