



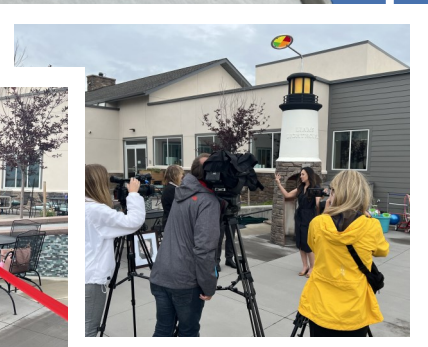
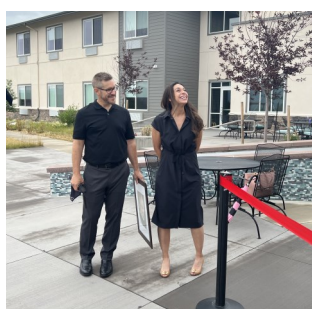
RMHC
of Southern Colorado

Heartstrings

Spring/Summer 2023



LIAM'S
LIGHTHOUSE



"And, a little child shall lead them."

This story is one of Hope. And, of heartache.

It's about a little boy and a family who wouldn't give up. It's about a Ronald McDonald House that provided the care and support they needed, when they needed it most. And, despite their deep pain, it's about choosing to bless others who are also facing an unforeseen medical crisis.

How many times have you felt as if you were 'hitting a wall' - when life was hard and complicated questions had no easy answers - when the help and support you needed felt just out of reach?

For more than ten months, Michelle and Chris Schulze knocked - then banged - on doors that were closed. As new parents, they were desperately seeking answers, looking for the care their young son, Liam, required. "We shared our concerns, asking doctors and specialists for diagnostic tests, to learn what was wrong with our beautiful, little boy."

When they finally received a diagnosis, it brought neither understanding, nor relief.

More questions were asked, as there was much to learn. Their quest took Michelle, Liam and Liam's "Grammie", Rose Ann, to Cincinnati, seeking the best possible medical care Liam required.

In the midst of much unknown, their family felt immense relief when they learned they didn't need to knock on the doors to the Ronald McDonald House - or try and push them open - to be seen or heard. *Instead, the doors to the Ronald McDonald House were lovingly held open for them, for as long as their family needed to stay.*

Michelle said, "Being able to stay at the Ronald McDonald House, just across the street from Liam, was our saving grace! They provided us with everything we needed, including meals and support. My mom and I took turns at the hospital while my husband stayed in Colorado, working to maintain our health insurance." She added, ***"We did that for six months. I don't know what we would have done if the Ronald McDonald House wasn't available."***



Michelle and Chris were first time parents. Liam was born premature, weighing just 4 pounds, 15 ounces. "He was small, but perfect in every way", they said.

At four months old, Liam developed a fever that lasted more than five days. The doctor said, "It's a virus. Treat him with Tylenol and Motrin." However, the next month, the same thing happened: another high fever, lasting five to seven days. These new parents were told it was common for babies to be sick within their first year. Chris and Michelle continued to treat Liam's symptoms, doing their best to keep him comfortable until the episode passed.

This pattern continued for nearly a year. Every time, Chris and Michelle asked doctors for more information. Referred to dozens of specialists, all the tests came back inconclusive.

Soon, Liam had other symptoms: his abdomen was distended; he had a sunburn-like rash on his arms and legs and a yellowish tint to his skin. Chris and Michelle couldn't bear watching their 14-month-old son suffer. They drove to Denver Children's Hospital, about an hour from their home in Colorado Springs.



A fellow on rotation saw Liam. She thought he might have HLH (Hemophagocytic Lymphohistiocytosis). A blood and bone marrow test were ordered. The results came back positive. At first, Michelle and Chris were relieved to learn it wasn't cancer, believing they could fight for their son from a place of knowing. The doctor shared that HLH was more aggressive and more unpredictable than most cancers. Liam started chemotherapy and steroid treatment immediately, hoping to increase his chances of survival.

So little was known about HLH. The prayer was that starting treatment would help save their little boy. At first, it seemed promising, with Liam responding well - eating and drinking and acting like himself again.

Rose Ann began researching an HLH specialist, finding Dr. Lisa Filipovich at Cincinnati Children's Hospital.

Cincinnati Children's Hospital.

Michelle said, "I was told that Dr. Filipovich and her team had treated more than 30 children with HLH in the last three years with bone marrow transplant with 95% currently surviving." She added, "Receiving this message was one of HOPE for us and for Liam!" Michelle, Rose Ann and Liam went to Cincinnati in search of a cure. They were willing to do whatever it took to have their happy, healthy son back.

Because that's what we do for those we love - we find a way. Hospitals and Ronald McDonald House Charities know this, providing family centered care that keeps families close during times of medical crisis.

"Arriving in Cincinnati, we quickly got settled into our room at the Ronald McDonald House", Michelle said. Across the street, doctors said Liam was the healthiest HLH kid there. They again felt their hope surge.



However, sometimes hope dances with despair. During the months that followed, Liam's suffering continued. It was hard on their family to be apart. Chris would fly out whenever he could, but the distance and the not knowing took its toll.

Michelle recalls hope starting to fade when they learned that from a 13-million-person international bone marrow search, not one match was found. Sadly, time was not on their side; they couldn't hold off on transplant anymore. Liam was slipping away.

Chris joined Michelle and Rose Ann in Cincinnati. They asked Liam's doctors if the end was near. The response was, "As of right now, no. But, it's an hour-to-hour basis."



Within 24 hours of his return to Colorado, Chris learned that Liam had contracted a virus and was in kidney failure. He immediately hopped on the next flight to be with his son and his family.

Reflecting back, Michelle said, "There were more than 20 medical staff in our room. I watched as Liam's vital signs plummeted." She went on, "I looked at the attending physician who was working on Liam. He returned my gaze, shaking his head as if to say 'no'. I knew the fight was over." Michelle's heart sank. Their son was dying and Chris was mid-flight trying to get back.

In just a moment, everything changed.

The profound beauty of a Mother's Heart. Michelle requested her Liam be disconnected from all the

equipment so she could just hold her son. She told him it was okay to go be with Jesus. She sang his favorite songs to him as he took his last breath. Sadly, Chris did not arrive in time to say goodbye to his son.

Travelling back to Colorado, Michelle found everything as she had left it six months earlier. Her arms ached to again hold her beloved son. Even in the midst of experiencing profound grief ***Michelle knew she needed to channel her energy, her passion and her love for her son into something meaningful. From that, Liam's Lighthouse Foundation (LLF) was born.***

The legacy Liam left has lit a path for other families facing the same diagnosis. LLF raises awareness, creating and providing the medical community with unbiased, factual information about HLH, ensuring others aren't left in the dark. In addition, they raise awareness about becoming a blood and bone marrow donor. Their family hopes - and prays - that more research will bring safer and more effective treatments and, one day, a cure for HLH.

Michelle said, "My heart is filled with gratitude that, to date, LLF has donated just under a million dollars to directly support our mission." Part of that comes from a decade of hosting an annual 5K run. This year, for the first time, the 5K to Fight Histo will be held in Colorado Springs on July 16th, with a portion of the proceeds supporting our House. This race brings Histo families together from all over the world, helping them know they are not alone. To donate or to register, go to www.5KToFightHisto.org.

Looking back, Michelle said, "One thing we will FOREVER be thankful for was our six-month stay at the Ronald McDonald House in Cincinnati." She paused. *"I honestly don't know how we would have made it there as long as we did without the House. They are an incredible organization and such an integral part of families surviving journeys like Liam's. I knew from the start of LLF that supporting RMHC would be mandatory for us."*



Fast forward to 13 years later. After their experience at the Cincinnati Ronald McDonald House, Rose Ann began volunteering at our House. While there, she learned we were doing a playground renovation, ensuring the outdoor space was accessible for ALL children to play. Together, she and RMHCSC staff began dreaming of how LLF might be of help in creating new, adaptive spaces.

This led to the creation of a custom-built lighthouse that stands 12' high. This "beacon of hope" delights kids and adults who turn the wheel, watching the "light" caught from the sun, refracting a rainbow onto the ground. And, isn't that the way? Liam was a bright light. When the sun shone on him, he reflected that to all around him. Even in his passing, Liam has been a beacon of HOPE, lighting the way for other children and families who are knocking on doors to learn more about HLH.

It's been said, "A little child shall lead them." And, Liam has. As the first permanent installment to an inclusive outdoor playground, Liam has led the way. At a ribbon cutting ceremony, Chris, Michelle and Liam's brothers, Callan and Finn, were joined by Rose Ann and husband, Frank. They shared what it meant to have Liam's memory be a permanent harbinger of hope at our "House that Love Built".



If you would like to help ensure families like the Schulze's never need to be alone, please use the enclosed envelope to respond. To learn more about HLH, please visit www.liamslighthousefoundation.org

The Adapted Outdoor Playground



Maya Angelou said, "I did then what I knew how to do. Now that I know better, I do better." In 2019, when we opened our Ronald McDonald House, the Kiwanis Adventure Zone was an awesome outdoor play area. And, we soon learned that for some of the children and families we served, it presented difficulties. Changing that, we have made adaptations that invite EVERYONE out to play.

Thank you to the generous donors who made the adaptation possible!

- | | |
|-------------------------------|-------------------------------|
| Liam's Lighthouse Foundation | Tuck & Liz Aikin |
| Weed Man Lawn Care | Blue Accessibility Consultant |
| RMHCSC High Roller Raffle | Hesslink Family |
| Brett & Rebecca Axton | Patricia Hudson |
| North Colorado Springs Rotary | Rich & Robin Fickle |
| HBA Cares | Doug & Diane Kathol |
| Sunflower Landscapes | Elevation Dance Academy |
| The Woodshed | Deborah & Frank Dowis |
| Blu Ridge Transportation | |

Our Programs



Ronald McDonald House

Families entering the doors of the Ronald McDonald House are welcomed with care and compassion and invited to make themselves at home. More than a comfortable place to sleep within minutes of their hospitalized child, the House is also a place where guests can find support from a community made up of other families, volunteers and staff. Shared areas, such as the spacious dining room, several inviting seating areas, and the recently updated all-inclusive playground, provide a wonderful setting for families to connect, unwind and find some stability in an otherwise unpredictable time.

Our intention is to provide all that a family needs to care for their daily needs so that they can focus on being fully present for their ill child. This is only possible to achieve due to the combined efforts of our caring volunteers and donors. All of our guests enjoy nightly home-cooked meals, a stocked pantry and fresh-baked treats. Planned activities, such as live music, therapy dogs and high tea service, provide opportunities to recharge before returning for another long day at the hospital. I

invite you to visit and see for yourself why we are called the "The House that Love Built".



Heather Gannaway, House Manager

Heartstrings 6



Ronald McDonald Family Room

In recent months the Family Room has become a bustling place with an increasing stream of guests and visitors. In January the room extended access to seven days per week, reflective of the increase we have seen in caring volunteers joining our small but mighty team.

Within the Family Room you'll find many changes including beautiful new decor helping to warm the space while setting it apart from the hospital. This space - while small in size - is large in its capacity to love and make whole.

Following a successful March Open House, we've continued forward increasing resources offered within the room. Our goal is for the Family Room be an extended reflection of the beautiful Ronald McDonald House, next door. We look forward to the months ahead and give thanks to the partners and friends helping make it possible.



Jennifer Hunt, Family Services Manager

Volunteers are the heart and soul of our organization. Volunteers do it all! Sanitize our House, welcome families with a smile, baking birthday cupcakes, folding laundry, driving families in our shuttle, restocking our beautiful Family Room, preparing meals and gardening. This is just a taste of what happens behind the scenes at RMHCSC.

In 2022, volunteers served a total of 16,867 hours throughout all of our different programs. The estimated value of volunteer time (according to IndependentSector.org as of April, 2022) is \$29.95 per hour. We use this estimate to quantify the enormous value our volunteers have here at RMHCSC. Volunteer service in 2022 was valued at an incredible \$505,165.65!

We are so grateful to have such a committed and compassionate group of volunteers dedicated to serving our families and fulfilling our mission.



"Volunteers do not necessarily have the time; they just have the heart."
-Elizabeth Andrew

Alex Lightfoot, Volunteer Manager

2023's Best Events

Benefit Our Ronald McDonald House!



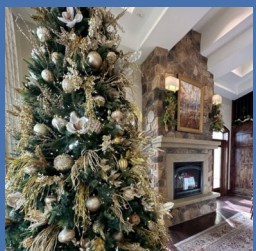
You're invited to the **5th Annual Sporting Clays Shoot** on Friday, June 2nd, at the Pikes Peak Gun Club. Please join us for the afternoon team shoot including lunch, all field fees and gratuities, 100 clay targets with ammunition, gift bags, hearing & eye protection, live and silent auctions plus awards reception with refreshments. Learn more at: <https://www.rmhcsoutherncolorado.org/sporting-clays/>



The **31st Cameron Memorial Golf Tournament** benefiting RMHCSC is October 2nd at Perry Park Country Club, Larkspur. Join us for the golf season's last big hurrah! Breakfast & lunch included plus multiple opportunities for prizes and awards. First come first served. Find registration and sponsorship opportunities at: <https://www.rmhcsoutherncolorado.org/golf-landing-page/>



Now in its 12th year, our annual **Radiothon** is a day-long broadcast, on 95.1 Cat Country. Join us November 3rd, for stories from our families, volunteers and care partners, highlighting the importance of keeping families together while their child receives vital medical care nearby. To reserve your spot on this impactful broadcast go to: <https://www.rmhcsoutherncolorado.org/radiothon/>



December 3rd, 2023, join us for the 2nd annual **Christmas Tree Festival** at The Pinery at the Hill. This holiday brunch features 30 beautifully decorated, themed Christmas Trees (valued at \$150 each) one of which you could possibly take home with you! To learn all about this fun holiday event go to: <https://www.rmhcsoutherncolorado.org/the-christmas-tree-festival-2/>



**Ronald McDonald
House Charities®**
of Southern Colorado

4223 Royal Pine Drive
Colorado Springs, CO 80920
<https://www.rmhcsoutherncolorado.org/>

Non-Profit Org.
**U.S. Postage
PAID**
Col. Springs, Co
Permit #816

Your Support Matters!



Although we don't always ask, your support is both needed and very much appreciated.

Whether you have chosen to become a donor, make a meal for our children and families staying at the House, volunteering of your time and efforts, participating in one of our fun events, and/or, becoming a sponsor of an event, what you've done matters.

It matters to the Moms and Dads who get to be with their kiddos for morning snuggles and goodnight hugs - and everything in between, and also for the critically ill child who wants, most of all, to have their families with them while they're hospitalized and receiving treatment. Your support and care mean the world.

Thank you for choosing to help by supporting our Ronald McDonald House Charities of Southern Colorado. We couldn't do it without you.



**Ronald McDonald
House Charities®**
of Southern Colorado