

The Donna Crandall FOUNDATION NEWS



PROVIDING PROGRAMS AND SERVICES THAT POSITIVELY IMPACT CYSTIC FIBROSIS PATIENTS. • WWW.DONNACRANDALLFOUNDATION.ORG



1,000th Gift Bag
MEANS COUNTLESS SMILES!

Seven-year-old Lacey Meridith was the lucky recipient of The Donna M. Crandall Memorial Foundation's 1,000th gift bag while being hospitalized in June. It was Lacey's first time at Albany Medical Center and her first gift bag. Her extra-special tote contained a check for \$1,000 in addition to the customary gift card to the hospital cafeteria, in-room TV/ phone service, parking passes, a portable DVD player, DVDs including *Despicable Me*, *Annie* and *Charlie and the Chocolate Factory*, books, nail polish, craft projects, Uno cards, a Crazy 8s game and snacks. The first-grader, from Sidney, NY, loves soccer, dancing and horses.

Lisa Cheney recognized with Jefferson Award, The "Nobel Prize" of Community Service

Lisa Cheney, Donna Crandall's sister-in-law, was honored recently with the American Institute for Public Service's Jefferson Award in recognition of ordinary people who accomplish extraordinary things.

Nominated by several local CF families for her work with The Donna M. Crandall Memorial Foundation, Lisa was one of seven Capital Region residents to achieve 'medalist' status, selected from a pool of 18 finalists. Awards were presented at the Century House in Latham.

Considered a "Nobel Prize" for community and public service, Jefferson honorees are recognized for volunteering their time, energy, talents and experience to improve the lives of others and strengthen the organizations they support.

One of Lisa's nominators wrote: "Anyone can make a promise. The hard part is keeping it, unless you are Lisa Cheney. Lisa promised her sister-in-law Donna Crandall, who died in 2000 from cystic fibrosis (CF), that she would never be forgotten...Lisa dedicates herself to helping CFers focus on their health instead of the every-day worries associated with their disease, and in so doing, more than keeps her promise: She changes lives."

The late Jacqueline Kennedy Onassis and U.S. Senator Robert Taft, Jr., created the national Jefferson Awards in 1972 to highlight the works of unsung heroes and as a call to action for volunteers in local communities. In 1977, the Jefferson Awards embarked on a media partnership with local newspapers and television stations to highlight community service in America. Capital Region sponsors are St. Peter's Health Care Services, NewsChannel 13 and the *Times Union*.

Past winners of the award include Nancy Brinker, founder of the Susan B. Komen Foundation, Elizabeth Dole and Oprah Winfrey.



Pictured at the Jefferson Awards ceremony are (left to right) Stephen P. Baboulis, Vice President and General Manager for NewsChannel 13, Lisa Cheney, George R. Hearst III, Publisher of the *Times Union*, and Steven P. Boyle, President and CEO of St. Peter's Health Care Services.

Photo by Times Union.

2ND ANNUAL RYAN'S RUN

Poker Run Honors Son

In 2004, Tom and Tina Hamilton from Coeymans began supporting cystic fibrosis and The Donna M. Crandall Memorial Foundation when they volunteered their time as DJs at the Get Rev'd Up for CF benefit poker run. Tom had grown up on the same street as the family running the event but had never known of their tie to CF until then.

Ironically, a few years later, Tina learned that her son, Ryan MacDonald, had CF. In 2006, Ryan was 20 years old when a flu he just couldn't shake finally landed him in the emergency room with the pneumonia that led to his diagnosis.

Although Ryan was born premature and was diagnosed with type 1 diabetes at the age of 7, CF was not suspected. According to Tina, "this was frustrating because some doctors thought his diabetes was not being managed well." Even though he had an enormous appetite, "He would eat and eat, but he could just not get up there into his growth percentile," she explained. In hindsight, it made sense: This is a classic symptom of CF.

Once diagnosed, Ryan was hospitalized quite a bit. He became resistant to many antibiotics and his situation was made even more precarious because he would get infections at the cannula sights of his insulin pump.

Ryan's family was re-introduced to the Foundation through John Nash, the social worker at Albany Medical Center who works as a liaison with patients. Extended-stay parking passes, gift bags and using the computer in the E5 patient lounge were some of the Foundation-provided perks that Ryan appreciated most.

"Ryan was a very goodhearted person, and could be very stubborn at times," Tina recalls. "He loved to cook and just wanted to be without all these health issues, which weighed very heavy on him."

His favorite things were not things at all, but his grandparents, Oma & Opa; his Springer Spaniel-lab Travis (who happened to die the same year as Ryan), and his girlfriend Janet and her kids, Decker, Jayson, Dezamora and Damaz.

Ryan's Run, the poker run organized by Tina and Tom, has "become my 'therapy,'" Tina said, and a way to honor Ryan by raising funds in his name. "We will forever be grateful for the Foundation." To date, the Ryan's Run Donation Fund has raised \$4,300.

Set for Saturday, August 20th at Ravena Coeymans Sportsman's Club, the event will include all-you-can-eat-and-drink all day, a pig roast, entertainment by DJ Billy Hardy and live music by the Nite Train. For more information or to sign up, email rymac@brickrow.net or call (518) 756-9312. Donations may also be made through the National Bank of Coxsackie, Faith Plaza, Ravena, NY 12143.



"We will forever be grateful for the Foundation."

~ Tina Hamilton

Pictured above: Ryan MacDonald (center) is pictured with Grandmother Ana Urizar (left) and his Mom, Tina Hamilton; Tina presents a check from the first Ryan's Run at Emerald Eve 2010.



Mr. and Mrs. Kevin Luibrand and guests.



Leslie Kassel, Heather Daniels, and guests.



Caroline Crandall and Cece Carsky-Bush sell raffle tickets.

2010 EMERALD EVE HIGHLIGHTS

Emerald Eve Continues Tradition

The Donna M. Crandall Memorial Foundation is pleased to confirm that the 11th annual Emerald Eve celebration is set for Saturday, November 19, 2011, at the Canfield Casino in Saratoga Springs.

"We have considered changing venues to accommodate our ever-expanding guest list," explained David Crandall, Foundation President. "But after much consideration, and more importantly, based on the feedback of those who have been with us year after year, we have decided to carry on our tradition at the Casino."

Feedback from attendees indicated that the Casino's atmosphere and unique dining experience, which includes passed hors d'oeuvres, carving stations and an extravagant raw bar, facilitates socializing and interaction among guests, making the evening's party atmosphere special. The wine raffle, which made its successful debut last year, will return, and for each \$20 chance, guests can take home wine valued from \$10-200. Increased valet parking service will also be available. Thanks to the meticulous care and organizational skills of Terri Snow, the Foundation strives to provide an exceptional selection of silent and live auction offerings. Those who wish to contribute items to be included are encouraged to contact Terri at snow43056@aol.com.

UP CLOSE & PERSONAL

WITH **DAVID AND JEANNE VONDELL**



Newlyweds are grateful for help, optimistic about future

They say that nothing else matters when you can't breathe. People waiting for lung transplants can tell you just how true that is.

David Vondell, who was recently put on the active lung transplant list at New York-Presbyterian/Columbia University Center for Lung Disease and Transplantation in New York City, said, "I can't wait to breathe again and not carry the oxygen tanks around."

"It's a lot of emotions," said his wife of just seven months, Jeanne.

"It's a waiting game," chimed in David, 40.

It's also a lot of work, especially for this couple, who live half an hour from the Canadian border in Malone, NY. A one-way trip to the transplant center in New York City takes about 6-1/2 hours, and it is about 3-1/2 hours to the CF clinic at Albany Medical Center, where David is also treated.

The transplant process, as it turns out, is not a matter of just sitting and waiting for "The Call." Following initial consultations with the transplant team, which includes a pulmonologist, surgeon, coordinator, social worker, psychiatrist and financial counselor, each patient undergoes an extensive battery of tests and procedures to obtain baseline information.

An important part of that preparation includes traveling to the transplant center at least once a month for a consult, procedure, test, or to attend one of the series of mandatory seminars offered. This can be taxing for even healthy people – imagine making these exhausting trips with a lung capacity of between 23 – 27%. Just walking from the hospital parking garage to the physician's office is an uphill challenge – literally. The process is time-consuming and expensive.

The Donna M. Crandall Memorial Foundation recognizes this and one of its missions is to alleviate the financial burdens and stress associated with the transplantation evaluation process.

"It is amazing how tolls, gas, eating on the go, parking, and the cost of a hotel in New York City can add up," said Lori Jenkins, Foundation Treasurer. "It's a lot on families who are already burdened by their circumstances."

The Foundation, Jeanne noted, has provided substantial financial support during the process that has "helped us in a big way. These are very caring people. It is amazing what people will do to help you."

"I don't know where we'd be without them," agreed David.

The middle of three CF children born to Mary and Ken, David and his siblings grew up waterskiing on Lake Chateaugay. He loved basketball

and soccer. Today, David's brother Bobby is 43 and lives in Fort Covington with his wife, Erin, who also has CF. In March of 2010, their little sister Suzanne Bilow (who was a guest speaker at Emerald Eve 2005) died due to melanoma five years after her double-lung transplant.

When Jeanne and David first met 15 years ago, he was an athletic, healthy correctional officer. He also owned Lake Chateaugay's Owlly Out bar and restaurant for 17 years, until January. In spite of being diagnosed with CF at birth, David was never hospitalized until a couple of years ago, when he started declining a bit. Jeanne explained, "At first he was hospitalized once or twice a year. Now, he is in the hospital every few months, for weeks at a time."

Last year he was in the hospital for most of the summer. In November, they traveled to Hawaii, accompanied by nine of their closest friends and family members, to be married. By December he was back in the hospital, where the newlyweds celebrated Christmas and the New Year.

"The Foundation tries to make it easier for you when you're in the hospital," Jeanne recalled, pointing out that at Christmas the Foundation had a steak dinner — complete with silverware, tablecloth and champagne — delivered to David's room so that they could enjoy a nice holiday meal instead of hospital fare. "It was really nice and made the holiday special."

In addition, the Vondells and other families who travel from far away for their care benefit from the Foundation's arrangement with the Hilton Garden Inn, where spouses and family members can stay. Hotel accommodations are a welcome alternative to sleeping on cots or sleeper chairs provided in patient rooms.

While the couple waits for the call that will change everything, David goes to pulmonary rehabilitation three times a week, and spends three or more hours a day doing nebulizer treatments and chest physical therapy. He keeps busy around the house watching M*A*S*H reruns and caring for their two cats. David, who Jeanne claims "eats for a living," spends time cooking, too, in order to keep up his weight.

When the call comes they will be transported via a Cessna Cardinal C-177 from Malone Airport to Teterboro Airport in New Jersey, courtesy of Wings of Life Over Malone, a free service provided by a local pilot and jewelry store owner, Victor Fellion.

After transplant, Jeanne and David are most looking forward to life without machines and oxygen tanks. Very simply, Jeanne said, "We are looking forward to life getting back to normal."

Girl Scouts help make patient lounge a cozy respite



People with cystic fibrosis have many names for the time they spend in the hospital – a clean out, a tune-up, time in the hole, a vacay – and some we can't print here. Whatever they call it, some CF patients spend weeks at a time, several times a year, on Albany Medical Center's E-5, the floor where adults are treated. Inspired by Donna Crandall's many 'visits', the Foundation has refurbished a patient lounge there to resemble a cozy family room.

To make the lounge even homier, every month Girl Scout Troops 1797 and 1175, from the Guilderland/Rotterdam area, decorate the room to reflect the holiday or season. These two troops consist of girls that are Brownies, Juniors, and Cadettes, ages nine - 12.

Troop 1797 Leader Christine Keating, a respiratory therapist with Anthem Health Services, was introduced to the Crandall Foundation while working at the Pediatric CF Center at Albany Medical Center in the early 2000s. "I first met Lisa Cheney when the idea of the Foundation was conceived," Christine recalled. "I was in awe of the concept and content of the gift bag program. It has been a pleasure working with them and watching how they have grown."

To help the girls understand life with CF and what the Foundation does, Christine shares with them the same videos shown at each Emerald Eve so that "they have a real sense of the Foundation, the kind of work it does, and how it helps people," she said. "They are very compassionate and have a true appreciation for the hardships sick people face."

Whether it's spring, summer, winter or fall, decorating the lounge demonstrates their genuine effort to make life better for CF patients. Each month the troops, Christine and her co-leaders choose a theme, set a plan and go shopping to select themed decorations, snacks and surprises to complete their project. Their favorite places to go are Party City, The Christmas Tree Shop and various dollar stores. Expenses are reimbursed by the Foundation.

"This is a perfect example of how we have the funds to support programs, but not always the manpower or time to carry them out ourselves," said Lori Jenkins, Foundation treasurer. "We appreciate our creative and thoughtful volunteers and are happy to provide funding for special projects."

In addition to sharing their decorating skills, the Girl Scouts have sewn squares used to create quilts and made chocolate lollipops for clinic visits.

This year the Foundation installed a beautiful hardwood floor (see picture, bottom left) to replace the rug and will update some of the furnishings. In addition to comfy furniture, and artwork reflecting Donna's favorite vacation spots (Lake George and the Adirondacks), the lounge has a microwave oven, mini refrigerator, PlayStation, flat-screen TV and DVD player, a selection of DVDs and electronic games, Wii fit, and a computer with printer. "We hope it offers a taste of home, a change of scenery and a pleasant alternative to a patient room when guests come to visit," said Lori.

Pictured above: Girl Scout Troop Leader Christine Keating (left) is pictured with her daughters Victoria and Emma and mother Terri Fazio, who, together with Troops 1797 and 1175, decorate the patient lounge every month.

NISKY SWIMMERS MAKE A SPLASH

The Town of Niskayuna's Swim Team, known as the Wild Turkeys, hosted its annual Swim and Dive-A-Thon last summer at the Town Pool, with 30+ swimmers raising \$1,685 for The Donna M. Crandall Memorial Foundation. Organized by Coaches Katie Dartt and Elizabeth Held, the evening was a fun one, complete with pizza, soda and ice cream donated by local businesses.

"As early as sixth grade, Elizabeth was well-organized and already helping numerous charities," noted her former middle school principal, David Crandall. "She continues to do so, and her dedication has helped raise more than \$5,000 for the Foundation over the past five years."

Elizabeth, who will be a senior at Bryn Mawr College in the Fall, was inspired by Donna Crandall's story at a young age, and said, "I have so much respect for the Foundation. It's a group that does a lot of good and I've really enjoyed working with them. I've loved watching the swim-a-thon grow from just three participants to what it is today. I also enjoy getting the kids excited about helping their community."

Since Elizabeth has taken on a summer assignment at North Carolina's *Gaston Gazette*, her brother Michael will take over her coaching duties at the pool, working with Katie to keep up the tradition.

"I'm really happy to leave the event in Katie



Seven-year-old Niskayuna resident and "Wild Turkey" Mary-Margaret Russo, whose aunt has CF, takes a deep breath before continuing her lap.

and Mike's hands. There's no one I'd rather see take over something I put a lot of time and effort into."

The Swim-A-Thon is set for July 29th. For more information, call (518) 381-6384.

2010 BURKE P. BEAR RECIPIENTS HONORED



Dr. Jim O'Brien

Dr. Jim O'Brien of Loudonville and Richard Flaherty of Saratoga Springs were the recipients of the Foundation's Annual Burke P. Bear Awards, announced at the 2010 Emerald Eve celebration. Dr. O'Brien is Director of Cardiac Arrhythmia Services at Capital Cardiology Associates in Albany and Mr. Flaherty is the President and CEO of First Cardinal LLC in Latham. "Long-time friends of our family, Jim and Rich heard our story and believed in our mission. For the past decade they have been generous and reliable sponsors, both

on corporate and personal levels," said Board Member Bob Crandall. "Year after year, we continue to be amazed by the kindness of others who make it possible for us to do what it is we set out to do."

Special guest presenters were Bob and Linda Derr, parents of the young man who inspired the Boyd's Bear Company to create Burke P. Bears 13 years ago.

"My wife Linda and I appreciated the opportunity to celebrate with The Donna M. Crandall Memorial Foundation. They provide a much-needed service in helping individuals and families affected by CF. We wish all CF organizations would follow their example," said Mr. Derr. While research money will always be necessary, Mr. Derr also pointed out that "all the research money in the world won't help someone who needs something — whether it's an air conditioner, CF-related equipment or financial help — to live a good quality of life today."

The Donna M. Crandall Memorial Foundation has chosen the collectible plush bear as its "trophy" to honor extraordinary supporters because it represents hope and commitment within the CF community.



Richard Flaherty



David Crandall (left) with Linda and Bob Derr at 2010 Emerald Eve.

Annual summer project means fun in the sun: ORLANDO VACATION TO BE GIVEN AWAY!



Knowing that there are lots of things patients would rather do than go to CF clinic during the summer, each year Donna's nieces and nephews organize a special surprise to help make appointments more endurable. And this year's summer give-away is even more exciting than usual! Kaitlyn and Sarah Cheney are spearheading the project, which features manila file folders containing \$25, \$50 or

\$100 KeyBank MasterCards patients can use for something fun – whether it's ice cream, tickets to the movies or admission to an amusement park. What's more, 20 lucky recipients will also find a Florida Trip Finalist card in their file. On September 10, one of the finalist cards will be selected for a grand prize trip for four to Orlando, Florida. Steve and Joan Hart, dear friends of The Donna M. Crandall Memorial Foundation, have donated Southwest airfare and a two-bedroom condo at the Reunion Resort in Orlando. The Foundation will also provide tickets to Disney World, Sea World and MGM Studios, along with a \$2,000 check for spending money.

Pictured above: Kaitlyn and Sarah Cheney organize the Summer Project.

COMMUNITY SUPPORT

The Donna M. Crandall Memorial Foundation would like to extend its gratitude to the many community based organizations and clubs that help us make a difference, including:

Jill Dougherty and Charlotte Hooper, who organized the Albany Starfish Swim Club's Ninth Annual Swim Mania competition at Niskayuna High School in January, raising \$4,600. To date, the club has raised over \$53,000 to benefit the Foundation.

The Shaker Modified Swimming and Diving Team, coached by Leslie Kassel and Heather Daniels, which raised \$982 at its annual Mile Challenge.

Schalmont Middle School's Sabre Service Club, led by Math Teacher Lorinda Gandrow, which created quilt squares to be assembled into quilts for CF patients and made chocolate lollipops for clinic visits.

Teacher Sarah Norton and the children from Veeder Elementary School in South Colonie, who collected \$350 from their Penny Harvest.

Amy Bellcourt, whose seventh-grade youth ministry class at St. Helen's in Schenectady wanted to bring comfort to people battling an illness. The students held a bake sale to raise funds to purchase supplies to make fleece blankets and worked on their project at the end of each class. Pastor Father Bob Longobucco blessed the blankets, which will be given to CF pediatric patients treated at Albany Medical Center.

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Thank You

TO OUR EMERALD EVE SPONSORS

EMERALD:

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SAVE THE DATE

11th Annual Emerald Eve
Saturday, November 19 • 7-11 p.m.
Canfield Casino, Saratoga Springs

The evening will celebrate the Foundation's 11th Anniversary and feature elegant carving stations prepared by Classé Catering, entertainment by The Tequila Mockingbirds and a silent auction. See inside for details!

IN MEMORIAM

The Donna M. Crandall Memorial Foundation gratefully acknowledges the generous donations made in honor of the CF community, including:

\$1,000 made in memory of Nathaniel Hammond from Lewis, NY who died in 2007 at 16 years old...The family of Ravena's Jamie Wiseman Mormile took up a collection for the Foundation, raising \$350 instead of exchanging Christmas gifts. Jamie died in 2010 at the age of 29....\$150 in honor of Patricia Backus from Schaghticoke... \$140 in memory of Stephanie Jones from Poland, NY.



In lieu of flowers, \$1,300 was raised in honor of Edward M. Potanovic (left), father of Schenectady resident and CF patient Tom Potanovic.

In his own words...

A message from scholarship recipient, Jesse Bly, a Grafton resident and recent Berlin Central School District graduate:



Jesse Bly and his girlfriend Leandra Kneeland.

“I was diagnosed with Cystic Fibrosis at three years of age. Since then my parents, family, and friends have been mostly supportive. One thing I will never forget is the kindness extended to me by this wonderful foundation. Before the age of 13 I had multiple surgeries to remove my tonsils, adenoids and polyps from my sinuses. I also had surgery to correct a lazy eye. EVERY time I received a care package from the Donna M. Crandall Foundation. The Foundation is nothing short of amazing. Now that it's time to graduate high school I have been selected to receive a scholarship! I am going to be attending Hudson Valley Community College's auto mechanic program, as I aspire to be a mechanic. The foundation has helped to make this educational goal easier. I want to say thank you from the bottom of my heart to all involved. Your efforts are more than appreciated. This means a lot to my family and me. It's really a wonderful thing and will never be forgotten.”

COMMEMORATIVE CHARMS AVAILABLE

To commemorate The Donna M. Crandall Memorial Foundation's 10th anniversary and as a way to say "thank you" for making a difference in their lives, patients commissioned Cindy Crouse, jewelry designer and owner of Refined Designs Original Fine Jewelry in Voorheesville, NY, to create a pendant reflecting the Foundation's logo. Pendants are available in silver or gold and prices vary based on the cost of each metal, but average \$60/silver and \$160/gold + tax. Chains are available. Visit www.refineddesigns.com or call (518) 765-3750 for more information.

