

# The Donna Crandall FOUNDATION NEWS



PROVIDING PROGRAMS AND SERVICES THAT POSITIVELY IMPACT CYSTIC FIBROSIS PATIENTS. • [WWW.DONNACRANDALLFOUNDATION.ORG](http://WWW.DONNACRANDALLFOUNDATION.ORG)

## DMCF celebrates the "Courage of CF" with the Beads of Courage® program!



DMCF is delighted to announce that we are spearheading and funding the start of the Beads of Courage program at Albany Medical Center. Beads of Courage is a nonprofit organization providing innovative arts-in-medicine programs that improve the quality of life of children coping with cancer and other serious illnesses. Children and teens enrolled in the program receive colorful beads that commemorate, communicate, and celebrate every step of their treatment journey. Beads of Courage, Inc. is an international organization helping more than 60,000 children in 240 children's hospitals annually. The flagship Beads of Courage program was originally designed for pediatric oncology patients, but has expanded to provide services for other serious chronic illnesses, including cystic fibrosis.

*continued on page 2*

## Foundation loses its biggest fan

In January 2019, the Crandall family sadly lost its patriarch and quiet leader, Dave Crandall. He loved ice cream, anything chocolate, and playing a round of golf with his wife or with his New Smyrna friends. He was always willing to teach a friend how to set up their computer and was tickled by their success. He enjoyed playing his keyboard and working on projects at his beloved Lake George camp. But at his core, Dave Crandall cherished time with his family most of all. He sincerely loved being a spectator at his kids' and grandkids' many sporting and

*continued on page 4*

*Dave Crandall with his wife Barbara at Lake George.*



Special thanks to our Newsletter Editor, Erin Snow.

## Beads of Courage program, *continued from page 1*

The core Beads of Courage program has been shown to decrease illness-related distress, increase the use of positive coping strategies, help children find meaning in illness, and restore a sense of self in children coping with serious illness. The program provides something visual and tangible that children can use to tell about their treatment experiences. Because of compromised immune systems, children with CF are frequently not allowed to attend support groups; the Beads of Courage program will help children chronicle their journey, while providing a meaningful symbol of strength and courage. Children may receive beads for treatment experiences such as attending clinic appointments, being hospitalized, having PFTs or chest x-rays, undergoing surgery, or having a challenging moment with medication.

Albany Med patients enrolled in the program will start with their first name spelled out in beads on a strand. They will receive more beads based on the Beads of Courage bead prescription that serves as the clinical protocol. "We are so excited to be able to bring this program to our CF clinic, thanks to the Donna Crandall

Foundation," said Maureen Sharkey, a child life specialist at Albany Medical Center. "We believe this program will have a profound impact on our cystic fibrosis patients. It can serve to validate and process feelings, emphasize accomplishments, enhance coping, and tell a patient's story. As the program literature states, 'Every time a bead is given, courage is honored, suffering is alleviated, and resilience is strengthened.'"

At the 19th Emerald Eve, the DMCF will celebrate the Courage of CF. We will highlight courageous young people who never let CF stand in their way, but accomplish great things in spite of it.



**Elias** Age: 8  
Beads of Courage Chronic Program Member

*"We were with Elias for every single bead he has received. The beads hang on his bedroom wall and are so beautiful. They turn all of those scary moments into something beautiful."*  
— Amber, Elias's mom

**beads of COURAGE**  
[www.BeadsofCourage.org](http://www.BeadsofCourage.org)  
#BelieveInBeads

### **Who is eligible?**

All pediatric CF patients who receive treatment at Albany Med will be eligible.

### **How do I enroll my child with CF in the Beads of Courage program?**

The AMC social worker and child life specialist will offer the program to each family and help them sign up.

### **How do I learn more about Beads of Courage?**

Visit [www.beadsofcourage.org](http://www.beadsofcourage.org) and follow @beadsofcourage on social media.



## Fifteen ways (*many of them easy!*) that YOU can help the Foundation this year!

1. *Sign up for Amazon Smile at [smile.amazon.com](https://smile.amazon.com) and select the Donna M. Crandall Foundation as your charity.*

A portion of every Amazon purchase you make by going to [smile.amazon.com](https://smile.amazon.com) will go to DMCF. It might not sound like much, but DMCF has already received hundreds of dollars thanks to Amazon shoppers!

**SUPER EASY!**

2. *Purchase one of the 450 limited tickets to the 19th Annual Emerald Eve.*  
Contact Lisa Cheney at [lisa@crandallfoundation.org](mailto:lisa@crandallfoundation.org).

3. *Donate an auction item—large or small!—to Emerald Eve.*

Contact Terri Snow at [snow43056@aol.com](mailto:snow43056@aol.com) to learn how.

4. *Donate a bottle of wine to the Emerald Eve wine raffle.*

Purchase your favorite bottle and drop off with the Foundation. Please note if you are purchasing the bottle in honor of or in memory of a CF patient. Contact Lisa Cheney at [lisa@crandallfoundation.org](mailto:lisa@crandallfoundation.org).

5. *Be one of the 23 table flower sponsors at Emerald Eve for \$100.*

Contact Lisa Cheney at [lisa@crandallfoundation.org](mailto:lisa@crandallfoundation.org)

6. *Donate three dozen cookies to be used in our holiday cookie tins, distributed to patients at Albany Med in December.*

E-mail Joan Hart at [JHart1987@live.com](mailto:JHart1987@live.com).

7. *Shop for the legendary DMCF gift bags or seasonal-themed treats, which are given to CF patients admitted to Albany Med.*

Contact Lisa Cheney at [lisa@crandallfoundation.org](mailto:lisa@crandallfoundation.org)

8. *Donate a package of UNO cards in memory of Mary Breton to be used in the gift bags. (Ship directly from [smile.amazon.com](https://smile.amazon.com)!)*

Mail or drop off cards to: DMCF / 50 Traditional Lane / Loudonville, NY 12211.

9. *Donate your favorite books or magazines to be given to patients in the DMCF gift bags. (Ship directly from [smile.amazon.com](https://smile.amazon.com)!)*

Mail to: DMCF / 50 Traditional Lane / Loudonville, NY 12211.

10. *Donate a \$25 gas card or Price Chopper gift card to the Foundation.*

Mail or drop off cards to: DMCF / 50 Traditional Lane / Loudonville, NY 12211.

11. *Consider being an Emerald Eve Corporate Sponsor. Amounts range from \$500 to \$2,500.*

E-mail Lisa Cheney at [lisa@crandallfoundation.org](mailto:lisa@crandallfoundation.org).

12. *Consider a donation to the Foundation in lieu of birthday or Christmas gifts this year.*

We will be happy to send you a card! E-mail Lisa Cheney at [lisa@crandallfoundation.org](mailto:lisa@crandallfoundation.org).

13. *Donate a favorite book to the "Living Room" on E5 at Albany Med. You could even ship directly from [smile.amazon.com](https://smile.amazon.com)!*

Mail to: DMCF / 50 Traditional Lane / Loudonville, NY 12211.

14. *Host a Lemonade Stand/Challenge in honor of Dawn McGuinness to raise money for the DMCF!*

15. *If you have other ideas for how to support or raise money for DMCF, please contact us—we are all ears!*

Contact Lisa Cheney at [lisa@crandallfoundation.org](mailto:lisa@crandallfoundation.org).

## DMCF helps CF Moms travel to Montana retreat

The Donna Crandall Foundation supported four Capital-area CF moms attending the "We Walk Together" retreat in Big Sky, Montana in September 2019. Julie Gosselin, Maribel Lape, Sarah Marlowe, and Emilie McHale each received \$1,000 from DMCF to cover their travel expenses. The weekend retreat, organized and hosted by the Cody Dieruf Benefit Foundation, is meant to give mothers of children with CF a chance to connect with each other, while sending them home renewed and perhaps with new ideas for how to care for themselves and meet the constant requirements of CF in their families. Sarah Marlowe, who also attended the retreat in 2018, shares, "I really enjoyed last year's retreat because I finally got a chance to bond with other mothers that I could relate to—none of my friends have children that have CF or suffer from a genetic disease. We all shared stories and provided guidance and support to each other."



*Dave looks at silent auction items with his daughter Lisa Cheney at Emerald Eve 2018.*

### ***Foundation loses its biggest fan,*** *continued from page 1*

musical events. He faithfully treated all of his kids and grandkids equally, but when one was in need, he was quick to reach out. Being available to help Donna in her CF journey was always at the forefront of his thoughts. He was one of the biggest supporters in her life and one of the Foundation's biggest supporters after her death.

Dave first heard about cystic fibrosis in the early 1960s when a colleague in Scotia discovered that three of his four children had the disease. Back then not much was known about CF, but Dave was always interested to learn more and felt helpless when they passed away.

Donna was a 1979 graduate of Siena College and went on to have a nearly 19-year career as a manager with Ayco. As Donna's disease advanced, so did her need for treatment and extra help. When Donna was home on IVs, Dave was always willing to pick up dinner, grab her daughter Kerianne from school, or sit at the house with Donna—just in case she needed something. When CF-related diabetes made driving a challenge in Donna's later years, Dave jumped in and drove her to work each day and delivered her safely home at the end of the day—Donna's own personal Uber.

During Donna's life, most doctors were still doing IVs in the hospital, but Donna didn't want to be in-patient. Rather, she wanted to be treated as an out-patient and

continue to be able to go to work each day. Dr. Jonathan Rosen and nurse Karen Cianci were always willing to figure out a treatment plan that allowed Donna to be treated outside the hospital. Donna was quite the pioneer on this front.

Donna was also fortunate enough to work for Ayco and have John Breyo at the helm of the company during those years. John was open-minded and allowed his hardworking employee to work from home when needed and allowed her to take extra time for appointments. Donna was grateful for the flexible schedule and the progressive thinking of her company.

Donna's family truly believes that Donna's life was extended because of the kindness and willingness of John, Jonathan, and Karen to think outside the box. As the disease was stealing so much, these individuals gave Donna the opportunity to be distracted by the details of her job and afforded her the opportunity to accomplish great things on a daily basis.

After Donna passed away, Dave provided encouragement as his children and their spouses navigated starting the Donna Crandall Foundation. He loved the Foundation and the service it provided the CF community. He knew from Donna the daily challenges those living with CF face, and he wanted to make it easier. He stamped



*TOP: Dave with two of his grandsons, Jack Cheney and Ben Crandall, at Emerald Eve.*

*BOTTOM: Dave and David Crandall help to set up the Christmas-themed 2016 Emerald Eve.*





Emerald Eve invitations, hung custom DMCF Christmas ornaments on the tree for the 16th Annual Emerald Eve Gala, and helped with setting up the Emerald Eve auctions every year—this year will be the first time in nineteen years the family does it without him. “My dad was so proud of the Foundation,” shares Bobby Crandall, Foundation Board Member. “He loved that his kids created a permanent tribute to Donna. He truly admired his daughter-in-law and was inspired by all the other CF patients that he was privileged to meet these last 19 years.”

His favorite time of the year was to watch and listen to the program and watch the video at Emerald Eve. “As his disease progressed, coming to Emerald Eve was non-negotiable,” explains Foundation Vice President Lisa Cheney. “Donna’s struggles had left a lasting impression on him and gave him the strength to come each year even when being in a large group had become more difficult. He put his own personal challenges aside to honor her memory and support the many patients he had met during the last 19 years; he so admired their courage too.” On every suit he wore—from Emerald Eve to weddings, he always accessorized with the Donna Crandall Foundation lapel pin. The pin represented so many courageous CF patients and families that had touched his life.

After his passing in January, the Donna M. Crandall Foundation received over \$15,000 in donations to honor his memory. Dave would be very humbled by those generous gifts, and yet so thrilled the CF community was receiving additional support. He would also be delighted that the Foundation’s “Summer Surprise” for patients visiting the CF clinic shares his love of Lake George with this community of people he so admired.

*See page 15 for more on this year’s Summer Surprise.*



*Dave helps John Franklin set up a kayak for Emerald Eve’s silent auction.*



*Dave and good friend Dale Dolezal enjoy the program at Emerald Eve.*



THE DONNA M. CRANDALL  
MEMORIAL FOUNDATION

# 19<sup>th</sup> Annual Emerald Eve

*Save the Date!*

**SATURDAY, NOVEMBER 16, 2019**  
**CANFIELD CASINO, SARATOGA SPRINGS, NY**

At this year’s Emerald Eve, the Donna M. Crandall Foundation will celebrate the courage of CF—we hope you will join us!

Interested in attending, being a corporate sponsor, or donating a bottle of wine to the wine raffle, contact Lisa Cheney at [Lisa@CrandallFoundation.org](mailto:Lisa@CrandallFoundation.org)

Interested in donating to the silent auction, contact Terri Snow at [snow43056@aol.com](mailto:snow43056@aol.com)

# Dawn's Room hosts its first visitor



The Donna M. Crandall Foundation is happy to report that after three years of planning, fundraising, and construction, Dawn's Room is "open" for patients at Albany Medical Center! Dawn's Room is a private, hotel-like, hospital room, inspired by Dawn McGuinness. Before she passed away in April 2016, Dawn was the Donna M. Crandall Foundation's guidepost and biggest advocate. Dawn, like many adult CF patients, had to spend several weeks each year in the

hospital. She considered herself blessed to spend her hospitalizations on the Dazian Floor at Beth Israel Hospital in New York City, which has special private rooms that look more like hotel rooms than hospital rooms. Dawn always wished that her fellow CFers back in Albany could have similar rooms at AMC.

The DMCF and its many supporters dedicated much of the last three years to making Dawn's wish a reality. Foundation Board Member Lisa Cheney worked closely with Meghan Baltich and Tom Burns from Blairhouse Interiors and Mike Lopez from Albany Medical Center to complete the plans for the new room. Adjacent to the E5 Living Room, the private room has many amenities and special features, including plank tile floors, dimmer lights throughout, plantation shutters, a closet system, charging station, sleeper sofa, refrigerator, TV, and pictures taken by Dawn at Ocean Grove (the beach town that she loved best). Further, the room has the only private bathroom with a shower on the CF floor (all other patients have to share a single shower on the floor). The bathroom, complete with a barn door and beautiful beach glass tile, has a smooth threshold from the room to make transporting an IV pole easier. Dawn's Room occupants will also receive a custom Donna M. Crandall Foundation throw that matches the room—for comfort during their time in the hospital and at home.

DMCF, thanks to its many supporters and friends, contributed over \$90,000 to build this special space. Officially completed in June 2019, Dawn's Room is a tribute to a wonderful friend and a wish for the comfort and well-being of its future patients.



**UPDATE:**  
**DMCF provides \$30,000**  
**in financial support for**  
**transplant hopefuls**  
**and recipients in just**  
**two years!**

Two years ago at Emerald Eve, Foundation President David Crandall announced the launch of a new program to support CF lung transplant recipients in our area. Since its founding 19 years ago, DMCF has provided \$1,000 to each patient who explores the option of a transplant and \$2,500 immediately after transplant. As of 2017, the Foundation gives an additional \$1,000 to each lung transplant patient annually to assist with the expense of follow-up care. As David reiterated, "we want all local CF patients to know that no matter where they need to travel for their transplant, DMCF is there to help." This expanded transplant initiative has been a huge success—15 Albany Medical Center patients are living today with new lungs, and, in the past two years, the Foundation has provided \$30,000 to those who are exploring or have received transplants.



In her own words . . .

## Rachel Clayton on her stay in Dawn's Room and how the Donna Crandall Foundation helps

*What were your favorite features of the room?*

My favorite feature in the room was definitely the fact that it has its own shower. It felt so freeing to just shower whenever I wanted and not have to worry about waiting for the ones down the hall to be free. It was such a boost in morale to be able to do that. The bathroom in the room is also gigantic and looks like what someone would have in their house!

*What is most difficult for CF patients during an inpatient stay, and how does the Foundation make those struggles a little easier?*

I think the most difficult thing about an inpatient stay for me is when I have to be there during a holiday. However, when the Foundation puts holiday themed things in the gift bags they give to patients, that helps cheer me up. Some of my favorite holiday things have been the marshmallow skewers from the 4th of July themed bag. I use them a lot!

*During the past 19 years, DMCF has tried to come up with ways to support patients and make life a little brighter. What are some of your favorite programs?*

DMCF has been making appointments and clinic visits a little brighter since I was a child. Around the holiday season and during the summer I remember going to clinic visits and there would be a raffle to win some prize money or some holiday cookies. I actually still have a holiday teddy bear from 2000! I put it out every winter.

*What would you tell your friends about the Foundation?*

The Donna Crandall Foundation has been working hard to make CF patients and family member's lives easier for a long time. They do things such as giving gift bags to patients and even paying for private rooms during hospital stays. It's certainly very much appreciated!

*Rachel, you were the first patient to stay in the newly renovated, "Dawn's Room." How did Dawn's Room compare to past rooms you have stayed in during hospitalizations?*

I can't believe I had the luck of being the first person in the room! Dawn's Room is so much nicer than any other room on E5 by far. The beach theme makes it feel much more relaxing, and the blue paint on the walls is just the most beautiful shade I've seen. I loved how private the room felt, especially compared to the rooms that just have an accordion door on one side. Once when I stayed in one of the accordion door rooms, the patient on the other side actually barged into my room while sleepwalking. No risk of that in Dawn's Room!

*Did having a more "luxurious" room make a difference in your stay? How did it make your stay better?*

Having a more luxurious room definitely made a difference. It made a difference for my mom as well. Because I was sicker than usual this past hospital stay, my mom ended up sleeping in the room with me for a couple nights. Having the pullout couch made that a lot easier for her (and me because I would have felt guilty if she slept on the chairs they have in other rooms). It also made it easier to have people, like my family and boyfriend, visit because the room looks a lot less institutional.

Lynn Stackrow received her lung transplant over four years ago, and she shares, "My life has been amazing since having my transplant! I have gone back to work full time and began ballroom dance lessons in the hopes of competing at the Transplant Games next summer at the Meadowlands. I also play pickle ball twice a week, sing in the choir at church, and volunteer with many organizations, including Donate Life AZ and the Transplant Team AZ. I couldn't do all this without the constant and ongoing support of the Donna Crandall Foundation! I miss her and all the others who we have lost to this disease—it is my decision to live well in their honor!"



# The Donna M. Crandall Foun



*Lemon Classic Founders—Mike Utzig, Danielle Utzig, Erin Mark, and Ryan Mark*

## Dawn McGuinness Memorial Golf Event

(a.k.a the Lemon Classic!) raised over \$16,000 at the sold-out event on June 8, 2019. In addition to the spirited round of golf, 104 golfers and guests enjoyed the beautiful day, lunch, dinner, drinks, and many golf challenges, including longest drive, hole in one, closest to the pin, straightest drive, and putting contest. Erin Mark, one of the organizers, shared her personal story of CF and the impact the Donna Crandall Foundation has had on her life. She and her co-founders—Mike Utzig, Danielle Utzig, and Ryan Mark—created this tournament five years ago as a way to give back to the Foundation, and in those years, have raised over \$70,000 for DMCF! They dedicated the tournament to Dawn McGuinness and her wonderful outlook on life. The tournament is affectionately called the Lemon Classic because of

Dawn's philosophy, "When life gives you lemons, make lemonade!" Save the date for next year's golf event—**June 13, 2020!**



*Ben, Bobby, Claudia, and David Crandall ready to golf!*



## Ryan's Run

The ninth annual Ryan's Run was on July 20, 2019—an extraordinarily hot day! Approximately 50 people participated in this annual motorcycle ride that honors Ryan Lee MacDonald, who had CF and passed away in 2009 at the age of 23.

Because of the extreme heat, they cut the distance in half, but riders still traveled over 50 miles! They enjoyed a raffle, food, and a band at the RC Sportsman Club in Hannacroix at the end of their ride. The first eight Ryan's Run events raised over \$30,000 for the DMCF.

## Wild Turkey Summer Swim



Organized by Caroline McGraw, the Niskayuna Wild Turkeys held their thirteenth annual Swim and Dive Team Swim-A-Thon in July 2019 and raised over \$2,000 for DMCF! Swimmers received pledges for swimming and diving; the team also held a bake sale and silent auction to raise funds.

DMCF received \$500 in **Sarah Ritchie-Crowther's** name as the SEFCU Top Volunteer with Distinction!

## The Shaker Junior High Swim Team,

with their coaches Leslie Archer and Heather Daniels and Shaker student Jenny Seo, organized a Carry-A-Bead fund-raising event to benefit the Donna Crandall Foundation. The team raised over \$200!



# Foundation Thanks Its Supporters!



Thank you to **Keara McCarthy**, mom of a CF pediatric patient, for putting together Halloween goodie bags for pediatric patients, which included Halloween toys, stickers, pencils, hand sanitizer, tissues, candy, pretzels, and a fun little Halloween joke to bring some cheer.

Thank you to **Paige Catalfamo** and **Kiera Dubois** for the superhero Christmas goodie bags for holiday clinic visits!

Thank you to **Terri Nugent** for sharing her amazing talent with the Foundation. She gifted 10 gorgeous, new Christmas stockings, which DMCF used to decorate the E5 Living Room and also filled to give the December gift bags a special holiday look.

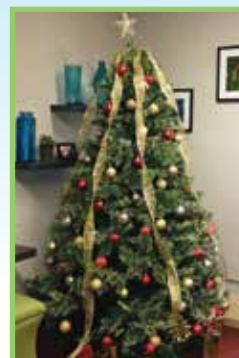


Thank you to siblings **Sophie** and **Alex Snow** (Donna Crandall's great niece and nephew) and their neighborhood friends for organizing a lemonade and (temporary!) tattoo stand to raise \$49.50 for the Foundation!



Thank you to **Corey, Serena, and Ryan Kirkpatrick** for stocking the DMCF Living Room with a variety of snacks on behalf of the Foundation.

Thank you to **Leo and Maryanne Breton** for delivering magazines to the E5 Living Room every month and for beautifully decorating it every year for Christmas.



Thank you to **Annette Phelps** for shopping for newly diagnosed babies and **the Fritz family** for shopping for gift bags. If any readers are interested in helping to shop for the bags or seasonal treats, please contact Lisa Cheney at [lisa@crandallfoundation.org](mailto:lisa@crandallfoundation.org).

Thank you to **Linda Carotenuto** for sharing her talent by making lap blankets to add to our gift bags!

Thank you to **Katie Nagy, Dan Crowther, Sarah Ritchie Crowther, and Paige Catalfamo** for sharing their photography talents at our events.

## Contributions honoring loved ones

We are honored and humbled that families and friends celebrating joyous occasions or honoring lost loved ones consider donating to The Donna M. Crandall Memorial Foundation. Such generosity makes it possible for us to reach out to others in need. Recent contributions commemorated the following:

### Contributions to Honor ~

- Dr. Paul Comber's birthday
- Carolyn Nichols' birthday
- 65th Wedding Anniversary of George and Jean Potanovic
- Tommy Potanovic's birthday

### In Memory Of ~

- Mary Breton
- David Carroll
- David Crandall (see article on page 1)
- Joseph Robert Eckert
- Margaret Morrell
- Tim Strang
- Sheila Taylor
- Stephen Tholepins
- Codey Walsh

# *Emerald Eve 2018 once again sets a fundraising high!*

Always a sparkling, fun-filled evening, the eighteenth Emerald Eve raised a record-breaking, \$157,000 for the Donna M. Crandall Foundation! More than 380 friends of the Foundation gathered together at the Canfield Casino on November 17, 2018. With live music provided by the Scott Bassinson Trio and special guest Ben Crandall (Donna's nephew), guests enjoyed drinks and a delicious dinner while browsing the incredible silent auction items.

The silent auction—one of the evening's highlights—featured many incredible getaways, tickets to sporting and entertainment events, jewelry, artwork, themed baskets, and more. Organized by DMCF board member, Terri Snow, the silent auction included trips to Anna Maria Island, Florida; Charleston, South Carolina; Ogunquit, Maine; and Lake George, New York. Lucky winners also took home tickets to Broadway's *To Kill a Mockingbird*;

Dave Matthews Band; and *Waitress* at Proctors. Sports fans scrambled to win tickets to see favorite teams—the Yankees, Mets, Red Socks, Notre Dame, Giants, and more!

The live auction was thrilling as guests outbid each other over several overnight adventures, including a weekend with the Crandalls at Lake George; a night out featuring Elton John tickets, a three-course chef's tasting menu at Yono's, and an overnight stay in Albany; and a *Hamilton* date night with tickets to the show, a three-course dinner for two with wine pairings, and an overnight stay at the Stockade Inn! In addition to the silent and live auctions, guests participated in both the traditional Emerald Eve raffle—with the chance to win either \$100, \$500, or \$1,000—and a wine raffle, in which every participant took home a bottle of wine.



1. Emerald Eve guests watching the program speakers and annual video. Photo by Dan Crowther.
2. Ben Crandall, Donna's nephew, performs. Photo by Dan Crowther.
3. Ryan and Erin Mark. Photo by Erin Nagy.

## *Burke P. Bear Recipients Honored*



Every year at Emerald Eve, the Donna M. Crandall Foundation recognizes some of its special friends with "Burke P. Bear Awards," our small way of acknowledging their dedication to the Foundation and people with cystic fibrosis. At the 2018 Emerald Eve, we were delighted to present Craig VanCott, Susan VanCott, Meghan Baltich, and Tom Burns with Burke Bears.

**Craig and Susan VanCott** have supported the Foundation since its very beginning, 19 years ago (Susan is David and the rest of the Crandalls' first cousin!). They are members of our Honorary Committee and steadfast enthusiasts, who have shared our story and mission countless times. To further share the Foundation's message, the VanCotts also always buy a table at Emerald Eve so they can invite friends to come for the evening and see what a special group the Foundation, its supporters, and the cystic fibrosis community are.



The evening celebrated those who have stood by their loved ones with CF and have been their anchor during stormy times. To recognize the family and friends who make a difference every day, guests received a custom anchor pin designed by Kevin Kim. The 2018 video highlighted the Potanovic/Wellington family. Friends of the Foundation recognize the name Potanovic thanks to Tommy Potanovic's beautiful (and popular!) photographs always up for auction at Emerald Eve. With three family members diagnosed with CF, the video detailed how CF affected their families, shared their perspectives on life with CF, and described how the Foundation has impacted them.

Erin and Ryan Mark, along with Mike and Danielle Utzig, presented the trophy to the winner of the Dawn McGuinness Golf Event. Ryan Mark eloquently shared his thoughts on being the spouse of someone with CF. He shared the challenges many face and the benefit the Foundation provides. He shared his worries and his incredible pride in his wife Erin who never lets the disease slow her down. Erin then pulled the CF patient winner for the First Annual "Erin's Salty Getaway." Cayden Egelston was the proud winner, and his family enjoyed their trip to Long Beach Island, New Jersey in August 2019! The golf committee chose to use part of the proceeds toward this surprise giveaway because Erin knows first hand the benefits of time at the beach—the salty air makes breathing easier. Donna Crandall would be thrilled: she always said she felt better at the beach. After returning from their trip, Cayden's mom, Tanya Egleston shared, "We are blessed to have been the lucky winners of Erin's Salty Giveaway! Our vacation was everything we all needed—time to enjoy each other's company, be goofs, and be freed of the everyday chaos. We enjoyed the beach daily and took it all in while we could, especially with the mosquito-free, nighttime air."

In one of the most memorable moments of the night, Tina Hamilton, in her speech to present the donations raised during Ryan's Run, asked all guests to raise their glasses to all CF patients waging the battle and to remember the journey of those who had lost their battles.

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To watch the 2018 Emerald Eve video, visit

[www.donnacrandallfoundation.org/2018-emerald-eve-video/](http://www.donnacrandallfoundation.org/2018-emerald-eve-video/)



1.



2.



3.



4.



5.

1. Mr. and Mrs. Brian Morris Dey. Photo by Erin Nagy.

2. Mary and Tommy Potanovic. Photo by Erin Nagy.

3. Erin, Linda, Brittany, and Bob Hedderman never miss an Emerald Eve. Photo by Dan Crowther.

4. Tina Hamilton and David Crandall raise their glasses. Photo by Dan Crowther.

5. The Utzigs and Friedsons. Photo by Erin Nagy.

**Meghan Baltich and Tom Burns** are both interior designers at Blairhouse Interiors who have worked closely with the Foundation to create beautiful spaces at Albany Medical Center—the E5 Living Room and most recently, Dawn's Room. As a 100% volunteer organization, the DMCF benefits greatly from in-kind support of talented people like Meghan and Tom. They have volunteered untold hours to make these renovation projects not just happen, but also look and function beautifully.

## Burke Bear Winners



Craig and Susan VanCott.  
Photo by Dan Crowther



Tom Burns and Meghan Baltich.  
Photo by Dan Crowther





# *“Project Cookie” spreads joy for bakers and patients during winter clinic visits.*



1.



2.



3.

One of the most beloved DMCF holiday traditions is the delivery of cookie tins to Albany Medical Center. The cookie tin project started 19 years ago in December of 2000 at the Strategic Solutions offices. Employees at the company, owned by DMCF Board Member Lori Jenkins, thought that delivering home-made cookies to CF patients was the perfect small gesture to honor Donna’s love of Christmas. Lori recalls, “We wanted to show how small acts of kindness can impact others. That first year, we thought we would be able to fill about 20 tins, but we had so many cookies that we had to buy more tins! I think we ended up filling almost 50!”

In 2007, Joan and Steve Hart took over managing “Project Cookie.” Joan remembers, “We started organizing the cookie project because, in the early years of the Foundation, there weren’t as many volunteers, so the DMCF board was doing most of the work. We thought that this was something we could do as a family that would help the board focus on their mission of helping CF families, while also teaching our daughters the importance of giving back.”

For the past 11 years, they have organized the cookie donations, packaging, and delivery of cookie tins to Albany Medical Center. The first year they took over the project, they put together about 40 tins. In December 2018, they put together 110!

Joan shares that it has become their traditional kick-off to the holiday season. She sends out an email right before Thanksgiving to past bakers, asking them to participate again and letting them know when the cookie drop-off day is. The Harts usually have the support of 25-30 bakers, some who participate annually. She adds, “Some of our bakers are those who have lost a family member to CF or currently have someone they love facing the challenges of the disease. They’ll share what these cookies meant to their loved one, and it just fills our hearts and reinforces the importance of the Foundation’s work. Our family genuinely looks forward to seeing the volunteer bakers each year, and we get such joy knowing the tins brighten the day of their recipients.”

1. *Joan and Steve Hart at the Lemon Classic 2019.*
2. *Sarah Ritchie Crowther was one of the volunteer bakers and created these works of art for the cookie tins.*
3. *Holiday Truck cookies ready to roll.*





After receiving 360 dozen cookies—that's 4,320 cookies!—on drop off day, the Harts package up the cookies in holiday tins to deliver to Albany Medical Center for the first clinic day in December. Patients with clinic visits or who happen to be in the hospital in December look forward to receiving their own cookie tin.

Sarah Ritchie-Crowther was one of 2018's bakers; she made 100 exquisitely decorated cut-out cookies in honor of her granddaughter, who has CF. Her works of art made the tins extra special. She shares, "I have always enjoyed 'creative' baking. I was known in my children's school for my crazy holiday and party treats. When Keira received a cookie tin at her CF Center appointment several years ago, the family told me I should make cookies for the Donna Crandall Foundation. This seemed like an awesome idea, but two years in a row I missed the deadline (although my co-workers were happy to get the cookies instead)! However, last year I got it done on time with my Holiday Truck cookies! I'm not sure what shape they will take this year, but the ideas are already coming, and I will definitely be getting them in on time again!"



1.



2.



3.

1. Ann Foster and Lisa Noel have helped the Harts put together the tins for the last several years.
2. Marissa and Kaylin Hart decorate cookies in 2015.
3. Cookie tins all boxes up and ready for delivery to Albany Medical Center.
4. A finished tin of cookies!



4.



## Foundation delivers 1,900th gift bag!

The trademark of the Donna M. Crandall Foundation is its generous gift bags delivered to cystic fibrosis patients admitted to Albany Medical Center. In summer 2019, Foundation Vice President Lisa Cheney dropped off the 1,900th gift bag, full of goodies designed to make hospital stays more enjoyable. In addition to a surprise check for \$1,900 (!), the 1,900th bag—a turquoise bag with the DMCF logo to match the color scheme of Dawn's Room—contained the usual treats for patients: a \$100 Target gift card, a \$50 Uber Eats gift card, a beach towel, scratch offs, games, books, snacks, Mike and Ike's (Donna's favorite candy), and UNO cards, in memory of Mary Breton.

Every year the hallmark LL Bean canvas bags get tweaked slightly, both to keep up with the technological trends and also to adapt to patients' ever changing needs. The newest addition to the tote bags is \$50 Uber Eats or Grub Hub gift cards! Getting extra calories is essential for CF patients, so DMCF volunteers thought a change of food venues might brighten spirits. Additionally, since a new Chipotle opened close to the hospital, patients will receive a Chipotle gift card in their bags.

The Foundation, with the help of volunteers Maggie and Mary Fritz, puts together and distributes approximately 100 bags per year. Nineteen years ago, when Donna's family was brainstorming ways to help local CF families, Lori Jenkins came up with the idea of creating little gift bags, recognizing that if the family's fundraising was not successful, they could likely fund a gift bag program on their own. The bags are targeted for the patient type—about two-thirds are for adult patients, who are frequently sicker and in the hospital more than children. The remaining third are distributed to children and newly diagnosed infants. The infant bags always contain special gifts, like a handmade quilt and a Burke Bear, so new CF families know the Foundation is always there with support.

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*If you are interested in shopping for the DMCF bags, contact Lisa Cheney at [lisa@crandallfoundation.org](mailto:lisa@crandallfoundation.org).*

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## DID YOU KNOW?

- There are approximately 30,000 people living with cystic fibrosis in the United States. Most are diagnosed by age 2.
- Most adult CF patients visit clinic 4 times per year, when well. Most pediatric CF patients have 6 clinic visits per year. At clinic visits, a medical assistant checks their vital signs, height, and weight. They then go to an exam room where a nurse verifies their medications. Pulmonary function tests are done to measure how well their lungs are functioning. Often, they are seen by other members of the team, including the social worker, dietician, and respiratory therapist. Then, either a doctor or nurse practitioner performs a physical exam and makes a care plan for them to take home and follow. On the way out, they schedule their next appointment.
- Annual doctor visits are usually more than 2–3 hours long because they need to have a chest x-ray and blood drawn.
- Those living with CF could take up to 30 medications and 4 different nebulizer treatments two times a day. They spend nearly 2–4 hours doing treatment each day.
- It is common for CF patients to have thousands of dollars in non-covered medical expenses each year.
- CF patients need to be at least 6 feet apart from one another at all times so that they do not share harmful bacteria!
- In 1990, the median predicted age of survival for a person with CF was 28, and today it is 47.
- Most CF patients go on to college and earn a degree. More people with CF today are adults than ever before, with families and full-time jobs.
- The oldest person living with CF in the Albany area is 77 years old!
- No other CF center in country has a foundation like the Donna M. Crandall Foundation and the support it provides!



# Summer Surprise shares the love of Lake George with clinic patients



Barbara and Dave Crandall enjoying Lake George



Yetis containing tickets for fun on Lake George!

Every summer, the Foundation likes to remember how much Donna loved summer—and subsequently loathed spending nice, warm days at the CF clinic. The “Summer Surprise”—now in its 19th year—is a small way the Donna Crandall Foundation pays tribute to Donna and makes Albany Med summer clinic visits more fun.

This year, the Summer Surprise honored not just Donna, but also David Crandall, Donna’s father-in-law. In January, Dave passed away at the age of 87. He loved Lake George as much as he loved the work of the Foundation, so CF patients received the gift of Fun on Lake George!

Everyone received a Yeti tumbler; pediatric patients found two tickets to the Great Escape Amusement Park inside, and adult patients discovered two tickets for a cruise on the lake aboard the Minnie Ha-Ha or the Mohican with the Lake George Steamboat Company.

After receiving her “Summer Surprise” at clinic, Barbara Yovine shared, “A gift at CF clinic during the summer is such a treat. Now, I have my own Yeti—not just my son’s! I’m looking forward to the lunch cruise on Lake George! The Donna Crandall Foundation is always very generous.”

From June through August 2019, the Foundation gave away 150 Yetis with 300 tickets inside! “Our dad was one of the Foundation’s biggest supporters. He loved seeing all of the good we were able to do in Donna’s memory,” shares DMCF Board Member Lori Jenkins. “We were so happy to share his love of Lake George with the CF summer clinic visitors this year. From the mountains to the lake air—and the fun of roller coasters at Great Escape!—we think everyone will fall in love with the lake, just like he did.”



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