

Love LETTER



Leaving a Legacy of Love

“A legacy isn’t leaving something for people, but leaving something in people.”

Early this year, Special Love families said a difficult goodbye to Tom Baker, a gentle and caring man who with his wife, Sheila, founded Special Love in 1983. The couple lost their 13-year-old daughter, Julie, in 1975 after a short battle with lymphoma. They turned their enormous grief into something positive: Special Love.

The Bakers had read about a camp in upstate New York that catered to children with cancer and wanted to provide that same opportunity to children like Julie in the Greater Washington area, so Tom approached the National Cancer Institute, where Julie had been treated, as well as the Northern Va. 4-H Center to partner on the



Tom and Sheila Baker, 2015

Thank you, Tom Baker, for your extraordinary vision and caring (1938-2018)



Special Love’s first Camp Fantastic in 1983 hosted 29 campers. Tom Baker (right) and then NOVA 4-H Center Director John Dooley led it.

week-long Camp Fantastic. After much planning, the first camp for children with cancer debuted in 1983, hosting 29 campers.

Tom and Sheila already knew that “when a child gets cancer, the whole family gets cancer,” so it didn’t take long for Special Love to host its first family weekend, an opportunity that was unheard of in those days. More programs quickly followed, with young adult programming and the siblings-only BRASS Camp, ultimately to offer year-round events. Financial assistance also was quietly added to Special Love’s mission through both the Emergency Relief Fund and the Kay-Moore Scholarship Fund.

Tom once said, “For me, camp is the one place where kids with cancer and their families can truly rest, get away from all the troubles and have a good time.”

At Tom’s funeral, Special Love’s Senior Director of Outreach and Programs Dave Smith said, “Through Tom’s own courageous personality, he taught us it’s okay to act silly, especially when it brings a smile to a child with cancer. And he taught us it’s okay to show people we care, because that’s why we’re here, to care for each other.”

Tom left an indelible legacy of Special Love for everyone who knew him – one that will last for generations to come. How How, Tom Baker!

A GUARDIAN SCHOLAR

College Student Jesse Smith Learned “Grace, Gratitude, and Grit” at Camp

At 19 years old, Jesse Smith has the world in front of him. He’s on course to earn his associate’s degree in Fire Science Technology from Reynolds Community College in Richmond next year and to become a career firefighter – his dream for many years.

“Beating childhood cancer is more than just beating a disease. It’s about beating a whole series of setbacks.”

But Jesse’s path hasn’t always been so clear. When he was four, the Chesterfield, Virginia, native was diagnosed with acute lymphoblastic leukemia. He underwent treatment for more than two years at then the Medical College of Virginia in Richmond. But the

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Jan Bresch Named Special Love's Executive Director

Special Love welcomes Jan Bresch, who has joined the organization in the newly created role of Executive Director, as Dave Smith decided to follow his passion for outreach and programs. Jan is responsible for leading all aspects of Special Love's mission to support children with cancer and their families.

Jan joins Special Love after spending the past 15 years as the Executive Vice President and Chief Operating Officer of the Prevent Cancer Foundation. Prior to her time at the Foundation, Jan was the Director of Development and Public Relations for the Children's Inn at the National Institutes of Health, and has served as an advisor for other non-profit organizations such as Stupid Cancer. She has also served as a member of the

Special Love Board of Directors for the past six years and worked closely with Dave in his role as CEO.

"Working and advocating for children and families has long been the core of who I am,"

"Working and advocating for children and families has long been the core of who I am."

Jan said. *"I'm excited to have the opportunity to work with Dave and the Special Love team to bring joy and comfort to our families."*

For the past 30 years, Dave has been the driving force behind Special Love's delivery of unique and essential programs in support of families dealing with childhood cancer. In his new role of Senior Director, Outreach and Programs, Dave will lead the organization's efforts to expand and enhance outreach and programs to better serve our families.



Dave shared that *"Jan's familiarity with Special Love and her extensive connections within the pediatric cancer world will help Special Love expand our community of support."*

Welcome, Jan!

Reach out to Jan via email at jbresch@speciallove.org or 888-930-2707. She's eager to meet Special Love's families and many supporters.

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A Salute to Buddies at Fantastic Friends Weekend

An important — and sometimes neglected — part of a pediatric patient's cancer recovery is maintaining joyful, supportive friendships.

When Tom and Sheila Baker looked back at their late daughter's cancer journey, they recalled her friends were unsure how to react to

her diagnosis. Her classmates were afraid to include her in activities, and they eventually stopped calling and visiting. *"In some ways, she was abandoned,"* Tom once said. Fantastic Friends Weekend grew from that need to hold on to this vital network of support.

This July, the weekend once again was bustling with "besties" doing what best

friends do at camp: swim, play kickball, eat huge amounts of pizza, relax, roast marshmallows over a campfire, tell stories — and laugh, a lot.

"Besties" do what best friends do at camp: swim, play kickball, eat huge amounts of pizza, relax — and laugh, a lot.

Thanks to the Danny and Julie Funkhouser Fund for generously sponsoring a portion of the weekend — and for taking the time to join these special campers at SplashDown Waterpark on Saturday and around the campfire that night.



A MOM'S LETTER

"Dear Special Love,

Your love is never ending. We feel your love as you all have gathered around us in our time of need.

Here's another example of the special love magic I want to share with you ...As we were explaining to our daughter about feeding tubes, trying to be as gentle as we could, she jumped in with, 'Oh, I know that. My friends at camp have those. Their food goes through a tube. I've seen them in noses and tummies.'

Being at Camp Fantastic is not only so fulfilling for her soul but the knowledge the campers gain is just amazing. And even though we never ever wanted to be where we are today, things are less scary for our daughter as she knows other kids who have them and saw them out having fun, too. Thank you so very much for this."



Calendar Alert: Putting the "Fun" in Fundraisers

Join us at these fundraisers and spread the word!

August 23-26 | 21st Comcast Outdoor Film Festival for NIH Charities | Four family films this year: Coco, Black Panther, The Lion King, Wonder Woman. Strathmore, North Bethesda. www.filmfestnih.org

September 22 | 7th Annual IBEW Local 26 Poker Run | Ride by bike or car and collect the winning hand.



Southern MD route. www.ibewlocal26.org

September 24 | Blacksburg Battles Cancer Golf Tournament | Great golf in beautiful southwest Virginia, hosted by the Blacksburg Country Club's Women's Golf Association. www.blacksburg-battlescancer.org

October 19 | PSI 21st Charity Golf Tournament | Fantastic golf and all-u-can-eat crabs — with a PSI matching donation. How How! Argyle Country Club, Silver Spring, Maryland. www.plan-sys.com

October 20 | 6th Fall in Love 10K Run & 5K Run/Walk | Hosted by Special Love, the race is both family-friendly and

runner-focused with professional timing by Federal City Runners. Run and/or sponsor! C&O Towpath, Washington, DC. www.speciallove.org/specialevents/fallinloverunwalk



December 13 | Celebration of Hope Charity Gala | Holiday event supporting the medical staff and mobile infirmary at Camp Fantastic. Winchester, www.celebrationofhope.net

"WHAT I CAN DO"

by Kristen Kellar-Graney, M.S., tumor biologist and clinical researcher — and Special Love pop-up camp guru

A borrowed quote: *Don't let what you cannot do interfere with what you can do.*

As a tumor biologist, I cannot take away the fear a parent has learning that their child has cancer. But as a Special Love

volunteer, I can lend an ear, a shoulder, or a hand when they need it. And I can bring snacks; I always have snacks.

As a tumor biologist, I cannot guarantee that chemotherapy is going to work, or not have side-effects, or make their child terribly sick, or even provide a cure. But as a Special Love volunteer, I can sit and talk or play with their child when a parent needs a moment with a clinician, or to take a phone call, or a walk to clear their head.

I cannot add hours to the day and months to the year, but I can give a parent a few moments of respite. I can put a smile on a child's face, making them forget, if even just for a moment, that they have cancer. I can turn them into superheroes and Mardi Gras mannequins, or bugs or butterflies, and together, we

can create things, beautiful things filled with joy and love and color, things that bring giggles on the best and the worst days. And we can create memories together. And I can be thankful that I become a small part of their journey.

What I can do is what I do. And I will do more.

This year to date, the Special Love team has been welcomed into the lives and families of more than 80 children in our nine (and increasing) hospital clinic "pop-up camps." Georgetown University Hospital will be added this fall.

Our local population of pop-up campers is being treated at Johns Hopkins, University of Maryland, and Sinai Hospitals, with about 20 patient interactions per month. I personally have the privilege of being in each of these hospitals monthly. We also spend time with children in

Washington, DC, and Virginia, including Fairfax County, Richmond, and south to the Norfolk area.

The success of this program has been overwhelming and enables us to invite more friends and colleagues to join us in our mission. If you're interested in volunteering with Special Love at one of the hospitals, or volunteering or sponsoring Children's Cancer Awareness Month in September (we're hosting a special event in Fells Point on September 15), or at any of the weekend or weeklong camps for our patients, their siblings, and their families, please reach out to Special Love.

I guarantee that after your first encounter with these wonderful children and their families, you will realize the power of *what you can do.*



Kristen and Brian Graney (center couple) give time and talent to Special Love. Here, they host an awareness event in the Baltimore area.



FantasticFlashback: To One Young Man, “Keep Your Chin Up” Made The Difference

On the last day of 2017, Special Love received a generous donation in honor of a former camper. Not unusual.



2018



1989

But when we tried to locate the camper to tell him he was remembered by a friend, we discovered a wonderful story.

Winnie Peele Morgan was a Camp Fantastic leader and

former board member in the 1980s. Today, she lives in North Carolina with her husband and is grandmother to four. When remembering camp, she recalls one young man in particular – Carl Price.

Three decades ago, Carl was a teenage camper battling nasopharyngeal carcinoma. He also had grown up as a foster child. Unfortunately, he was all too familiar with emotional childhood trauma.

At camp, Carl and Winnie forged a friendship. Through Winnie’s encouraging words (what Carl now calls “positive vibes”), Carl

learned to think more positively, to look at life differently.

“There is a reason you are the way you are, think the way you think, and have faced the things you’ve faced.”

... You once said keep my chin up, so I talk to the clouds above me, keeping my chin up as high as it will go.” Winnie kept the letter.

This January, the two arranged to meet again for the first time since camp. *“It was a wonderful reunion,”* Winnie says, smiling.

Today, Carl travels the country speaking about childhood trauma. (His website is www.carlmpri.com.) His book, *Tell Me Where Home Is*, tells his story of poverty, neglect,

childhood cancer, and foster care in Baltimore, Maryland.

“There is a reason you are the way you are, think the way you think, and have faced the things you’ve faced,” Carl writes. *“The world needs something only you can give it. Your dream, your story, and your contribution is what humanity needs.”*

Our Honored 2018 Guardian Scholarship Recipients

- **Heather Alba**, The Maria Kenny Guardian Scholarship
- **Tarik Green**, The Peggy & John Lingenfelter Guardian Scholarship
- **Alexandra Hancock**, The McGowan Family Guardian Scholarship
- **Kevin Hernandez**, The Atherton Family Guardian Scholarship
- **Andrew McCaffrey**, The Erik Andrew Stephens Guardian Scholarship
- **Hannah Neathery and Morgan Treon**, The Richmond Shag Club Guardian Scholarships
- **Erin Schulte**, The Bresch Guardian Scholarship
- **Jesse Smith**, The Caleb Ingram Guardian Scholarship
- **Abby Snider**, The Funkhouser Family Guardian Scholarship
- **Serena Wade**, The Dennis Chastain Guardian Scholarship

Interested in donating a scholarship in your name or the name of someone you love? Contact Robin Couch Cardillo at rcardillo@speciallove.org or 888.930.2707.

Grace and Grit *(cont. from p. 1)*

latent effects of the pediatric cancer and his chemotherapy have posed challenges in school.

“I’m one of the fortunate ones who beat cancer,” Jesse explains. *“But beating cancer is more than just beating a disease. It’s about beating a whole series of setbacks, physically, mentally, and emotionally. It’s about overcoming physical limitations such as nerve damage and muscle weakness caused by chemotherapy. It’s about overcoming cognitive deficits induced by more chemo drugs. It’s about overcoming the insecurities related to my appearance. It’s about overcoming the lack of confidence on the soccer field, on the volleyball court, on the basketball court. It’s about overcoming a victim mentality and replacing it with an ‘I’ve got this!’ attitude.”*

Honoring Jesse’s resilience, Special Love recently named him a Guardian Scholarship winner, the prestigious award presented to former campers with the help of important donors.

Jesse was honored with the Caleb Ingram Guardian Scholarship, generously donated by David and Annette Ingram of San Pedro, California. The Ingrams and Jesse have shared thanks and well wishes across the country.



Throughout the turmoil that pediatric cancer brings to a child, Jesse remembers his

time at camp as therapeutic – *“celebrations of what we could do, not pity for what we couldn’t ... I firmly believe my success is tied to the three attitudes I learned at Special Love camp: grace, gratitude, and grit.”*

(Above) The Caleb Ingram Guardian Scholarship recipient Jesse Smith now and at Camp Fantastic in 2008



Casino Royale Shines Light on Long-time Supporters



Special Love's annual gala – Casino Royale! – once again was a smashing success, with more than 300 guests dancing, dining, bidding on auction items, and “gaming” at the Hilton McLean Tysons Corner in April.

ed at the gala, Etter marveled at “everyone’s enthusiasm and genuine caring. The impact Special Love is making is impressive, and the Laulhere Foundation is fortunate to play a small part.”

Former president of NIH’s Recreation & Welfare Association Schools accepted the third annual Light of Love Award, which fittingly will be renamed in his honor. Randy has been instrumental in the nonprofit’s growth since its beginning, serving children with cancer and their families for more than three decades.

The gala included a special tribute to Special Love’s late co-founder Tom Baker and his wife, Sheila – with gifts supporting weekend camps and a memorial at the Northern Virginia 4-H Center, the site of many Special Love camps.

We honored two very important partners: The Gwen Laulhere Foundation and long-time volunteer, supporter, and board member Randy Schools.

The Laulhere Foundation has funded BRASS Camp and other camps since 1999, surpassing the \$1-million threshold. Bill Etter, the husband of Foundation President Tracy Laulhere, was on hand to accept the Circle of Love trophy. With BRASS Camp leaders well represent-



(Top) BRASS leaders surround Bill Etter (blue suit) of The Gwen Laulhere Foundation, inducted into the Circle of Love

(Bottom) Light of Love recipient Randy Schools talks of more than three decades supporting Special Love

Heartfelt Thanks to Special Love’s Casino Royale Major Sponsors

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Generous, Energetic Real Estate Managers Keep Giving at 13th IREM Gala!

Once again, the Institute of Real Estate Management Chapters 8, 77, and 92 knew how to party at its 13th charity gala. And Special Love was the lucky benefactor!

Presenting Special Love a generous gift of \$82,000, IREM topped its previous record, for a total of \$668,000 donated since the gala began in 2006.

This important donation goes to vital programming for children with cancer and their families, including weeklong camps and weekend getaways.

Thank you to all the IREM leaders, members, and sponsors who make this a “go-to” event each year, filling the ballroom at Congressional Country Club in May.



(Above) Special Love campers painted a colorful watercolor to auction at the IREM gala (it sold for \$1,300!)

(Left, above) Camper Kate, an honored guest representing Special Love at the gala, is wowed by magic tricks

(Left, below) IREM leaders take a break in the fun to present a check for \$82,000 to Special Love’s Dave Smith and Camper Kate





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BackBurner | Mark Your Calendars for Fun, Fun, Fun!

September 22 | Special Love's KOA Cares Day | A fun day filled with games and camper antics at the KOA Campground in Williamsburg, VA. Free for all Special Love campers and open to all camp-eligible families. Williamsburg, VA. www.koa.com/campgrounds/williamsburg

October 12-14 | Octoberfest Weekend | Get ready for more fall fun — pumpkins, games, special treats! Open to all

camp-eligible families. Northern Virginia 4-H Center, Front Royal, VA

November 17-18 | Parents' Getaway Weekend | Take a break and meet other parents on the same pediatric cancer journey as you. The relaxation and networking are invaluable — you deserve it! Open to camp-eligible and bereaved parents. George Washington Hotel, Winchester, Virginia

December 2 | The Holiday Party! | If you've been here before, you know it's non-stop festive fun. If you haven't been here, you need to join us to launch the season. All camp families (old and

new) are welcome! Franconia Fire Department, Franconia, VA

January 4-6 | Fantastic Winter Weekend | Skiing, tubing, sledding, or sipping cocoa — it's your choice! Don't miss this fun weekend for 13- to 25-year-old cancer patients. 4-H Center, Front Royal, VA, and Bryce Resort, Mt. Jackson, VA

January 18-21 | Ski Family Weekend | Schedule your holiday weekend to spend with Special Love families. You'll love the fun and camaraderie of this special camp event. Open to all camp-eligible families. Canaan Valley Resort, Davis, WV



Families take advantage of adaptive ski equipment during Ski Family Weekend at Canaan Valley Resort



Special Love, Inc., is a non-profit, IRS 50(c)(3) organization, and all donations are tax-deductible. Audited financial statements are available on our website, www.speciallove.org.

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