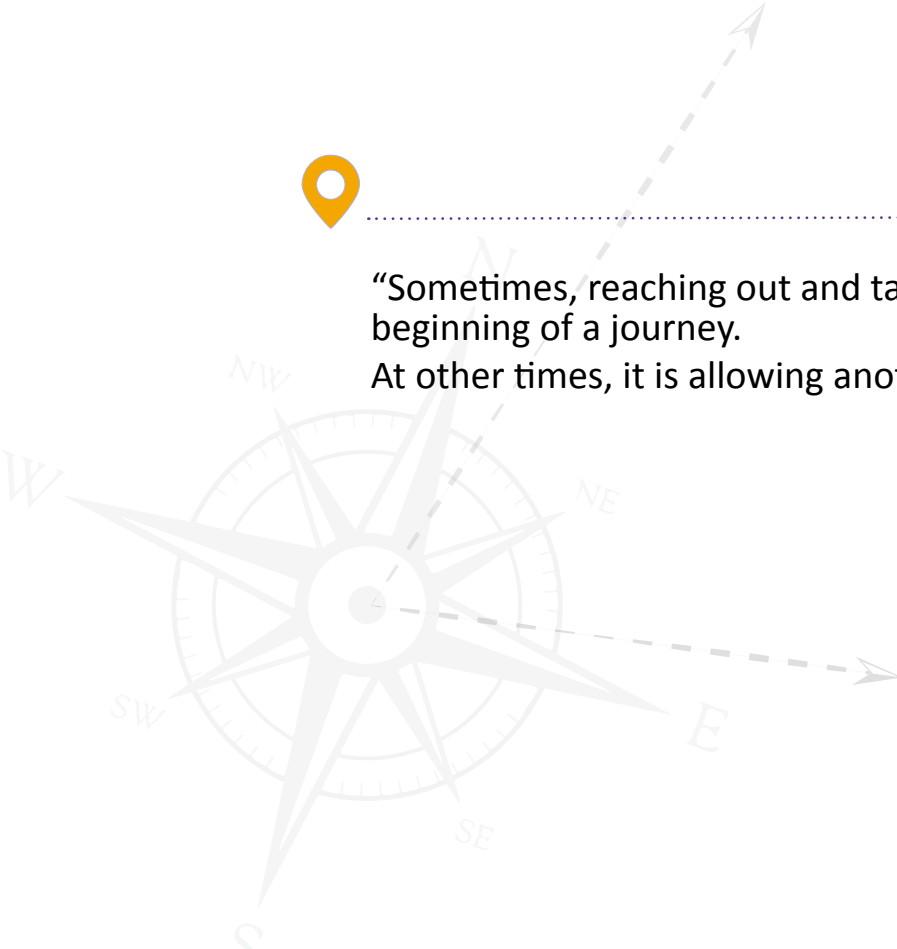


The Journey Together

Circle of Care Annual Report **2019**



“Sometimes, reaching out and taking someone’s hand is the beginning of a journey.

At other times, it is allowing another to take yours.”

- Vera Nazarian



Founders note

Thanks to you, our loyal supporters, we have been able to ease the pediatric cancer journey for the families in our Circle for the past 17 years. And it's because of you that we are able to provide programs that create hope, inspire dreams, relieve financial burden, and make lasting connections.



*Liz Salguero and Liz Vega,
Interim Co-Executive Directors*

Dear Friends,

Until no parent has to hear the words, “your child has cancer,” we will be here...no matter where the journey leads. For us, this is not just a mission statement. It’s the commitment we make every day to the children and families in our Circle. It’s the promise to be here from day of diagnosis, through years of treatment, in good times and bad. And it’s why we take it very seriously when we say that someone is a “part of our Circle.”

2019 brought change and growth for Circle of Care, and it made us reflect on what it really means to “be here” for our families. In this report, we have the privilege of introducing you to Luis. His seven-year cancer battle began at age 12, and we have been honored to be a part of his journey since the beginning. Now a young man at age 19, he is finally cancer free, but he will always be a part of our Circle. We know that you will be inspired by his strength as you read his story.

We were able to enjoy some in-person events in 2019, something we will never take for granted again. Our families enjoyed the annual Thanksgathering event, sponsored by Equitable, in November, as well as our Life Within The Journey reunion, both held at our home base, the Circle of Care Barn. We celebrated our second year in the Barn, and we were thrilled to see our families using the Barn as a healing space, and a place to get together outside of clinic.

We found ourselves facing changes in our leadership in 2019, allowing us to re-evaluate our structure and needs going forward as Circle of Care continues to mature. As Founder and President of Circle of Care, and long-time Board Member, we joined forces to take on the role of Interim Co-Executive Directors. Now known as “the Liz’s,” we rolled up our sleeves and, as we like to say, “cleaned out and reorganized all the closets.” This year also brought changes to our Board of Directors. Veteran Board Member, Bob Hinckley, took on the role of Board Chairman, bringing his experience as an IBM executive to our strategic planning. We also welcomed Alex Ramos of BNY Mellon to our Board. And, we expanded our Advisory Board, bringing on experienced and influential members in the areas of cancer treatment and non-profit management.

As we look back on 2019, we feel pride in what we achieved, and gratitude for the support along the way. Thanks to you, the families who often have nowhere else to turn, were able to turn to us. Thank you. You are what makes our Circle so strong.

With much gratitude and warmth,





COMMUNITY



Keller Williams • KC's Restaurant & Pub • Young Women's League of New Canaan • Captain Oblivious • Joni & The Keepers • Soul Tonic • Miss Connecticut Jillian Duffy • Joyride • CT Police Departments: Bethel • Danbury • Hartford • Meridan • New Canaan • New Haven • Wilton • Western Middle School Steven Sudell Sprint and Color Run • Janet Montalbano's Sip & Shop

THANK YOU to our generous community of supporters for your fundraising this year!



Art from the Heart Teams: National Charity League Westport • Advanced Radiology • University of New Haven • Greenwich Courage/Campbell Team • Wilton ALIVE • Madison Moms • Amy Gonch Project • Glenville Elementary School • Team Commella • Greens Farms Academy



Volunteer Spotlight

Kacky

Kacky Theoharides is no stranger to pediatric cancer. In March 2013, her five-year-old daughter Lyla was diagnosed with Stage 4 Neuroblastoma. She remembers getting a call from Liz Salguero a few days after they received the news. “I truly was a deer in headlights,” recalls Kacky. “But Liz talked me through the logistics, doctors’ names, contacts, cancer lingo. She was so comforting and the emotional support was just what I needed.”

Several years later, after Lyla had completed her lengthy treatment, Kacky turned her focus to giving back. “Circle of Care helps children and families facing pediatric cancer in Connecticut. That was us,” she says. “What charity could be a better fit for us?”

An avid runner, Kacky has organized the Circle of Care 5K race for four consecutive years. Along with the Circle of Care team, she has built the race into an event that the town looks forward to each year. When asked about the emotion of seeing Lyla run across the finish line, she says, “Tears, tears, joy, pride and more tears! Lyla has been healthy enough to run in each race. She wears her yellow survivor ribbon with pride. My three boys have always volunteered, as does my husband Phil on race day. It’s now just a part of who we are as a family. We want to help ease the pain that these families endure. Lyla’s illness forever changed us and I think we will forever find opportunities to give back and make fighting childhood cancer our mission.”

Under Kacky’s leadership, the Annual Circle of Care 5K has raised over \$100,000. She has also dedicated her time to organizing four very successful annual spinraisers for Circle of Care. We are so grateful to have Kacky in our Circle.



Lyla, 5 year cancer survivor and friends



This year, we were honored to be selected as the beneficiary charity of Western Middle School's 3rd annual Steven Sudell color run in memory of Steven Sudell.





A moment to smile...

Eden sees her Art from the Heart room makeover for the first time

Cancer treatment is emotionally and physically draining, with long hospital stays and extended periods of time at home, away from school and friends. When your life is controlled by cancer and restrictions, having the opportunity to take back an ounce of control is immeasurable. Our Art from the Heart room makeovers provide a positive distraction for the families and can have a dramatic effect on our young patients' recovery.



Eden and AFTH team Leader Amy Gonch



Donor Spotlight Georgette

Georgette Geller is the Executive Director of Business Acquisition & Growth at Equitable. One of the corporate initiatives at Equitable is to bring employees together to do something for children in need. A cancer survivor herself, Georgette was drawn to Circle of Care, and together with co-worker Gina Santos and the Circle of Care team, they brainstormed a way to help our families.

Thanksgiving is an annual event that welcomes families into the Barn to reconnect with other families before the rush of the holiday season. Equitable provides

a basket filled with all that a family needs to make a holiday meal. “Everything feels so out of control for these families, and we wanted to do something that would give back that control,” says Geller.

But Thanksgiving is more than just a basket of food. The families who attend Thanksgiving are greeted with love from many of Equitable’s advisors, creating a warm family event with cookie decorating, the opportunity to design a centerpiece for the holiday table, and most importantly, a chance to give thanks.

We are thankful for Georgette, her commitment to helping children in need, and to the employees at Equitable who make this event possible each year.



Thanksgiving with our friends from Equitable



Our 2019 Circle of Care YNHCH Hospital Volunteers



CHILDHOOD
CANCER
ALLIANCE of
CONNECTICUT

Berni & Murcer

Camp Rising Sun

Circle of Care

Colin's Crew

Connecticut Children's Medical Center

Friends of Karen

Infinite Love for Kids Fighting Cancer

Leukemia and Lymphoma Society

LIVFREE

Make-A-Wish Connecticut

Ronald McDonald House of Connecticut

Ryan's Rebels

Special Wishes

Sunshine Kids

Team Impact

The Susan Fund

The Tommy Fund

Yale New Haven Children's Hospital

Alliance Highlights 2019

The Childhood Cancer Alliance of Connecticut celebrated another successful year in 2019, welcoming four new members and establishing an advisory board to help guide the Alliance as it continues its growth. Advisory board members include: Liz Salguero and Liz Vega of Circle of Care, as well as Brooks Tomb of Sunshine Kids, and Susan Carron of Make-A-Wish.

The Alliance entered its fourth year with a vision to better understand the growing adolescent and young adult (AYA) population and their needs. With a marked increase in the number of patients between the ages of 15-29 in the past five years*, the Alliance is focused on how to better serve this population. This spring, we welcomed CCMC's Dr. Eileen Gillan, a pediatric hematology-oncology specialist, to give an overview of the current state of pediatric cancer care. Mary Laliberte, CCMC, also spoke at the spring meeting, raising a number of issues related to the AYA population, and calling on Alliance members to consider the AYA population's needs in their programs and services. In the fall, Dr. Asher Marks and Amanda Garbatani continued that conversation, sharing information about Yale's AYA program.

Our bi-annual meetings continue to provide educational opportunities and a forum for networking and open sharing of information. This year we have added two resource days at each hospital in an effort to increase awareness of, and access to, all Alliance member programs for patients and their families. The Alliance remains dedicated to continuing to grow this platform for sharing of ideas and information among our members.

**As oncologists have found that the pediatric protocols are more successful in this age group, these patients are now being treated at children's hospitals.*



Luis' Journey



Diagnosis

2012



In **2012**, when Luis was twelve years old, he was just a typical seventh grade kid. His favorite school subjects were art and gym, and he was a big fan of basketball and the LA Lakers. But for Luis, seventh grade was going to be anything but typical. After a trip to the doctor for an unexplained fever, he was diagnosed with Acute Lymphoblastic Leukemia. And just like that, seventh grade was put on hold, and his long and complicated cancer journey began.

Luis Vega, 2020



Luis with his grandmother Ivette and Missy, Circle of Care Hospital Volunteer



Luis gives a thumbs up despite the rigors of treatment. Our Bags of Love bring the comforts of home and some color, like this fleece blanket, to the hospital environment.

Treatment

2013



The initial diagnosis was critical, and with grandmother Ivette at his side, Luis spent almost four months in the hospital. His protocol called for three years of treatment that would include weekly chemotherapy infusions, intrathecal treatments and multiple hospitalizations.

Moments of Joy
2014



"This experience was a lot of bad, but a lot of good, too. I met a lot of people who went through what I went through." Luis



Luis with Dr. Joe at Camp Jewell



Circle of Care Life Within The Journey photo shoot, 2014



A moment of peace at the hospital



1st Relapse 2015

Luis and his family celebrated the end of his treatment when he was 15 years old. But just one month after that celebration, he learned he relapsed at his first post-treatment checkup.



2nd Relapse

2016



3rd Relapse

2017

4th Relapse

2018

For a child with cancer, suffering even one relapse can be traumatic. Luis endured three more relapses after his first. In the summer of 2018 he was transferred to a hospital in Philadelphia where he spent two months undergoing CAR-T treatment, only to relapse again. The treatments simply were not working.

Circle of Care Life Within The Journey portrait shoot, 2016



Circle of Care Art from the Heart team provides room makeover for Luis...a welcome distraction at a challenging time.

“I loved watching him see the room for the first time. And he still has it exactly the same.” **Ivette**

While doctors worked to find alternative treatment options, Luis spent a lot of time at home. With a weakened immune system, it wasn't feasible for Luis to be in school or to be living the life of a healthy 17-year-old. And for a teenager, at an age when life is typically filled with school and activities and plans with friends, that time at home can feel isolating.



11:30am Yale New Haven Children's Hospital
April 1, 2019

Transplant

2019



Left only with the final option of a bone marrow transplant, the search for a match began. It took six months to find the first match. Unfortunately, at that time Luis was not well enough to have the transplant. He was suffering from a severe fungal infection—just one of the many side effects caused by six years of chemo.

His condition worsened and when his system completely broke down and he was hemorrhaging, he was admitted to the ICU at Yale New Haven Hospital, where he stayed for two weeks.

Ivette remembers when the situation was dire. “When they told me, ‘Call your family,’ it was like a door closed down in front of me. They said, ‘Call your family because we don’t know what’s going to happen.’ I said, ‘Everyone, let’s join our hands and pray.’ And then they hung another bag of blood and I said, ‘God, this is your blood.’ The blood coming out of the bag was so thick and I said, ‘Oh my God, that’s God’s blood.’ And then all of the sudden, he stopped bleeding. That’s my miracle. I have to tell it.”

And then he woke up.

After surviving this close call, the search for another bone marrow donor match continued. Without a donor match, he would not live. It took four months to find a donor who was a close, but only partial, match. The family faced a big decision—to go ahead with the donor, knowing that there was a risk of transplant rejection, or to hold out for a complete match, and risk succumbing to the cancer. The decision was made in March of 2019, and Luis underwent aggressive chemo and full body radiation to prepare for the transplant, which would require another 90 days in the hospital.

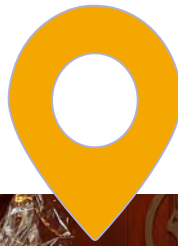
“He has had such a long journey with this,” says Ivette. But the one constant in Luis’ journey has been having his grandmother at his side. When Luis reflects on what got him through his many challenges, he emphatically says, “my amazing grandmother.”



Luis and his grandmother at home



Today



Thanksgiving event at the Circle of Care barn Nov. 2019

Luis endured more during his teenage years than most endure in a lifetime. When his cancer battle began, he was just a boy. Today, despite nine years of treatment, Luis has grown into a resilient young man with big dreams for his future.

Our Programs



Bags of Love The day of diagnosis is overwhelming. Our Bags are filled with thoughtfully selected items that families need in those first overwhelming days and weeks. Like the Purple Pages resource guide, a warm blanket, and a lighted pen for those late nights in a quiet hospital room. But a Bag of Love doesn't just provide the essentials...it gives you the comfort of knowing that there is someone who has been in your shoes, and who will be there to walk the journey with you.



Lifeline Peer Mentoring Lifeline connects families in treatment to a valuable support network that includes past and present Circle of Care families who have experienced their child's battle with cancer.



Hospital Volunteers Our specially trained hospital volunteers are there to offer a moment of respite for families who endure long, tiring days at the hospital. Whether it's to paint a child's nails, play a competitive game of checkers, or simply to lend an ear, our volunteers provide a much-needed distraction for patients, siblings and the families who are bearing the weight of a cancer journey.



Financial Assistance No family should ever have to choose between caring for a child or paying the bills. Our Financial Assistance program is there for families who are facing financial distress. We ensure that parents can focus on caring for their child without worrying about the bill collectors...so that they can rest assured there will be a roof over their heads and food on the table as they continue their journey.



Art from the Heart Children in treatment for a cancer diagnosis often spend a lot of time at home, away from school, their friends and their regular routine. Our Art from the Heart dream room makeovers offer something for a child to look forward to and have control over, whether they choose to create a princess wonderland or a room dedicated to their favorite sports team.



Life Within The Journey Our photojournalistic portrait series is an educational and intimate look at the real faces behind pediatric cancer, and into the lives of children and young adults who are living with cancer. The series has been exhibited in twelve different locations across the state.



Bounce Back to Fitness The end of treatment is a milestone. Bounce Back to Fitness helps children and young adults rebuild their strength and stamina. Our partnership with CT Fitness Lab and Dynamic Edge allows us to offer children the opportunity to work with specialists in physical therapy and exercise physiology to regain strength, balance, coordination, agility, and most importantly, confidence.

We Walk Together



Bags of Love



Lifeline Peer Mentoring



Hospital Volunteering



Financial Assistance



Art From The Heart



Life Within The Journey



Bounce Back To Fitness

2019 Impact

\$120,000 In Direct Financial Assistance...



Housing **62%**



Transportation **11%**



Utilities **10%**



Funeral **10%**



Food **4%**



Special Needs **3%**

...where it's needed **MOST**

53%

Extremely Low Income

34%

Very Low Income

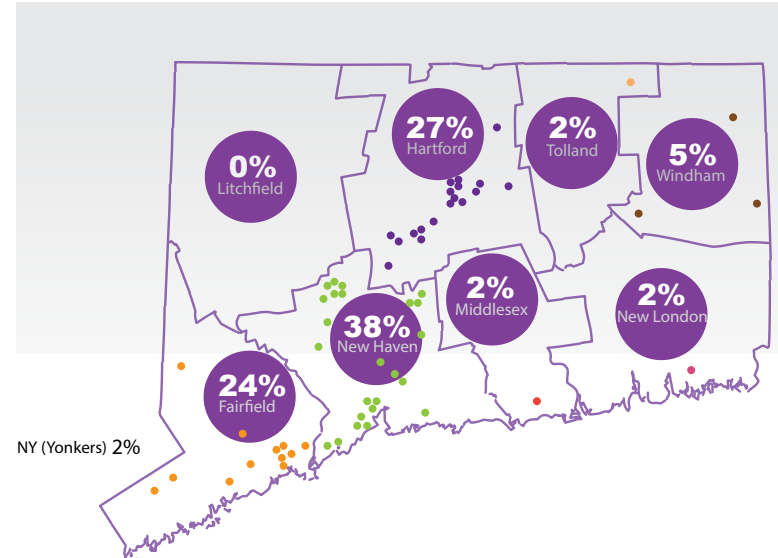
13%

Low Income

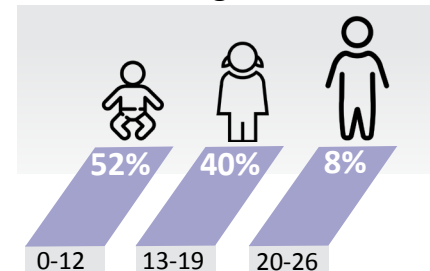
Source: 2019 U.S. Department of Housing and Urban Development (HUD)

Reach...

Geographic Distribution

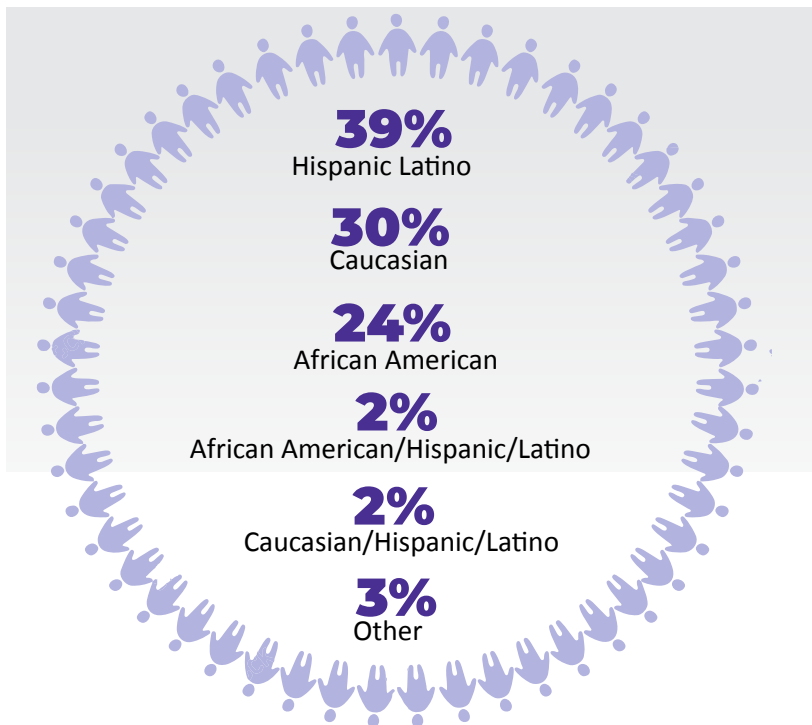


Patient Age Distribution



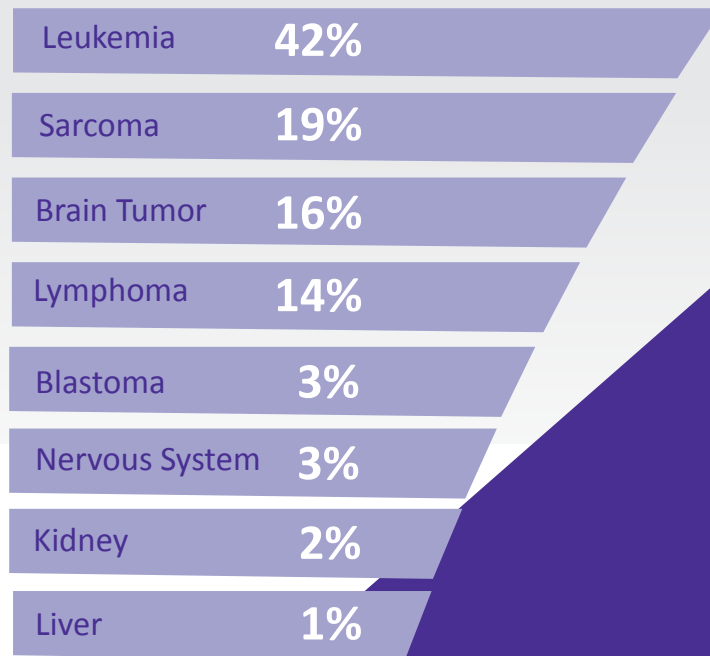
Depth...

Ethnic Diversity



Scope...

Cancer Types



In **17** years, Circle of Care has never turned away a family in need.

2019 Financials

Financial Statement

Year ending December 31, 2019

Revenue

Source of Funds

Contributions	282,247
Special Events Net	28,407
Grants	93,700
Other	4,265
Investment Income	<u>6,598</u>
	415,217

Expense

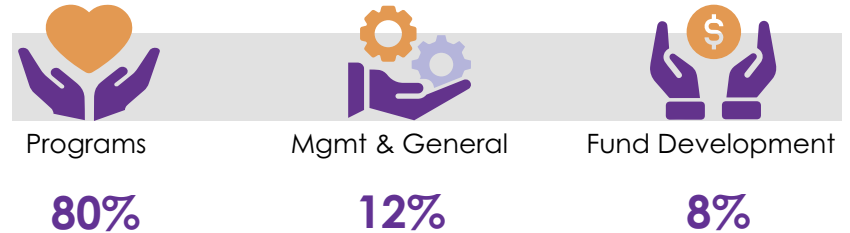
Use of Funds

Programs	328,173
Management & General	46,670
Fund Development	<u>33,606</u>
	408,449

Net Assets

End of Year	579,285
Beginning of Year	586,053
Change in Net Assets	6,768

Operating Expense Distribution



Program Distribution %



5-Year Compound Annual Growth Rate (CAGR) **+17%**



We understand that children need more than medicine to heal.

Bags of Love: **1,650** delivered
Hospital Volunteers: **20,000** hours served
Financial Assistance: **1,050** families served
Art from the Heart: **137** room makeovers
Life Within The Journey: **75** family portraits

Our Partners

Circle of Care offers thanks and gratitude to our collaborative partners who are instrumental in helping ensure our programs and services reach those families in need.

Boston Children's Hospital

Connecticut Children's Medical Center

Maria Fareri Children's Hospital

Memorial Sloan Kettering Cancer Center

**NY Presbyterian Kids- Morgan Stanley
Children's Hospital**

Yale New Haven Children's Hospital

Smilow Cancer Hospital

Circle of Care is especially grateful to the corporations and foundations who partner with us at the highest level in support of our critical programs.

American Savings Foundation

**Community Foundation of Greater New
Haven**

LeClerc Charity Fund

MBIA Foundation

St. Matthew's Episcopal Church

The Young Women's League of New Canaan

Leadership

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Officers

Liz Salguero

President and Founder

Dawn Ladenheim

Treasurer and Founder

Bob Hinckley

Board Chairman

Jeffrey Salguero

VP, Chief Marketing Officer

Elizabeth Vega

Vice President

Stacey Savas

Secretary

Directors

Missy Dorsey

Ray Eckert

Susan Kobylinski

Zelie Pforzheimer

Alex Ramos

Katarina Tchakarov

John Weidner

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Co-Interim Executive Directors

Tammi Small

Director of Programs and Events

Maria DiPierro

Operations Manager

Heather Stabinsky

Development and Communications Associate

Advisory Board

Dr. Mary Jane Hogan

Pediatric Oncology, Yale School of Medicine

Ceci Maher

Past Executive Director, Person to Person

Liz Marconi

MSW, Connecticut Children's Medical Center

Maurice Segall

Attorney, Maurice Segall LLC



After having his central line removed in 2020, Luis said, “I finally feel free.”



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E: info@thecircleofcare.org

Join Our Cause



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