

PATIENT VOICE

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Advocacy in the virtual world. ACS CAN Advocates snapped a few pictures during their training and legislative sessions.



How Patients Are Navigating Advocacy Landscape

Virtual Legislative Meetings and News Reports Giving Patients a Voice

#TXCancerWeek A Big Success -Cathleen McBurney

Forty one advocates from across the state of TX participated with the American Cancer Society's Cancer Action Network (ACS CAN) in this year's Cancer Action Week.

Normally held at the state capitol in Austin, this year looked a little different with legislative meetings held virtually via zoom. But that didn't stop those 41 volunteer advocates from participating in 68 different meetings.

Cancer survivors and caregivers themselves, the advocates used their own journey with cancer to express the need for continued funding of the Cancer Prevention & Research Institute of Texas (CPRIT). In 2019 a \$3B bond was reauthorized after voters passed it with a majority vote. Advocates looked to the legislators to ensure that CPRIT remained fully funded in the next budget.

CPRIT funding has had a profound effect on cancer survival in Texas and around the world. There have been 228 cancer researchers and labs brought to TX, including Dr. Jim Allison, the Nobel Prize winning researcher at MD Anderson Cancer Center for his work in immunotherapy.

A 2015 CPRIT funded grant that was awarded to Radiation Oncologist Dr. Jack Phan at MD Anderson Cancer Center studied the use of Stereotactic radiation on

laryngeal cancer. Had he not been awarded that grant, he may not have had the necessary research to later study the use of SBRT (Stereotactic Based Radiation Therapy) on recurrent Head and Neck cancers like mine which was treated in 2018. A treatment that saved my life.

CPRIT also funds 7M early detection and prevention services. There are currently 171 childhood and adolescent research projects as well.*

CPRIT is the largest state cancer research investment in the history of the United States and the second largest cancer research and prevention program in the world.* It is no wonder advocates took to the virtual halls of the capitol to protect it.

In addition to CPRIT, additional efforts were around funding the Breast and Cervical Cancer Services (BCCS) program for low income uninsured and underserved women. BCCS provides important early detection and prevention programs. With early detection the 5 year relative survival rate is 99% for localized breast cancers and 92% for cervical cancer according to the American Cancer Society.

The advocacy efforts led to hearings in both the TX Senate and House floors on the funding effort for all the initiatives.

Source:

*<https://www.cprit.state.tx.us/about-us>

TX Colorectal Cancer Early Detection & Prevention Bill

HB 3588/SB 1028

ACS CAN advocates also focused meetings on getting co-sponsors for the Colorectal bill which would change the recommended age of colorectal screenings from 50 to 45 to account for the increase in incidents for this age group. It would ensure that insurers cover the cost of colonoscopy if a non invasive screening showed a positive reading. Colonoscopy would be considered a part of the overall screening process if necessary and would remove the co pay requirement.

Colon cancer is the second leading cause of cancer in the US among men and women combined. Screening can prevent cancer through the detection and removal of polyps and precancerous growths.

VisionTree NEWS...

As the use of apps becomes more common in the workplace, we are excited to announce our SSO embedded app for patient outcomes assessments (ePROs). With only one click from within the hospital or centers EHR, patients can access their forms without a separate login, care team alerts can be generated from the forms and improved patient engagement can begin. Find the VTOC app in the Epic App Orchard.



Denise Durgin
Proton Advocate
& Author

DID YOU KNOW?

The beginning of a patient's advocacy can be the simple act of filling out their ePROs. By sharing their experience, they are helping to shape treatments and policies for future generations. It's great practice to let your patient's know how their information is being used. You'll be amazed at the response.



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**PATIENT
VOICE**

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Empowering and Educating: Themes of New Proton Book

How One Patient Turned Author is Looking to Expand the Proton Narrative

Denise Durgin has had several successful careers since entering the workforce. She has volunteered as a at The Beryl Institute as the Co-chair of the Global Patient Family Advisory Board, and Chaired the Inova Schar Cancer Institute Patient and Family Advisory Council, and is an integral Champion Advocate for The Alliance for Proton Therapy Access. "I've become so passionate about helping support and create meaningful patient experiences that focus on what matters most to each patient," says Denise. Now she works as a Patient Experience Performance Advisor at Inova Fairfax Medical Campus. Before her time in patient experience, she spent her career at Marriott, The Ritz-Carlton, Host Hotels & Resorts and even launched her own coaching company, so she knows very well how to direct information to the appropriate audience.

Writing a book has always been a goal, she just never thought it would be about cancer treatment and what patients endure trying to get insurance to pay. But after Denise's own challenges with cancer treatment coverage, she knew she wanted to do more to help others. Denise battled breast cancer in 2018, and was told after a mastectomy, lymph node removal and reconstruction, that there was lymph node involvement and she would need radiation. She was originally prescribed photon radiation, but due to a family history of heart issues, as well as her own, her doctor at Inova Schar Cancer Institute prescribed proton therapy as it was the best course of treatment to spare the healthy tissues around her heart and lungs. Her insurer disagreed and denied her claim not once, but twice, calling it "medically unnecessary." Doctors, not insurers, should be the ones to determine that. This decision from an insurance company that states on their website "connecting you to care that works for your life; talk to a doctor whenever." Denise was never able to get in touch with a peer to peer doctor at the insurance company. She felt backed into a wall and made the difficult decision to pay for the treatment on her own. After her doctor (Dr. Eblan) wrote a nine page appeal letter to the insurer and had yet another peer to peer review, the insurer finally decided to cover the treatment. Denise was successfully treated at Maryland Proton Center. Inova prescribed the proton treatment, but didn't have a proton center open yet at that time. Ultimately, Denise's insurance covered the treatment, but it was only because of Dr. Eblan and his tireless efforts, that the insurer caved in. But many patients are not that lucky. That is the story Denise wanted to tell.

In her book Empowered Proton Survivors, Overcoming Cancer and Insurance Denials, due out in August, she speaks to 15 cancer patients who had experience with proton therapy. Of her book, Denise says, "I want to contribute to the body of knowledge around protons from a patient's perspective." Patient stories detail the efficacy of proton therapy, yet many discuss a similar experience with insurance companies denying treatment altogether or having the burden of proof placed on their care teams even when they said it was medically necessary.

Denise also interviewed nine physicians from six different proton centers, including Maryland Proton Treatment Center (where she was treated), NY Proton Center, California Protons Cancer Therapy Center, Loma Linda University, Inova Schar Cancer Institute Mather Proton Center (where she interviewed 2 different doctors, including her own), University of Toronto Princess Margaret Cancer Center as well as the Chief Medical Officer at Varian (the maker of the proton radiation machine). The overarching themes of the book are to Educate, Advocate and Legislate for proton therapy. After publishing costs, proceeds from the book will go directly to some of the cancer organizations that talked about in her book. Advocacy at its finest!!

Alliance For Proton Therapy Access Advocate Battles Insurer

NBC News Investigative Report Details Advocates Denial and How She is Fighting Back

Alliance Advocate Kate Weissman was diagnosed with Stage 2B cervical cancer in 2015. She was treated at Dana Farber Cancer Institute/Brigham and Women's Hospital in Boston. After having photon radiation and chemo, she was left feeling weak, extremely fatigued, and nauseous. Despite her treatments, later scans would show that while the cancer they treated had dissipated, it had spread to her paraaortic lymph nodes. Due to the location of the tumor by the vertebrae in her lower back, her renowned doctors acted quickly removing the tumor and prescribed proton therapy due to the proximity of her kidney and bowels. Kate's treatment was denied by her insurer, claiming it to be "experimental, investigational and unproven" despite evidence to the contrary supplied by her doctors. "It was very surreal to not only be battling the cancer but also my insurance company. I remember calling the insurance company from my chemo chair, begging them to overturn their decision." They didn't overturn their decision and her family was forced to pay for the treatment. They have since filed a class-action suit against UHC for failing to uphold its fiduciary duty to her. Kate says, "There are countless other cancer patients with stories like mine that need oncologist recommended proton therapy to cure them and secure a healthy life post-cancer."

In early March, NBC News in Boston did an investigational report on Kate's experience, and just days after it aired, the federal judge in Kate's case denied UnitedHealthcare's previous motion to dismiss, alleging it "deceptively and unfairly administered their ERISA plans by refusing to cover Proton Beam Radiation Therapy (PBRT) ... because it is more expensive than more traditional cancer treatments."

The Alliance For Proton Therapy Access assisted the reporter and helped push the story. They also assist many patients battling denials by providing resources and media intervention. View the NBC story above.