

BOARD OF DIRECTORS

Gerald McNamara, *Chair*

Robert Levin, *Treasurer*

Jared Sher, *Secretary*

Jamie Gillespie

Mary Gushée

Beverly James

Cheryl Taylore Lee, MD

Seth Lerner, MD

David Pulver

Neal Shore, MD

David B. Schulman

Diane Zipursky Quale
Co-Founder

STAFF

Andrea Maddox-Smith
Chief Executive Officer

Joslyn Brown
Administrative Assistant

Stephanie Chisolm, PhD
Director of Education & Research

Bernadette Fitzsimmons
Research Coordinator

Anita Parker
Director of Development

Morgan Powell
Education & Outreach Manager

Andrea Shedler
Walk Manager

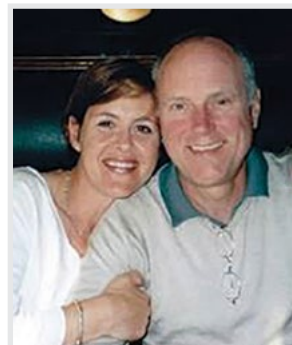
Trenny Stephens
Office Manager

Mark Story
*Director of Communications
and Marketing*

Rebecca Yannopoulos
Senior Walk Manager

BCAN's Co-Founder Looks Back on the Last 15 Years

As we look back on 15 years of progress in the fight against bladder cancer, BCAN recently interviewed Diane Zipursky Quale, BCAN's co-founder to get her perspectives on milestones that have occurred during that time. As her husband John's disease worsened, they became dismayed and frightened to learn about the limited treatment options available and lack of research addressing the need for better treatments. In the spring of 2005, John and Diane decided to try to change the national conversation about bladder cancer, and the Bladder Cancer Advocacy Network or BCAN, was born.



John and Diane
Quale

What things stand out to you most over the last 15 years at BCAN?

Diane: I can confidently say that BCAN would not be where it is today without the countless volunteers and supporters we've had over the last 15 years. Patients, their families, friends and the medical community are truly what helped BCAN get started and keeps our community vibrant today.

As you look back, what do you reflect about most?

Diane: No anniversary date would be complete without remembering those who have lost their lives to bladder cancer, including my husband, John, and many friends who I met through BCAN. It is estimated that more than 250,000 people have died from this disease since 2005, and the impact on the lives lost as well as on those left behind cannot be quantified. As BCAN moves forward, we know that our work will never be done until we have a multitude of treatments that are

BCAN ANNIVERSARY MOMENTS: 2005

BCAN was founded in 2005 and that same year, launched its first web site.



[Continues on page 4 >](#)

THE BLADDER CANCER ADVOCACY NETWORK MISSION

To increase public awareness about bladder cancer, advance bladder cancer research, and provide educational and support services for the bladder cancer community.

1-888-901-BCAN

WWW.BCAN.ORG

INFO@BCAN.ORG

A Note From Andrea...



When a new year begins, it's natural for us to think back on the prior year while looking ahead to the new year and beyond. In 2020, what's exciting is that we get to do both. 2020 is BCAN's 15th anniversary — we were founded in 2005.

Looking back, it is incredible to think that the Bladder Cancer Advocacy Network came to be based upon the vision and determination of our co-founders, John and Diane Quale. When John was diagnosed with bladder cancer in 2000, he and Diane had never heard of the disease before. Their determination and vision, along with the support of John's physician, Dr. Mark Schoenberg, led them to start the Bladder Cancer Advocacy Network.

In the 15 years since, I am proud to say that BCAN has grown to be the leading national advocacy organization devoted to advancing bladder cancer research and supporting those impacted by the disease. BCAN tirelessly advocates for greater public awareness and increased funding for research to identify effective treatments and a cure for bladder cancer. In that time, BCAN has also funded nearly \$5 million in bladder cancer research through our Young Investigator and Research Innovation awards and the Bladder Cancer Genomics Consortium.

The wonderful part of celebrating our 15th anniversary is looking forward to the next 15 years as we all work toward a world without bladder cancer. As we celebrate this anniversary, we could not be more excited.

Andrea Maddox-Smith
Chief Executive Officer

P.S. As always, I welcome your thoughts and feedback. Feel free to email me directly at amsmith@bcan.org or send correspondence to the Bladder Cancer Advocacy Network, 4520 East West Highway, Suite 610, Bethesda, MD 20814.



WALK WITH US

Register today to participate in a 2020 Walk to End Bladder.
Find a location near you and register today at bcan.org/walk.

2020 WALK TO END BLADDER CANCER LOCATIONS

Albany, NY	Cleveland, OH	Lehigh Valley, PA	Pennsauken, NJ	Seattle, WA
Baltimore, MD	Denver, CO	Long Island, NY	Philadelphia, PA	Southern IL
Boston, MA	Detroit, MI	Miami, FL	Pittsburgh, PA	Washington, DC
Central Ohio	Houston, TX	Nashville, TN	Richmond, VA	Virtual
Chapel Hill, NC	Jersey Shore, NJ	New York, NY	San Diego, CA	
Chicago, IL	Kansas City, MO	Northeast, TX	San Francisco, CA	

What Patients Should Know About Clinical Trials



Dr. John Gore

BCAN recently interviewed Dr. John Gore of the University of Washington Medicine. We asked him about the importance of clinical trials and research, as well as patient participation in trials.

What got you interested in research and clinical trials?

Dr. Gore: At the beginning of my career, I had the opportunity to work with Dr. Mark Litwin who is now the Chair of Urology at UCLA. That year that I worked with Mark was very important to my thinking because I learned that I wanted research to be part of my career. Research demonstrates effectively how the gaps in care that we witness every day in our clinical practices have the potential to be solved. We have traditionally thought about those gaps as the treatments we need to enable patients to have better health outcomes. The year that I spent working with Mark opened my eyes to all of the other gaps in care that we don't necessarily see in our clinical practices. Gaps like access to care, quality of care, and quality of life, which is still an understudied issue.

It opened my eyes to how we can help patients be healthier in general, and not just in terms of their chief complaint. This means things like working with bladder cancer patients who are smokers and finding the teachable moments

“What is cool about a research career is that it becomes part of your clinical practice, and your clinical practice becomes part of your research career.”

BCAN ANNIVERSARY MOMENTS: 2007

In 2007, BCAN took its operation from John and Diane Quale's home to its first-ever office location in Bethesda, Maryland.

In October 2007, BCAN hosted its first solo patient educational forum at the University of Chicago, “Understanding Bladder Cancer.” More than 75 survivors, caregivers and family members attended the program and engaged in a lively question and answer session with a panel of bladder cancer experts. One participant noted afterwards, “My wife and I thank you for putting on an informative forum. The knowledge and perspective I gained is invaluable.”

to talk with them about smoking cessation. What is cool about a research career is that it becomes part of your clinical practice, and your clinical practice becomes part of your research career.

Can you tell us a little bit about the clinical trial “CISTO” and the Patient Survey Network? How did the project evolve?

Dr. Gore: CISTO stands for a Comparison of Intravesical Treatment and Surgery, the comparison being bladder removal surgery as a treatment option for recurrent bladder cancer.

If you're going to do a clinical trial, it makes a lot of sense to talk to patients before you come up with the plan for the trial. CISTO is a tremendous illustration of the power of patients to help us do better research.

For CISTO, the origins began with BCAN's Patient Survey Network, a group of patients who have agreed to answer survey and research questions a few times a year. It is amazing to see some of the questions that came out of patient input rise to the top of prioritized

Continues on page 8 >

successful for patients and their families so no one has to experience this tremendous loss.

When you and John set up BCAN in 2005, what did you envision for the future?

Diane: Through our own personal experience and our research, we just knew that an organization like BCAN had to be established. At that time, we certainly did not have a 5, 10- or 15-year plan. We recognized the need to make every effort to raise the profile of bladder cancer. We were determined to ensure that there would be more money and more people devoted to research and better treatments.

How has awareness improved since 2005?

Diane: It's better. Bladder cancer's profile, in terms of the attention that it receives from the research, biomedical and pharmaceutical communities, has increased. Public awareness has also improved, but we still have far too many people who learn about bladder cancer for the first time when they are diagnosed. That's unacceptable.

BCAN has had a huge impact on awareness and focus at both the FDA and the National Cancer Institute, but rates of bladder cancer diagnosis and deaths have remained constant during that time, and that must change.

Given that the organization's name is Bladder Cancer Advocacy Network, what has changed over the last 15 years in regard to bladder cancer advocacy?

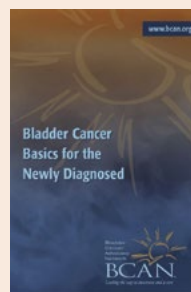
Diane: When John and I got involved in the early 2000s, there was not a bladder cancer patient advocate voice. We founded BCAN as a small grassroots organization and I believe that we became much more effective when, as patients and families, we united to demand better treatments.

What would your 2020 self tell your 2005 self about co-founding an advocacy organization?

Diane: I would tell myself to continue to be flexible and adaptable and just keep going when there are challenges, financial and otherwise. Just keep going.

I would not have done anything differently,

BCAN ANNIVERSARY MOMENTS: 2008



BCAN published its first edition of "Bladder Cancer Basics for the Newly Diagnosed." This publication, now in its fourth edition with a fifth coming in Spring 2020, helps patients and loved ones learn about diagnosis and treatment options to enable them to make informed choices about their continued

medical care. Since 2008, BCAN has printed and distributed more than 300,000 copies of Bladder Cancer Basics, and demand has grown each year.

In the Fall of 2008, BCAN also launched its first online community through its partnership with Inspire, a place for people to "meet" online and connect with other patients, families, friends and caregivers for support and inspiration. In 2020, the Inspire community has grown to more than 34,000 members.

though. I am so proud of what we have done and the community that we have created.

From the beginning, BCAN has maintained very good relationships with the medical community. Why?

Diane: When John and I were considering starting BCAN, the first person I spoke to about it was John's urological surgeon, Dr. Mark Schoenberg. Dr. Schoenberg's response was "You must do this and I will help make it happen." So, our partnership with the medical community is an essential part of our foundation. The clinicians and researchers in the bladder cancer field—which in 2005 was much smaller than it is today—saw the need for a strong patient voice to raise the profile of the disease and to raise more funds, both private and public, to support bladder cancer research. Our Scientific Advisory Board (SAB) began in 2005 with 18 urologists, and today we have 70 professionals across the bladder cancer spectrum, including urologists, medical oncologists, radiation oncologists, research scientists, pathologists, and social scientists. BCAN has encouraged and supported collaboration among all the parties dedicated to the study of bladder cancer. Medical

research can sometimes be siloed and having those in the medical community share ideas about bladder cancer prevention, diagnosis, and treatments fostered new ways of thinking and novel approaches to fighting this disease.

I continue to be gratified and humbled by the support BCAN receives from the medical community to identify the best and most promising research that will provide the greatest opportunity to advance the understanding of bladder cancer. BCAN has invested nearly \$5 million in research grants to experienced investigators with novel approaches and potential breakthrough ideas as well as to early-career investigators to support transformational bladder cancer research.

BCAN's scientific meeting, the Think Tank, grew from about 35 people in 2005 to more than 300 people in 2019. Why do you think this is?

Diane: I give credit to Dr. Mark Schoenberg and his vision of “thinking outside the box” and bringing people together to just talk about bladder cancer. The Think Tank continues to grow because of our collaborative approach and a common desire to advance progress against this disease. Think Tank offers clinicians and researchers, along with survivors, patient advocates, nurses and other advanced practitioners, the opportunity to hear presentations and formal discussions about important issues in bladder cancer. It also provides a more personal opportunity for networking and collaboration.

Each year, we have widened the circle a bit and invited more people, which presents a bit of a challenge to our desire to keep the meeting's

informal and casual nature. As more clinicians and researchers are interested in bladder cancer and want to attend the Think Tank, handling our growth is a good problem to have.

BCG is considered the standard of care for many bladder cancer patients. There have been shortages of this important treatment throughout BCAN's history. Now in 2020, the most recent BCG shortage continues. What do you want people to know?

Diane: Unfortunately, the BCG shortage has become the new normal. The way that our regulatory process works, we cannot force new drug manufacturers to come into the market or produce more. BCAN is focusing our energy during this incredibly difficult time on getting access for as many people as possible. We need to look to the future and advocate for and support the development of new drugs to replace BCG. BCAN continues to work with the research community and the FDA to ensure that trials are designed in the best way possible and that the drugs that are approved are safe and effective.

What can people do to support the bladder cancer community?

Diane: I hope that people will take part in their own community efforts to raise awareness of this disease. As I have said before, bladder cancer is one of the most commonly diagnosed cancers in the United States, yet far too many people first learn that bladder cancer exists when they are diagnosed.

On their local level, people can work with BCAN to help continue to create partnerships with the medical community, including community practices and major cancer centers. They can also work to raise awareness among the state and federal governments about the ongoing need for additional funds for bladder cancer research.

Finally, I would encourage everyone to support all of BCAN's programs so that we can continue to grow our educational and support services, as well as advance bladder cancer research.

BCAN ANNIVERSARY MOMENTS

2009: BCAN hired its first full-time employee.

2010: The first **Bladder Cancer Awareness Day** was July 17, 2010.

2011: In 2011, BCAN held its first-ever **Walk to End Bladder Cancer**.

Continues page 8 >

Milestones in BCAN's 15 years of

2005



BCAN is co-founded by John and Diane Quale

BCAN hires its first full-time employee, an executive director



BCAN launches \$300,000 Bladder Cancer Research Innovation Fund

The first BCAN Think Tank takes place in 2006 in Colorado



BCAN makes its first three \$50,000 Young Investigator Awards



2005

2007

2008

2009

2011

2013

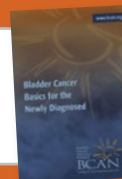
In October 2007, BCAN hosted its first solo patient educational forum at the University of Chicago, "Understanding Bladder Cancer."



BCAN holds its first-ever Walk to End Bladder Cancer



First edition of Bladder Cancer Basics is published



progress against bladder cancer 2005-2020

BCAN wins its first
Bladder Cancer
Advocacy Award



In addition to its fourth consecutive four-star
ranking from Charity Navigator, BCAN is named
one of its Top Ten Medical Research Organizations



With BCAN's support, Food and Drug
Administration approves the first new drug to
treat bladder cancer in almost three decades



2014

2015

2016

2017

2018

2019

BCAN celebrates
its 10th anniversary



BCAN launches the
Bladder Cancer
Genomics Consortium



BLADDER
CANCER
GENOMICS
CONSORTIUM

BCAN launches its Lunch and Learn
series, bringing together local
bladder cancer experts and patients



2005-2020 FIFTEEN YEARS OF PROGRESS
IN THE FIGHT AGAINST BLADDER CANCER




Photo from the first Think Tank meeting in 2006.

In December 2019, there were two new drugs approved to treat bladder cancer. What needs to be done to ensure that there are new treatment options every year?

Diane: We need to continue to demand new treatments, continue to support research, and continue to support collaboration that has helped advance new treatments. These are wonderful developments, but there is not a silver bullet in any cancer which is the cure for everyone. We need to keep pushing for more knowledge, increased understanding and improved treatments for all types of bladder cancer.

What do you envision for the next 15 years?

Diane: In addition to continuing to advance bladder cancer research and more effective treatments, we need to ensure that BCAN resources are available to every person who is diagnosed with bladder cancer, including educational resources and patient and caregiver support. We need to expand relationships with other advocacy groups and with community-based care providers to ensure that all patients have access to good medical care to get the best treatments available. Finally, we need to continue to improve public awareness about the risks, signs and symptoms of bladder cancer, so that both men and women get diagnosed at the earliest possible time when most patient outcomes are better. 


research questions. Not surprisingly, the most commonly asked question was about what to do when BCG stops working.

There are many examples of bladder cancer clinical trials where a lot of money was put into comparing two different treatment options, but the trial ended up failing because one of the treatment options was simply observational. This means that patients would randomly be assigned to one of two groups: a treatment arm or observation arm. For bladder cancer patients, this could mean that participants could get a radical cystectomy or they may not.

“We are so grateful for every single patient that signs up for a clinical trial because they are directly helping us make care better.”

At the end of CISTO we will be able to better understand which patients are best for more aggressive treatment with bladder removal.

What do you want patients to know about research and clinical trials?

Dr. Gore: I want them to know that clinical trials are a really important part of discovery. One of the hardest things for patients to consider as they think about a clinical trial is, could there be any chance that this clinical trial is going to harm them? What I would encourage patients to understand is that in these clinical trials, we're trying to compare known, established treatments with experimental treatments. We're never excluding a patient from care or restricting him or her from care. We are just trying to figure out how to make care better. The involvement of patients in this research process is so critical. We are so grateful for every single patient that signs up for a clinical trial because they are directly helping us make care better. So that's what I would emphasize, that we are tremendously grateful to patients for even considering participating in a clinical trial. 

This Year, Update Your Estate

*Lose weight! Volunteer five hours every week!
Get back into running!*

Most of us start a new year with good intentions. But sometimes, they just don't stick.

Here's one resolution you can complete with ease; one that delivers immediate peace of mind and helps you and your family for the long haul.

Update your estate plan!

Maybe you already have a will, a retirement plan and life insurance. But here's the catch: how long ago did you make your plans? Has your family dynamic changed? Do the provisions still meet your needs? Do your plans factor in recent tax and economic developments?

Estate planning is not a one-and-done task. Estate plans are based on evolving variables, like assets, career, retirement, family needs, philanthropic priorities and property transfer costs. As life circumstances and priorities change, so should your estate documents.

The good news is: updates are easy.

Here are some life events that require you to revisit your estate plan.

Who will be a beneficiary?

- You marry, remarry or divorce.
- New children or grandchildren are born.
- Minor children grow up, become self-supporting and no longer need the financial protection you set up for them.

BCAN ANNIVERSARY MOMENTS: 2013

In 2013, BCAN launched its **Young Investigator Awards**. These one year, \$50,000 grants fund early career researchers working in basic, translational, clinical, epidemiologic, bioengineering or any other scientific or research field, and are working in a research environment capable of supporting transformational bladder cancer research. From 2013 through 2019, BCAN awarded 18 grants to support early career investigators on their path to becoming leaders in bladder cancer research.



- You've provided significant lifetime support to one of your adult children and now want to equalize the benefits your other children will receive.
- Along with providing for your family, you want to support your alma mater, church or a charitable organization whose mission you believe in.

What are your assets, and what are your needs?

- A new job provides better retirement and insurance benefits than you previously expected.
- You decide to retire earlier than you originally planned.
- You decide to retire later or start a second career.
- You've retired and find your living expenses are higher than you anticipated.
- You sell your primary residence or a vacation home your family shared.
- Your health, or your spouse's health, has changed, and you anticipate needing long-term care.

When should you transfer assets?

- You move to a different state.
- Changes to the federal estate and gift tax are enacted.
- Income or capital gains tax rates are increased.
- Income-tax treatment of retirement plan withdrawals to fund charitable gifts becomes more favorable.

Still not convinced you need an update? Read on.

Why update your plan?

- Double-checking your estate documents is easy!
- You want estate plans to benefit important people and causes.
- You want to save on current taxes and administrative expenses.

It's a lot easier than losing weight. Wouldn't you agree?

Where to start?

- Read your will.
- Review your retirement and bank accounts. Who are your beneficiaries?
- Check your life insurance policies. What are the current coverage amounts? Who are your beneficiaries?

How to make changes:

To update your estate documents, you may need these helpful folks:

- Your lawyer: to re-write or adjust your will.
- Your accountant: to double-check the latest tax code changes.
- Your retirement plan administrator: to change beneficiary designations.
- Your insurance broker: to change your policies.

This is your A-Team. They're there to help you get it done.

Some planning points:

- Minor adjustments in your will or trust do not require writing a new document. Your lawyer can prepare a simple amendment that lists your changes and reaffirms all

BCAN ANNIVERSARY MOMENTS: 2014

In 2014, BCAN awarded its first **Bladder Cancer Research Innovation Award**. This award provides \$300,000 over a two-year period for an experienced investigator who will break new ground in the field of bladder cancer. This award supports exceptionally novel and creative projects with great potential to produce breakthroughs in the management of bladder cancer. The Bladder Cancer Research Innovation Award funds projects that may not be funded elsewhere and may represent "out of the box thinking" and approaches to bladder cancer.

BCAN ANNIVERSARY MOMENTS: 2016

The way bladder cancer was treated had not changed appreciably in 30 years until May 2016 when the FDA approved a new medicine, **TECENTRIQ®** (atezolizumab), a drug that works with the body's immune system. It was the first in its class of drugs, called PD-1/PD-L1 inhibitors, approved to treat bladder cancer. The **TECENTRIQ®** approval created new possibilities for those with limited treatment options — the first major treatment advance in a long time.

other provisions of existing documents. It's simple and inexpensive.


- If you're giving a specific item of property through your will ("I give my nephew Herbert my collection of White Sox memorabilia;" or, "I give Charity XYZ all the shares of IBM Corporation that I own at the time of my death"), remember to amend those gifts if you sell or dispose of the items.

A golden opportunity

One last thing: Reviewing your estate plans offers a perfect opportunity to secure your legacy by including a gift to the Bladder Cancer Advocacy Network. Giving through your estate provides significant, long-term support to us without affecting your cash flow.

Ready to give?

Whether you want to make a gift to us through your estate or modify an existing gift plan, we are here to help. We can collaborate with you and your advisors to make the process smooth and enjoyable. We welcome the opportunity to help plan your legacy and to dream with you about the future. Just call!

Questions? Please contact BCAN at: aparker@bcan.org or call **(301) 215-9099**. There is no cost or obligation to you. 

This publication is intended to provide general gift planning information. Our organization is not qualified to provide specific legal, tax or investment advice, and this publication should not be looked to or relied upon as a source for such advice. Consult with your own legal and financial advisors before making any gift.

Chapter Spotlight: BCAN's North Carolina Triangle Chapter



BCAN has six chapters across the United States. These chapters are built by volunteers who share BCAN's vision for changing the lives of those affected by bladder cancer: Each chapter is unique and embodies the BCAN mission to increase awareness, advance research and provide education and support to those with bladder cancer in their communities. In this edition of the BCAN newsletter, we want to give you a peek into what is happening with the North Carolina Triangle Chapter.

Organized in 2013 and located in the Research Triangle region of North Carolina, the North Carolina Triangle Chapter organizes the Chapel Hill annual Walk to End Bladder Cancer and 5k run that has raised nearly \$50,000 to date.


The volunteers in the NC Triangle Chapter also host a golf tournament every year that raises funds to help patients and caregivers in their community. Examples of how the chapter has used the funds include: a gift card program for patients who are getting induction BCG therapy. The gift card program helps offset the financial burden for patients who have to travel to and from the hospital; contributions to the housing fund at SECU House (UNC) and Caring House (Duke) that cover the cost for patients and their caregivers to stay at these facilities; and for travel

BCAN ANNIVERSARY MOMENTS: 2016

In 2016, BCAN launched the Bladder Cancer Genomics Consortium (BCGC). The Bladder Cancer Genomics Consortium is an innovative collaboration between BCAN and eight leading medical centers to develop an enriched understanding of the genomic profile of bladder cancer and accelerate the development of novel treatments. The first BCGC project, which focuses on patients with advanced bladder cancer, completed patient enrollment in December 2018.

expenses for chapter members to attend BCAN conferences.

We are proud to feature this chapter and are thankful for everything they do for North Carolina bladder cancer patients and caregivers.

Learn more about BCAN's chapters by visiting <https://bcan.org/chapters/>. To start a BCAN chapter in your community contact Morgan Powell, mpowell@bcan.org or **201-215-9099**. 

BCAN ANNIVERSARY MOMENTS: 2018

Since 2015, BCAN's strong financial health and commitment to accountability and transparency earned it a 4-star rating from Charity Navigator, America's largest independent charity evaluator. In 2018, BCAN received an additional honor as one of Charity Navigator's "Top Ten Best Medical Research Organizations," reflecting BCAN's commitment to tirelessly pursuing new and effective options for the diagnosis, treatment and management of bladder cancer.





2005-2020 FIFTEEN YEARS OF PROGRESS
IN THE FIGHT AGAINST **BLADDER CANCER**

4520 East West Highway, Suite 610
Bethesda, MD 20814

Non-Profit
US Postage
PAID
Suburban, MD
Permit #4297

BCAN'S ANNUAL **WALK TO END BLADDER CANCER** WILL TAKE PLACE IN 25+ CITIES IN THE US IN 2020.

The Walk to End
Bladder Cancer is
a great way to get
some exercise and
help those most
impacted in the
bladder cancer
community.



TO FIND A WALK NEAR YOU, PLEASE VISIT BCAN.ORG/WALK OR CALL 1-888-901-2226.