

FROM THE HEART



Sharon's Story

Learn more about Sharon on page 4.



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Follow us on social media for RMHD news, family updates, & happenings around the House! Simply search for **rmhdallas**.



MY LIFE AT RMHD



Hello RMHD friends,

I wanted to take a moment to introduce myself. My name is Kennedy Robinson, and I started as the new Marketing & Communications Manager for the Dallas House in March.

While I'm not the only new face to join our team over the past year, I can definitely say my onboarding process looked a little different than most of my colleagues. Born in Carrollton and raised in Austin, I consider myself a Texan through and through. However, my pursuit of a Journalism degree led me to the University of Missouri in Columbia, and then to St. Louis, where I've been residing the past five years. After struggling with being away from my family throughout the Covid-19 pandemic, I realized it was time for me to come home. Little did I know my search for a job in Texas would not only bring me closer to my tight-knit family... it would also bring me a renewed drive and passion in life.

As external factors wouldn't allow me to completely relocate to Dallas until late May, the RMHD team graciously worked with me to create a plan that would fit both of our schedules. For four of my first six weeks, I was able to live here at the House!

Not many people get the opportunity to live where they work, but doing so allowed me to completely immerse myself in RMHD and our mission. I was able to spend time with our night staff, chat with our evening and weekend volunteers, and interact with our guest families in such a unique way. From morning meals to nightly housekeeping – I was able to witness firsthand just how much goes into running the House. It was truly inspiring to see how strong our families are, and how much hard work goes into taking care of them during their time of need.

I am honored to be a part of this organization and look forward to communicating with all of you, our supporters, in this newsletter, on social media, and website!

- Kennedy Robinson
Marketing & Communications Manager

HAPPENINGS AROUND THE HOUSE

Dining Room Reopened

On April 1, 2022 we reopened our dining room, which had been closed for almost 25 months, due to the Covid 19 pandemic. Our staff celebrated by cooking a special lunch for our families that day!

We were also able to resume breakfast, lunch, and dinner groups every day of the week!



Volunteer Appreciation

April was National Volunteer Month, so the RMHD team held an appreciation event for our volunteers at the Texas Discovery Gardens on Tuesday, April 26. We want to thank our Volunteer Services Manager, Caitlyn Carter, for organizing the event. We also want to thank all of our wonderful RMHD volunteers. We couldn't do what we do without them!

Therapy Horse Valor

We had a special visitor at the House earlier this month! Mini Hooves of Love stopped by with Therapy Horse Valor for an afternoon.

Valor enjoyed all of the pets and hugs he received. Some of our kids had the opportunity to take him on a walk around the courtyard!



Easter Egg Hunt

We held an Easter egg hunt on April 17th. Families had a blast looking for eggs in the courtyard before heading to the dining room for a special Easter bunch!





Sharon's Story

Sharon was born on May 8, 2016. At first, everything was perfectly normal. According to her parents, Graciela and Cesar, she was a completely healthy, happy toddler. Sharon was talking and walking, and was on the right developmental track for her age. However, a little before her fourth birthday, all of that would change.

When Sharon was 3 years and 8 months old, she suffered her first seizure. She began to regress all her age-appropriate abilities, which was something her parents really struggled to witness. She suddenly began to present difficulty in speaking, walking, and kept having seizures. Her parents did everything they could to find the cause and visited all the neurologists in Paraguay looking for a possible diagnosis.

That diagnosis would come in November 2020. Sharon, now 4 and a half years old, was diagnosed with an ultra-rare disease called Batten CLN7, which impacts an estimated 4,000 patients globally. According to LivingBatten.com, "Batten CLN7 is caused by a variant in the CLN7 gene, also called the MFSD8 gene, which leads to disruption of normal CLN7 protein function." This disease affects the eyes and brain, causing regression, seizures, blindness, and ultimately, death. Unfortunately, there is currently no cure, but there have been some emerging treatments.

During their research into Sharon's disease, Graciela and Cesar stumbled upon the Batten Hope Foundation website, where they learned of an investigational gene therapy to treat Batten CLN7 in Dallas. After fulfilling all the inclusion requirements in April 2021, Sharon was approved to be the first girl in the world to be tested with the gene therapy, which is being conducted in partnership with UT Southwestern Medical Center, Children's Health, and the Batten Hope Foundation. The treatment consists of replacing the missing protein, and Sharon received her first treatment last May.

During her treatments, the family has been staying with us at the House. "The Ronald McDonald House of Dallas has been a true home for us, a great blessing," Graciela began. "The medical team were the ones who contacted the House because Sharon had to feel safe since her body received a protein that was a foreign body. And she has to take medication to keep her in an immunocompromised state so that her body does not reject the protein."

The first phase of the investigational gene therapy lasts two years, and Sharon has just passed the first-year mark! Graciela said, "Today Sharon is stable, and we believe that the disease has stopped! We are more than grateful to God for blessing us with the Ronald McDonald House of Dallas and with their amazing work they are able to continue to be a blessing to countless families like us."



Audrey's Children

We have exciting news to share with our RMHD family! This fall, screenwriter and producer Julia Fisher Farbman will be bringing her new film, Audrey's Children, to the big screen. Audrey's Children is a film that shares the "true story of revolutionary oncologist, and co-founder of Ronald McDonald House Charities, Dr. Audrey Evans."

While working as the first Chief of Pediatric Oncology at Children's Hospital of Philadelphia, Dr. Audrey Evans recognized the need for families to have lodging and resources while their children were receiving medical care. In 1974, co-founders Dr. Audrey Evans and Jimmy Murray, the former general manager of the Philadelphia Eagles, opened the first Ronald McDonald House in Philadelphia. Since opening, the Ronald McDonald House Charities has over 375 locations, including RMHD which opened in 1981.

Audrey's Children follows the life and impact of Dr. Audrey Evans. During her time at the Children's Hospital of Philadelphia she founded the Children's Cancer Center and developed the Evans Staging System, "which analyzes cancer progression and groups patients based on common traits to determine the best treatments for kids with Neuroblastoma."

Audrey's Children is currently in production and is expected to be released in 2023. More information and updates on this project can be found on the film's website, www.audreyschildren.com.

Photos courtesy of www.audreyschildren.com.

Pictured from left to right: Julia Fisher Farbman, Dr. Audrey Evans



Pictured from left to right: Ronald McDonald, Jimmy Murray, Dr. Audrey Evans



Pictured: Dr. Audrey Evans



Bajo La Luz De La Luna

On Cinco De Mayo, we held our Bajo La Luz De La Luna (*Under the Moonlight*) gala for the first time since 2019. Special thanks to our presenting sponsor, LiquidAgents, who has been sponsoring this event since 2018. Co-chairs April & Chad Cook and Holly & Paul Wittorf worked tirelessly with Hamilton Sneed, HAS Events, to make this a fun and festive event as we honored Haylie & Bert Crouch. We want to extend our sincerest gratitude to those who supported this evening. We were able to raise nearly \$400,000, which will go towards helping our RMHD guest families.

Enjoy this quick snapshot into the most festive party of the year! Photos courtesy of Sheryl Lanzel.



We also want to thank our event sponsors, live surprise and auction donors, development committee, and all other event partners for your contributions to Bajo La Luz De La Luna! This event wouldn't have been possible without your generosity.

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Keeping families close™

Ronald McDonald House of Dallas (RMHD) is keeping families together, inspiring strength, and giving love and support to families whose children are receiving essential medical care.

In an effort to lessen the burden, reduce stress, keep the family intact, and enhance the quality of life for these families, RMHD provides temporary housing in a caring home-like atmosphere. The Ronald McDonald House program was built on the simple idea that nothing else should matter when a family is focused on healing their child – not where they can afford to stay, where they will get their next meal, or where they will lay their head at night to rest.

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2022 RMHD Upcoming Events



CALLING ALL GOLFERS



ADDISON ROTARY OPEN
Monday, September 12, 2022
Gleneagles Country Club
addisonrotary.com

MILES OF SMILES



THE TRAINS AT NORTHPARK
November 12, 2022 - January 1, 2023
NorthPark Mall
thetrainsatnorthpark.com

Wishlist

- Ziploc Bags
- Tide Pods
- Individually-Packaged Snacks
- Water Bottles
- Kleenex
- K-Cup Pods

Questions? Contact Johnathan Elder at jelder@rmhdallas.org or 214-624-5355.