THE BEACON
Connecting the Bladder Cancer Community

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

Volume III

Dan Lochner took his love of climbing and added a meaningful twist to it. The benefits continue to multiply. Dan's father was diagnosed with bladder cancer in 2015. With excellent care that included informed decisions regarding his treatment path, his father is happy to report a two-year post-cystectomy follow-up without any signs of cancer. Dan’s dad credits BCAN as a “critical support tool” during his research and an important resource to “interact with the community of others impacted by the disease.”

For over 15 years, Dan’s passion for high-altitude mountaineering has taken him across the globe. In fact, climbing and cancer have been a part of Dan’s life since 2003 when he linked his climbing interest to raise money for prostate cancer, a disease both his grandfather and uncle were battling. “Climbing seemed like a natural way for me to generate awareness for prostate cancer back then. It was this prior experience that led me to the idea of K2 for Cancer in 2018, this time focusing on bladder cancer.”

K2 (also known as Mount Godwin-Austen or Chhogori), the second highest mountain in the world, is located on the border of Pakistan and China. Dan set out to conquer it in 2018. “Mountaineering is a

Taking BCAN To New Heights!

Dan Lochner raised money for BCAN when he climbed the second highest peak in the world.
I am continually amazed at the ingenuity, stories and creativity of those of you in the BCAN community. Whether it is family members raising funds for awareness, researchers searching for new treatments and procedures, or advocates working tirelessly to direct federal dollars to combat bladder cancer, the BCAN community is committed to our mission of advocacy, awareness, and elevating research.

Our video series, “Conversations: Let’s Talk About Bladder Cancer” is expanding to include two important topics. The first helps explain why you should consider clinical trials and why they are so important for patients and researchers. We have added two new videos about healthy eating and even have tasty recipes for you to try at home.

Don’t miss the article on planned giving. This may be an ideal way to secure your legacy and help those who are combatting bladder cancer.

As we prepare for Bladder Cancer Awareness Month and Walk to End Bladder Cancer events in May, I am humbled by this community’s commitment to finding a cure. All of our awareness events are designed to educate the general public and help shine a light on this under-recognized disease. So many families and caregivers working together is really something that lifts us all in the work that we do.

Please do us a favor: we want your feedback. Please complete the Readership Survey on page 11 and mail to us. You can also complete the short survey online at www.SurveyMonkey.com/r/TheBeacon.

I would be honored to have a direct conversation with you and share more information about BCAN’s goals for the future. My hope is that you will take a moment to return the enclosed envelope, and we can schedule a time to talk.

Thank you for being a part of BCAN. We could not do this work without the support of our friends like you.

Sincerely,

Andrea Maddox-Smith
Chief Executive Officer

P.S. I look forward to speaking with you and planning together! You can use the enclosed envelope, or you can just reach out to me directly with your ideas and thoughts. My number is 301-215-9099 and my email is amsmith@bcan.org.
The BCAN “Conversations: Let’s Talk About Bladder Cancer” in-depth interview videos provide valuable, comprehensive insight on key treatment and quality of life issues for bladder cancer patients, caregivers, family members, and friends. With a talk show format, BCAN Co-Founder Diane Zipursky Quale engages experts with questions that patients or caregivers may be reluctant to ask about important topics. The newest “Conversations” focus on clinical trials and nutrition.

Clinical trials are an essential part of cancer research. They may provide treatment alternatives to patients who have not received benefit from standard approved therapies. “Are Clinical Trials Right for You?” features leading bladder cancer research expert Dr. Jonathan Rosenberg from Memorial Sloane Kettering Cancer Center and research nurse Blaine Brower, FNP-BC of the University of North Carolina explaining how to unravel the mysteries of bladder cancer clinical trials.

Many patients and their families want to know what they can do to help prevent or fight bladder cancer. Our second Conversations video is divided into two courses (the first provides tasty tips for “Eating Healthy with Bladder Cancer”, the second will fill you up with great suggestions for “Eating Healthy Before and After Bladder Cancer Treatment.”) featuring dietitian Jill Hamilton-Reeves, PhD, RD, CSO, from the University of Kansas and oncology nurse specialist

BCAN would like to thank Ferring Pharmaceuticals and Merck for making these Conversations possible. Special thanks to the Smith Center for Healing and the Arts for sharing their beautiful kitchen with us.
sport that values perseverance. It continues to teach me that many things people consider impossible are possible.”

To date, Dan and his team of supporters have raised $51,186 for BCAN. The funds were raised through the BCAN Do-It-Yourself fundraising website. Dan also used Instagram with the BCAN link and email to spread the word generating awareness. He also speaks about his experience at work and community events to connect with others and further awareness about bladder cancer.

When asked about advice to others who are thinking about doing something special to raise awareness and funds for BCAN, Dan said, “We just need to take that initial leap of faith knowing that we might initially fail. But we may also succeed, which is the key to opening the door for the possible!”

Rebecca Yannopoulos, part of BCAN’s development team says, “We want to help you with your projects and can offer technical support for success.”

BCAN makes it easy for you to have your own fundraising events with our Fundraise Your Way platform

www.BCAN.org/Fundraising
New Cancer Numbers from ACS

According to the American Cancer Society the death rate from cancer in the United States has declined steadily over the past 25 years. Lower cancer mortality rates may be due to steady reductions in smoking and advances in early detection and treatment.

Bladder cancer is the 6th most common form of cancer in the U.S.

80,470 new patients will be diagnosed this year

New Hampshire
Highest incidence of bladder cancer
47 men per 100,000

Hawaii
Lowest incidence of bladder cancer
23.6 men per 100,000

It’s been said that “Statistics are people with the tears wiped away,” and BCAN is aware that every new case of bladder cancer is one too many. Learn more about bladder cancer risks, signs and symptoms, treatments including immunotherapies, by visiting us at www.BCAN.org.


Tasty Nutrition Tips from Jill Hamilton-Reeves, PhD, RD, CSO

Most of us want to know how to eat healthier. And many wonder if changing our diets can reduce the risks for bladder cancer or help us recover when in treatment. Sharing these recipes may be the best answer to “what can I do to help?” when friends or family offer to help when you undergo treatment.

Dr. Hamilton-Reeves offers many tasty tips and flavorful facts about nutrition and bladder cancer. For instance:

- Broccoli (specifically the isothiocyanates in broccoli) is powerful for non-muscle invasive bladder cancer patients. Studies are underway to see if eating broccoli may prevent recurrence. Garlic (specifically the myrosinase in garlic) helps us absorb the isothiocyanates. Adding pungent foods like garlic or radish, when you’re eating your cruciferous vegetables, can help you absorb important nutrients even better.

- Salmon is very high in Omega 3 fatty acids that help calm inflammation, which is important for keeping cancer at bay from recurring, and for overall health.

- Turmeric is anti-inflammatory, perfect to add to recipes.

- Green tea, healthy smoothies, and water with a little bit of citrus are great for hydration. Remember, if you’re eating more fruits and vegetables, you are also increasing your water intake.

Get this information and more by watching the two new BCAN videos on nutrition and bladder cancer at www.BCAN.org/Nutrition-Bladder-Cancer
The term advocacy (ˈad-və-kə-sē) means the act or process of supporting a cause or proposal. Advocacy works to influence the introduction, enactment, or modification of legislation, related to bladder cancer. Advocacy can occur at the Federal, State, or County level. Because you or someone you care about has experience with bladder cancer, you are part of the bladder cancer community. You are part of our Network. Many voices united can make some noise to raise awareness, and advocate to make some change, but BCAN cannot do it alone. We need your help.

From time to time, BCAN asks you to raise your voice on behalf of bladder cancer patients and their families. It may entail contacting your legislator, sharing your bladder cancer experience, and your perspective on an issue, and asking him or her to vote a specific way on a bill. We send alerts through our newsletters and social media as new issues emerge that need the support and voice of the bladder cancer community.

There are many issues BCAN cares about in 2019. These include advocating for bladder cancer research to be included in the annual Congressionally Directed Medical Research Programs (CDMRP). BCAN CEO Andrea Maddox-Smith recently visited the offices of Rep. Tulsi Gabbard (HI), Rep. Brian Mast (FL), Senator Amy Klobuchar (MN) and Senator Dan Sullivan (AK) to support their introduction of a “Burn Pits Accountability Act” in Congress. This legislation, will help evaluate and document the exposure of U.S. servicemembers and veterans to open burn pits and toxic airborne chemicals, possible risk factors for bladder cancer and other diseases. BCAN advocates for bladder cancer to be included in the list of diseases presumed to be caused by Agent Orange.

Patient advocates joined Stephanie Chisolm, PhD, Director of Education and Research, on Capitol Hill for the Rally for Medical Research this past September. We advocate for research, for affordable insurance coverage with pre-existing conditions, and to insure the National Institutes of Health and National Cancer Institute are properly funded to keep advancing the science and healthcare in the U.S. We want to speak up when repeals of EPA environmental regulations may put our loved ones at risk for bladder cancer.

Are you willing to help us? Maybe you want to walk the halls in D.C. with us? Maybe you want to write a letter, or email? Can you pick up the phone and call your representatives? Visit www.BCAN.org/Advocacy to sign up for alerts and announcements of key advocacy issues important to our bladder cancer community.
The Many Faces of Bladder Cancer

Walks To End Bladder Cancer give voice to the many faces of bladder cancer: patients, survivors, caregivers, friends, family, and those who have lost a loved one.

Together, since the Walk program began, we have raised $3.7 million and every dollar raised brings us closer to a world without bladder cancer.

We invite you to join us, this spring, as we walk to end bladder cancer. Register today at www.BCANWalk.org.

2019 WALK LOCATIONS:

- Albany, NY
- Baltimore, MD
- Boston, MA
- Central Ohio
- Chapel Hill, NC
- Chicago, IL
- Corpus Christi, TX
- Detroit, MI
- Houston, TX
- Jersey Shore, NJ
- Kansas City, MO
- Lehigh Valley, PA
- Long Island, NY
- Nashville, TN
- New York City, NY
- Pennsauken, NJ
- Philadelphia, PA
- Pittsburgh, PA
- Richmond, VA
- San Diego, CA
- San Francisco, CA
- Seattle, WA
- Washington, DC

NEW THIS YEAR!

You can create a Facebook Fundraiser from your walk personal page.

Look for information on how to start your Facebook Fundraiser in our FAQ section at www.BCANwalk.org.

VIRTUAL WALK

No walk in your area? Pick your own date and time between now and June 30, 2019 to participate virtually.

Participants who raise $100 or more will receive the 2019 Walk to End Bladder Cancer Commemorative t-shirt.

Email walk@bcan.org or call 301-215-9099 for more information.
Do you want to make a significant gift that will transform the work of the Bladder Cancer Advocacy Network for generations to come?

You can do it today—with a legacy gift through your will.

✓ Costs you nothing during your lifetime.
✓ Preserves your savings and cash flow.
✓ Can be changed or revoked as needed.
✓ Allows you to be far more generous than you ever thought possible.
✓ Easy to arrange. A simple paragraph added to your will is all it takes.

For more information on how you can make us part of your family, please contact us today.

WWW.BCAN.PLANNEDGIVING.ORG
Now is the time to make a mark on the future.

More and more friends of BCAN are choosing to leave a lasting legacy by making a gift through their will or estate. Some of the largest gifts we’ve received — the kind that really make a difference for future generations — come from planned gifts.

If you don’t have a will, what are you waiting for?
Without a valid will in place, you leave it up to the courts to decide how to distribute your assets. You’ve worked hard to achieve what you have, whether it’s a little or a lot, and you deserve the right to say what happens to it. A will gives you the control you deserve. Writing a will isn’t difficult, and it’s well worth the time. It’s also a great opportunity to leave a legacy gift to organizations you care about, like BCAN.

What Counts as a Bequest?
You can give (“bequeath”) many kinds of assets — in whole or in part — in your will, including:

• A paid-up life insurance policy
• Cash
• Securities
• Real estate
• CDs
• U.S. Savings Bonds
• Artwork
• A percentage of your estate’s value

The “leftovers” after all debts are paid and your loved ones are cared for.

Don’t be Shy
Please let us know if you decide to make a bequest to BCAN. We realize many donors wish to remain anonymous, and if this is your wish, we will absolutely guard your privacy. However, knowing about your plans helps us plan better for the future. It also enables us to thank you in the way you deserve. It’s especially important to contact us in advance if:

• you’d like to make a bequest of something other than cash or appreciated marketable securities; or
• you wish to designate your bequest to a specific purpose.

Bequest Verbiage
Many people think a bequest is complicated. Not so! It really couldn’t be easier. Simply fill in the blanks and pass along this language to your attorney to include in your will or living trust:

I give, devise and bequeath to the Bladder Cancer Advocacy Network, located at 4915 St. Elmo Avenue, Bethesda, Maryland, 20814, or its successor, the sum of $_______________ (or a description of the specific asset) to be used for such charitable purpose(s) as the governing body of the Bladder Cancer Advocacy Network or its successor, may decide in its discretion (or for the support of a specific fund or program).

Get in touch!
If you believe in our mission and want to help carry it forward to the future, please contact us. We would be pleased to work with you and your advisor(s) to determine the gift that best suits your situation and interests. Contact: Anita Parker at 301-315-9099.

Contact Us:
Anita Parker, Director of Development
301-215-9099 ext. 202
aparker@bcan.org
BCAN.PlannedGiving.org
301-215-9099 ext. 202
Bladder Cancer Summit For Patients and Families

October 3-5, 2019. Baltimore, Maryland.
Details coming soon.

Images from this year’s Summit, held in Houston, Texas

Read more than 30 stories of patients and caregivers. What is your bladder cancer story?

www.BCAN.org/my-bladder-cancer-stories
THE BEACON READERSHIP SURVEY

1. What is your favorite part of The Beacon? (mark all that apply)
   □ Stories about patients and survivors
   □ Articles about research developments in bladder cancer
   □ Resources with information helpful to me
   □ Other___________________

2. I like to receive my information from BCAN (mark all that apply)
   □ Electronically/Email
   □ Paper copy/Snail mail
   □ I’m OK with either

3. What would you like to see in future issues of The Beacon?

_______________________________________________________________________________________
_______________________________________________________________________________________

4. Name (optional)

_______________________________________________________________________________________

Please clip this survey and mail in the envelope provided. You can also answer the survey online at www.SurveyMonkey.com/r/TheBeacon

BCAN Chapters Corner
Want to get active with your local bladder cancer community? Learn more about what the BCAN Chapters do and how to get involved at www.BCAN.org/Chapters. Chapters are located in:

• Albany, NY
• Corpus Christi, TX
• North Carolina Triangle
• Pennsylvania
• Richmond, VA
• San Diego

Bladder Cancer Basics for the Newly Diagnosed
BCAN's handbook is available, free of charge, to help bladder cancer patients and their caregivers learn about their diagnosis and treatment options. With the help of their medical team, this resource will enable them to make informed choices about their continued medical care. Available for download or request a free paper copy.

www.BCAN.org/Handbook
BCAN STORE NOW OPEN - SHOP TODAY!

Bladder Cancer Advocacy Network
Leading the way to awareness and a cure

Support BCAN.
Get your #BCANOrange gear!

stores.inksoft.com/BCAN

4915 St. Elmo Avenue, Suite 202
Bethesda, MD  20814