Circle of Care

CLOSING THE SUPPORT GAP

2014 Annual Report

www.thecircleofcare.org
Circle of Care At A Glance

107 Bags of Love in 2014
1,640 Bags of Love over 10 years

354 volunteers in 2014
276 families served in 2014
1,700 families served over 10 years

serving Smilow Cancer Center at Yale New Haven, Connecticut Children’s Medical Center, Maria Fareri Children’s Hospital, Memorial Sloan Kettering Cancer Center, and Dana Farber Cancer Institute

$88,128 in direct financial support in 2014
$932,427 in support over 10 years
# Table of Contents

Letters from Founders and Executive Director .......................................................... 4

Circle of Care Programs
   Bags of Love ........................................................................................................ 5
   Hospital Volunteers, Lifeline Peer Support .......................................................... 6
   Art from the Heart .................................................................................................. 7
   Financial Assistance: Lifeline Emergency Funds .................................................. 8

Circle of Care Support Events and Community Engagement
   Holiday Meal Gifts .................................................................................................. 9
   ImNOTmymcancer™ .............................................................................................. 10
   Ring the Bell and the Mary MacArthur Story ...................................................... 11

10th Anniversary Gala: Celebrating 10, Roaring to 20 ............................................. 12

Our Donors
   Who Fills the Gap .................................................................................................. 13
   Investing in Circle of Care ...................................................................................... 14
   Ways to Give in 2015 ............................................................................................ 15

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Closing the Gap

When a child is given the diagnosis of cancer, the news is devastating to the whole family. Things move so quickly. The diagnosis often requires immediate hospitalization with initial stays requiring weeks in a hospital without the comforts of home or knowledge of the surrounding area. It is overwhelming to keep up with blood counts, protocols, scans, the merits of clinical trials, impending surgeries, and chemotherapy drugs. That’s why Circle of Care is here: to provide comprehensive support services from this first frenzied day through the years of treatment these children face.

2014 marked our 10th anniversary of caring for children with cancer and their families. We started out with a simple Day of Diagnosis care package and quickly grew to more than six programs throughout the state. We are so proud of and grateful for our strong partnerships with Smilow Cancer Hospital at Yale New Haven, Connecticut Children’s Medical Center, and Maria Fareri Children’s Hospital, the only three pediatric oncology treatment centers in Connecticut and Westchester.

Each year 175 children in Connecticut will receive a diagnosis of cancer while more than 500 children are currently in treatment and looking for support. The good news is that more than 80% will be cured of their cancer. But cures comes at a tremendous cost: lost years in school, long-term physical and emotional effects on the child and parents, and the overwhelming financial burden of treatment. Of these families, 70% will come to us for help with paying their basic monthly bills.

We believe that no parent should have to choose between caring for their child and providing for their family. The impact we have, the direct impact, is significant, but there is still so much more we can do. Circle of Care is about children and families. We are about being with families during the difficult moment of their life and saying, “We’re here with you, no matter what.” It’s about forming a circle of care.

I am humbled and honored to serve as the first Executive Director of Circle of Care. Thanks to Liz, Dawn, and the Board of Directors we have an exceptional program in place to support children with cancer and their families. Although our culture of innovation and excellence dictates that we will always look to improve, the reality is I am fortunate to be walking into an organization that is one of the most respected in its field, that has an unbelievably dedicated board and volunteer network, and a carefully prescribed program that addresses the many overwhelming needs our families face.

My challenge is to close the support gap and raise the funds required to fully meet our families’ needs. Imagine the impact we will have when we can reach every family who benefits from our services. To do this, we need to work hard to reach more donors, more volunteers, and more members of our circle. You play a critical role in helping us close this gap.

To those who have supported our effort this past year: thank you so much – rest assured that your generosity is having a direct impact. And if you are thinking of making a charitable gift this year, please consider making Circle of Care and the families we serve a priority.

Together, we can close the support gap.
Our Bags of Love, made by volunteers, come at a time when the family feels most isolated and vulnerable. Bags of Love are delivered to families at the hospital on their day of diagnosis at Yale Smilow Cancer Center, Connecticut Children’s Medical Center and Maria Fareri Children’s Hospital, the only three pediatric oncology centers in Connecticut and Westchester County, NY.

Each Bag of Love is a canvas tote bag filled with the day-to-day items most needed during the initial hospital stay and messages of support from other parents who have been on this journey. Having some of the comforts of home is very helpful those first few days.

Our bags are created for boys and girls in five different age groups from infant to teen. This year Circle of Care added a young-adult bag for patients aged 18 to 25 as more and more patients in this age group are being treated with pediatric protocols at children’s hospitals. Circle of Care also provides bags for transplant patients that contain some of the very specific items needed to help them during treatment and extended isolation.

Also, included in each Bag of Love is the Purple Pages, our guide to life in the hospital and to pediatric cancer resources in Connecticut and nationally. Each source is vetted and covers topics including: specialized treatment centers, personalized websites for posting updates, information about art and music therapy, where to get wigs for children, sibling workshops, family support services, navigating return to school, nutritional support, specialized camps, insurance, financial assistance, and more.

“We still have our purple Bag of Love that we received the night Tristan’s cancer was diagnosed. He was flown to CCMC via Lifestar from the Waterbury Hospital ER, and we had nothing packed. The social worker gave us this bag filled with everything we needed until one of us could get home to gather our belongings for the 6-month hospital stay. I remember feeling so thankful that we were being taken care of so well while Tristan fought for his life. I still have the bag and the socks and they serve as a reminder that in times of an emergency there are amazing people looking out for you.”

Courtney Campbell, mom of Tristan, age 1
Hospital Volunteers

Treatment for pediatric cancer is different from adult cancers. Treatment is typically 3 to 4 days a week for the first year and then once a week for the following 2 years. Many of the treatments take place over the course of a day, and sometimes require in-patient stays of days or weeks. The net result: children spend long, often boring, hours in the hospital. Volunteers at Yale Smilow Cancer Center are Circle of Care–trained and certified to provide support and much-needed diversions. Sometimes it’s a game, craft activity, reading a story, painting a little girl’s nails ... and sometimes it’s lending a sympathetic ear to a parent who needs to talk.

Lifeline Peer Support

Lifeline is Circle of Care’s peer-counseling telephone support network that pairs survivor families with families with a new diagnosis. Families have the opportunity to talk to someone who truly understands what they are going through, easing the isolation, and helping to create a sense of community, hope, and shared experience. Our volunteers have all been carefully selected and trained to listen and provide support to families of cancer patients. Families find us through referrals from our website and the hospitals we serve in Connecticut and Westchester—Smilow Cancer Hospital at Yale New Haven, Connecticut Children’s Medical Center, and Maria Fareri Children’s Hospital—as well as Sloan Kettering Cancer Center and Dana Farber Cancer Institute where many Connecticut families are treated.
Art from the Heart transforms cancer patients’ home bedrooms into personal dream rooms. Room makeovers are offered by lottery at the three area pediatric treatment centers: Maria Fareri Children’s Hospital, Yale Smilow Cancer Center, and Connecticut Children’s Medical Center. Makeovers are conducted by community volunteers – typically high school or college students, working in concert with volunteer designers. Art from the Heart creates a new and beautiful space as a respite from the daily rigors of treatment and the isolation of being at home and not at school or activities with their peers. It is truly a special haven and gives patients something to look forward to other than their next round of chemotherapy.

Zach: Age 8
“Zach’s bedroom makeover was just completed, and we are so very grateful for the wonderful experience! Zach was over the moon all weekend and LOVES his new ‘underwater’ room. And, the timing could not have been better. Zach had a four-week delay in treatment, which caused all of us a lot of anxiety. The room makeover was such a bright spot during this time. What a wonderful program, and what a fantastic team at Circle of Care. We cannot thank everyone enough!” Elise Libow, mom of Zach

Support at Home

Art from the Heart

11 🌟 rooms completed in 2014

71 🌟 rooms since inception

8 🌟 teams in 2014

across Connecticut in Fairfield, New Haven and Hartford Counties

180 🌟 Art from the Heart volunteers in 2014
No parent should have to choose between caring for a sick child and providing for their family. Circle of Care established our **Lifeline Emergency Fund** to alleviate some of the financial difficulties experienced by families when their children are undergoing treatment for cancer. With 70% of families facing a financial crisis during treatment, our program acts as a “last resort and first responder” to families in crisis. With all other resources exhausted, families seek funds for basic essentials such as food, gas and housing (mortgage, rent and utility payments).

In 2014 we provided $88,128 in direct financial assistance but, funds are limited and we cannot yet meet the full demand. Circle of Care works closely with the hospitals to assess where the need is greatest, with a current maximum annual allotment of $2,000 per family.

**What Emergency Funds Pay For...**

![Pie chart showing percentage of expenses funded by emergency funds]

- Food: 15%
- Rent/Mortgage: 50%
- Electric: 4%
- Funeral: 10%
- Heat: 9%
- Car Expense: 9%
- Funeral: 10%
- Food: 15%
- Phone/Internet: 3%

“I cannot thank Circle of Care enough. It is a very trying time for us. Our entire focus is on our son. Work is difficult when our son is literally screaming in pain. We are self-employed, so fortunately we do not have a limitation on time-off. Unfortunately, when we don’t work, we don’t earn. Circle of Care’s generosity will help us to keep our heads above water. God Bless you. When your child is suffering, nothing else matters, and financial concerns become secondary, although not to the bill collectors.”

Leslie, mother of Carlo, age 22

More children are getting a cancer diagnosis and undergoing longer and more expensive treatments than **20 years ago**.

**70%** of families, regardless of economic status, experience a financial crisis at some point during their child’s treatment.

As medical debt spirals, the line between solvency and bankruptcy narrows, with more than **30%** of families declaring personal bankruptcy.

Having medical insurance doesn’t make a family immune from financial problems: **65%** of personal bankruptcies involve high medical bills.

According to the Henry J. Kaiser Family Foundation, the average out-of-pocket expense for a child with cancer is **$34,558** per family and the average cost of treatment is approximately **$500,000** per child. The Kaiser Foundation estimates that **28%** of families cannot afford treatment.

Immediate need to serve Connecticut’s pediatric cancer population: **$1.7 million**
Thank you so very much for thinking of all our families during this holiday season. Circle of Care’s generosity and thoughtfulness comes to us in a way that many others do not consider. As a family of four, with two small children (our oldest son is in his 19th month of treatment), most of the time it is the simple things that are difficult (gas, food). So, thank you!!! Wishing you the happiest of holidays and a great 2015!!"

Jessica S.

"To all the Circle of Care Staff, Volunteers and Donors:
Thank you so much for the gift card this holiday season. It really helped us have a wonderful Christmas. Attached is a photo of my daughter, who is being treated for leukemia, and her grandparents on Christmas Eve. We had a lovely dinner, which your gift helped make so special. I am a single mom, working full time, and was off work for a month when my daughter received her diagnosis, and I have only recently gone back to work. Your gift helped take so much stress off our holidays and for that I am truly grateful. Happy New Year to you all."

Heather C.

Thank you to all the community organizations that support Circle of Care
Alex and Ani
Women Over 40
Moore Physical Therapy
Frannie Faith Music & Meditation
Help Change Cancer and Alexa Steckel
Cactus Rose – “What about Me” Ladies Night Out
New Canaan Community School
Moments By Andrea Photography
New Canaan National Charity League
National Charity League of Westport
Wilton High School
Amity High School
Daniel Hand High School
W by Worth
The Turnover Shop
Clinton High School
Greenwich High School
Staples High School
Peachwave
Stella & Dot
Hold onto Hope
Signature Style
Young Women’s League of New Canaan
Greens Farm Academy

HOLIDAY MEAL GIFTS

$100 for 100 Families

Our donors’ generosity took Circle of Care’s holiday giving a little further this year.

Thanks to overwhelming support in 2014, we were able to provide 100 families with $100 gift cards towards their holiday meals in addition to the $6,000 in holiday gifts we already provide each year. You made this possible!

"Thank you so very much for thinking of all our families during this holiday season. Circle of Care’s generosity and thoughtfulness comes to us in a way that many others do not consider. As a family of four, with two small children (our oldest son is in his 19th month of treatment), most of the time it is the simple things that are difficult (gas, food). So, thank you!!! Wishing you the happiest of holidays and a great 2015!!"

Jessica S.
Too many children feel they are defined by their illness – they’re known not for their myriad talents and accomplishments, but as “Jane, who has cancer...” or “Will, the 9th grader with leukemia...” Those living with cancer have a simple message they want to share with the world: I’m not my cancer!

They’re kids, teens, young adults – who are just like everyone else, and, yes, who are also living with cancer. That’s why Circle of Care thought the best way to celebrate Childhood Cancer Awareness Month was to bring attention to the individuals. In September 2014 we started a movement, beginning in our home town of Wilton, CT to honor kids living with cancer. We were touched and elated by the great spirit all these children showed and look forward to this coming September when the program expands to more towns.
In 2011 Circle of Care lost one of the most beloved and valued members of our circle, Mary MacArthur. Mary began as a patient services volunteer in 2008, working initially at the Yale New Haven Children’s Hospital outpatient clinic in Guilford and eventually moving to the new pediatric oncology clinic at Smilow Cancer Hospital at Yale New Haven. Mary had a special way with the children – they were always so happy to see her and had their games and crafts ready to go as soon as she walked in the door. With Mary you received undivided attention; she was interested in what you had to say and how you felt. This quality is especially important to children who often feel overlooked by adults. Mary brought comfort, loyalty, and joy to those who knew her.

The strength and courage Mary found in her own battle with cancer was made somewhat easier by her connection to the children at Yale. Every Tuesday, even while Mary was undergoing her own chemo treatment, Mary went to Smilow to play with the children for the morning. She often said those children were her inspiration. She was always so honest and totally at ease with the children, even taking her baseball cap or wig off to show them her bald head with pride.

We miss Mary’s smile, playful personality, and eternal optimism. Mary continues to touch children’s lives. Donations in Mary’s memory have been used to create a plaque at the Yale clinic with a poem and a bell for children to ring when their treatment has ended. This plaque is a permanent reminder of the spirit of hope that Mary always embodied and inspired in our children.
Excerpt from co-founder Dawn Ladenheim’s remarks at the 10th Anniversary Gala

We met “Dr Joe,” which is what he likes to be called by the families he treats, in the pediatric ICU after finding out our son had leukemia. My husband and I, like every family who experiences this diagnosis, were afraid and filled with despair. Dr. Joe sensed this, asked to talk, and looked us square in the eyes and said, “He’s going to get better – he will make it through this.” Then throughout treatment he reminded us to laugh, to have fun, to push through the tough times, and to share our optimism with everyone. And as our son’s treatment was ending, he inspired us to harness our energy and do something positive to carry this vision to families all over the state. For inspiring the formation of Circle of Care, and for inspiring the lives of so many, we are pleased to create what we are now calling the Dr. Joe Inspiration Award.

Dr. Joseph McNamara has been recognized as one of the most outstanding pediatric oncologists in the state of Connecticut. He serves as a clinical associate professor at the Yale School of Medicine and practices at the Smilow Cancer Hospital at Yale New Haven and its affiliate clinic in Trumbull, CT. Dr. McNamara is also the medical director of Camp Rising Sun, a free camp for children with cancer in northwestern Connecticut.
Numbers tell a story, and in the case of Circle of Care, that story is about the impact every gift makes, from $1 to $1 million. Thanks to the generosity of our donors, we grew the number of our donors by 57% and the amount of money raised by 103% over 2013 — that’s truly extraordinary — thank you. Throughout this report, you have seen in real human terms the impact each gift has on the lives of children with cancer — there can be no greater measure than that. But to better understand the quantitative impact of a gift, Circle of Care recently conducted an analysis of our program and its impact on the community. Using standard measures for the value of volunteer hours, and metrics generated by government data around things such as unemployment and bankruptcy, we looked at various aspects of our program and the numbers were striking: our volunteer program generates a Return on Investment (ROI) of $5.76. Art from the Heart, utilizing hundreds of volunteers throughout the state, generates a $4.79 ROI. Our Lifeline program tops out at an ROI of $8.88.

What does this mean? It means that we’re not only a worthwhile investment, but also an investment that has a ripple effect in the community. “You don’t have to be the biggest to have a very large impact,” noted Jeff Kimball, Executive Director.

Here’s the bottom line, for every dollar invested in Circle of Care, we return $5.66 in services to the community.
“Circle of Care is unique in that it works with families from the moment of diagnosis and supports them throughout treatment, has more personal interaction with the whole family and addresses both child and family needs”

Ways to Give

Donating to Circle of Care
Check: Make your check payable to Circle of Care and mail to:
Circle of Care • PO Box 32 • Wilton CT 06897

Online by credit card: Making an online donation is an easy and secure way to make a gift. Go to thecircleofcare.org and click on the Donate Now button.

Corporate Matching Gifts: If your company or organization offers matching gifts, please provide company contact information or required links with your donation so that Circle of Care may submit.

Stock/Securities Transfer: To arrange the transfer of stock or securities, contact Jeff Kimball, Executive Director, at 203.255.3333 or jeff@thecircleofcare.org.

Legacy Gifts/Estate Planning: To discuss estate planning and other legacy gift options, contact Jeff Kimball, Executive Director, at 203.255.3333 or jeff@thecircleofcare.org.

In Honor/In Memory: If your donation is in honor of or in memory of someone special and you would like a card sent, please make sure to include the recipient’s name and address when you make your donation.

GuideStar Exchange
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