

## The Ties That Bind Us All

# Together



The following story is about the ties that bind us all together. Some of those bonds are strong, like the bond between mother, Allisa Whitt, and her daughter, Leslie. On a Sunday afternoon last October, their lives became bound in a very profound and intimate way with Ronald McDonald House night supervisor Mary Merendino.

There are so many stories we can tell about the lives of people who stay at the House, and not all of them have happy endings. But because of the love and compassion of these three women, this is a story about how that love and compassion continues to grow to this day.

The journey that brought them together began with Leslie Whitt, a bubbly young woman who loved polka dots, Reba McEntire, the Cincinnati Reds, and origami paper cranes. She was that special sort of woman who knew at a very early age who she was and where she wanted to go.

As a freshman in high school in the Cincinnati area, she began volunteering with Starfire, a foundation dedicated to the inclusion of children and adults with disabilities into the communities around them. She donated her time as a counselor at a summer youth camp for diabetic children. She saw the world around her, and found her own ways to make it better.

When she was accepted at Case Western Reserve University, she made the decision to become a dietician. Everything seemed great, except for some persistent and sometimes alarming symptoms that began for Leslie in high school.

Leslie seemed to lack energy. She had gastrointestinal problems. She had a terrifying seizure in the presence of her parents. Unfortunately, the cause of those symptoms were misdiagnosed until she entered college.

When she began passing out at school, she went to see an endocrinologist at the Cleveland Clinic Foundation who then referred her to a neurologist, Dr. Bruce Cohen. After a neurology work up, the Whitt family finally had an answer: Leslie had a disorder called Mitochondrial Disease.

Mitochondria are present in almost all of the cells in our bodies. They are the "powerhouses" of the cell, supplying energy to them. In Mitochondrial Disease, effected cells do not get the energy they need from the mitochondria, in some cases causing cell death and failure of organ systems. While Leslie was glad to finally have an answer to her constellation of symptoms, Dr. Cohen told her and her family she "would never be healthy." There were ways to control the disease, but there was no cure.

While Allisa and Leslie were at a United Mitochondrial Disease Foundation (UMDF) meeting in Arizona, Allisa heard Dr. Sarah Friebert, a palliative care doctor at Akron Children's Hospital, speak. After the meeting, Allisa contacted Dr. Friebert to see if she would be willing to see Leslie as a patient. When Leslie had her first appointment with Dr. Friebert, she "fell in love," and began treatment at Akron Children's Hospital. At almost this same time, Dr. Cohen, Leslie's neurologist in Cleveland, moved his practice to Akron Children's, so she was able to see both for her treatment.

Her treatment continued in Akron for one-and-a-half years, with Allisa and Leslie making the drive from Cincinnati and staying at the Ronald McDonald House during the time Leslie was at the hospital.

In that time, Leslie got married. She got an assistance dog, Billy, from ADAI (Assistance Dogs for Achieving Independence.). She began working on her bucket list: riding on the blimp, seeing Reba McEntire via the Dream Foundation, going to an Amish farm to milk a cow.

***She wanted to make 1,000 paper cranes, but when her strength waned, her sister, Megan, sent out a plea on Facebook and received 5,664 paper cranes.***

Over that year-and-a-half, Leslie's disease began to take its toll on her strength and her body. On October 1, 2012, she had reached the point where treatment was no longer effective, and Dr. Friebert said it would be only a matter of weeks.

But in true Leslie fashion, she decided that she and her family should participate in the UMDF walk on Saturday, October 20 at Lock 3 in Akron. On Friday, Allisa and Leslie headed north to Akron for the walk, stopping in Lebanon, Ohio, to see Leslie's dad on the way up. Leslie's husband, Jeff, and her sister, Megan, met them late on Friday in Akron, and she spent time with family and friends.

On the day of the walk, Leslie's energy level was so low that she could not walk, so Allisa and Megan walked for her.

That Saturday evening, Leslie again spent the evening with family and friends, including a surprise visit from a good friend from Philadelphia. At the end of the night, Jeff and Megan headed back to Cincinnati with Leslie and Allisa to follow on Sunday. At the end of the night, Leslie asked her mother to give \$250, half of what she had brought for the trip, to a family at the House that was having a rough time.

The first true sign of trouble was after lunchtime on Sunday. Allisa was hesitant to leave Leslie to eat lunch in the House dining room, but when she asked Mary Merendino (RMH supervisor that day) to help her get Leslie into a wheelchair, they found her unresponsive.

After a consultation with an employee from ACH's Palliative Care Unit, he suggested that Leslie could be admitted to the hospital, but he also felt that she could make it home to Cincinnati. All that Allisa could think was, Leslie did not want to die in the hospital. Her decision was to take Leslie home.

As Mary assessed the situation, she became alarmed that Allisa was planning to drive alone to Cincinnati with Leslie. Over protests from Allisa, Mary insisted she go along. After a call to Anne Collins, the Executive Director of the House, Anne came to tend to the duties at the House while Mary and Allisa took Leslie home.

On the trip to Cincinnati, Mary and Allisa, who had only known each other casually from the House, talked about their families - Allisa about her two daughters, and Mary about her three children. While Allisa drove, Mary kept a watchful eye on Leslie's breathing monitor. As long as the light on the monitor was green, Leslie was breathing.

*continued inside*



*Leslie with Reba McEntire, arranged for by the Dream Foundation.*

*Allisa and Leslie on the Blimp ride.*





# The Ties That Bind Us All Together

The plan was for Allisa and Leslie to meet their family at the Grove City exit and to then head home. This was an exit where mother and daughter had stopped many times to shop or eat on the way to Akron.

Somewhere near Dublin, Ohio, Mary saw that the light on the monitor had turned red; Leslie was no longer breathing. She quietly told Allisa, and they drove on, determinedly, toward the Grove City exit without speaking.

Once they arrived at Grove City, Mary took Billy, Leslie's assistance dog, on a long walk to give Allisa and her arriving family time alone with Leslie. After a time, Mary moved into the back seat and, with the help of ACH's Palliative Care Unit, confirmed that Leslie had passed away. At this point, a decision was made for the family to proceed to Cincinnati, as they did not want Leslie to go to the coroner's office in Columbus. After they left, Mary waited in Grove City for volunteer Elaine Forsch from the House to come and pick her up.

This could be such a sad story except for one thing: the bond between this one extraordinary woman, Leslie, and the people around her, continues to this day.

Leslie's family is finishing her "bucket list" for her. The Whitt family has been allowed to adopt Billy, Leslie's assistance dog, and he has been a big part of the healing process for them all. Mary and Allisa have become close in a way that few others can understand. Occasionally, Mary will find one of the paper cranes from Leslie's funeral in her purse or her car and remember the journey they took on that day in October.

Incredibly, Allisa made the decision to volunteer at the Akron Ronald McDonald House. With all the volunteer work Leslie did in her life, Allisa felt like Leslie was telling her that she should do this. She makes the trip from Cincinnati once a month to volunteer for shifts on Mary's weekend at the House. Allisa says, "Leslie felt like it was home here at the House." Then she adds, "I also feel close to her here."

In some very real ways, the journey that this mother and daughter began continues to this day.

For more information about UMDF, visit their web page at [www.umdff.org](http://www.umdff.org).

For information about the Akron walk for UMDF, go to [www.energyforlifewalk.org/akron](http://www.energyforlifewalk.org/akron).



## You Can Start Helping Now — Sponsor a Room Today!

While our rooms are full every night, there is still an opportunity for you or your company or organization to sponsor a room at the Ronald McDonald House of Akron.

The cost to sponsor a room annually is \$5,000, and it helps us to maintain our existing twenty rooms. This provides us the resources needed to give our families a safe, comfortable and high-quality room for their time with us.

To date, we have secured room sponsorships from the Ronald McDonald House of Akron Volunteers and Staff, the Ronald McDonald House of Akron Board of Trustees, the Alpha Delta Pi University of Akron Chapter, the Junior Women's Civic Club (JWCC), the Friends of the Ronald McDonald House, and the Grguric Family.

We are excited to announce that we have received two lifetime sponsorships, an investment of \$50,000, from Ronald McDonald House Charities of Northeast Ohio, and from GPD, in honor of John W. Zachardy.

In return for your sponsorship, you will receive an attractive Don Drumm plaque with your name mounted outside one of our guest rooms, as well as a replica for your own personal display, publication

in this newsletter, as well as on our Facebook page and website, an invitation to our Annual Donor Open House, and thank you letters directly from our families.

But beyond that, you will have the satisfaction of knowing that you are part of this greater community with a mission to provide a place to stay for the families of sick children from around the state and around the world. You can be a part of our promise to keep families together when it matters most.



### UPCOMING EVENTS AT AKRON'S RMH

- 2013**
- 12/7 Pictures with Santa at Every Blooming Thing
  - 12/12 Tips for Tots at Winking Lizard in Peninsula
  - 12/14 Pictures with Santa at Every Blooming Thing
- 2014**
- 2/14 Zumba Dance Event
  - 2/22 Portage Lakes Polar Bear Club Polar Bear Jump
  - 6/23 JWCC Golf Outing-Canton Brookside
  - 7/17 Dinner on the Farm
  - 7/28-8/3 Bridgestone Invitational
  - 8/30 Akron Car Club Car Show



### Campaign Update

If you remember the picture that was in this space in our last issue, this is the parking deck that grew from the giant sandbox! Even more exciting than the new (and needed) parking at Akron Children's Hospital, the deck was opened ahead of schedule and under budget. Best of all, the interactive lights on the outside can be remotely controlled and changed by the patients at Children's!

### A Message From Our Executive Director, Anne Collins



As I write it is a beautiful fall day here at the House. The House as usual is full, but being Sunday a more casual atmosphere prevails. Our families are having breakfast and gearing up for another day over at Akron Children's Hospital.

It reminds me that the people who make this House a home are also a very unique family all unto themselves. The dedicated Staff who day in and day out make sure that all our guests' needs are met; their instinctive ability to know which family may need some additional care and attention and which family needs that extra space to deal with their situation in their own private way. Not to mention the hours of work put into running the office, scheduling, meal planning, fundraising and preparing for an expanded House to better serve our families.

Then there is the lifeline of our family; the Volunteers who our House would literally close without. Every day they show up to cook, clean, repair, mow the lawn and keep the House running. They range from 8 years old accompanying their parents to 93 years young. Each night a meal is served to the families staying with us that is prepared by these volunteers or is supplied by area restaurants or groups, all part of the Ronald McDonald House family.

We have some new members to our family. Two new groups have formed to help our House grow; The Friends of Ronald McDonald House of Akron and The Red Shoe Society. Please go to our website [www.rmhakron.org](http://www.rmhakron.org) to check out these groups and see if one may be right for you. We welcome these two new groups to the family.

Last but not least two very important parts of our family: the Board of Trustees and the Children's Family Care who guides our families and ensures our success and continued growth.

As you can see, families come in all shapes and sizes, and as we move into that time of year to give thanks and giving remember "family" is what is important and matters most. From our family to yours have a peaceful and caring holiday season.

## Donation Wish List:

Single serving packaged:

- ♥ Granola bars, Nutri-Grain bars
- ♥ Fruit cups
- ♥ Applesauce
- ♥ Pudding/Jello cups
- ♥ Snack crackers (cheese, peanut butter)
- ♥ Fruit snacks, raisins
- ♥ Chips
- ♥ Pretzels
- ♥ Crackers
- ♥ Potato chips
- ♥ Cereal boxes
- ♥ Juice boxes/bags
- ♥ Fresh fruits (apples, bananas, pears, oranges)
- ♥ Yogurt cups
- ♥ Lunch meat
- ♥ Sliced cheese
- ♥ White/wheat bread
- ♥ Hot dogs
- ♥ Frozen store purchased soups-family size
- ♥ Stouffer's/Lean Cuisine ind'l serving entrees
- ♥ Laundry detergent
- ♥ Paper towels
- ♥ Ziplock bags-all sizes
- ♥ Dryer sheets
- ♥ Dishwasher detergent
- ♥ Swiffer Sweeper wet cloth refills
- ♥ Pledge furniture polish
- ♥ Purell (travel size)
- ♥ Chap Stick
- ♥ Gift cards: Acme, Giant Eagle, Sam's Club, B.J's or Bed, Bath and Beyond

Every issue, along with our typical Wish List items, we ask for gift cards. Why a gift card? Because it provides us with the flexibility to purchase what we need when we need it to care for our families and run the House efficiently. With changes to our House and to our meal program (see the article in this issue), it only makes sense.



# Dinner is served.

The RMH feeds guest families with the help of the community!

Here at the Ronald McDonald House of Akron, we often hear exclamations of surprise when we show new friends or residents around, but when we explain our meal program to guests and visitors, it usually strikes a chord! Every night of the year, we serve a full dinner to our residents. Weekends, holidays – you name it, dinner is served! What is even a little more surprising to people is that this program began the day our House opened on January 13, 1985. That comes out to roughly 10,500 dinners in an almost 29 year span!

In its infancy, the nightly meal program had little structure. As the House continued to develop its programs and services, staff and volunteers began to truly realize how much a well-planned, hot meal on a long day came to mean to our families. As our current resident, Jenny V., puts it, “It takes a huge burden off of us especially for families that do not have the cash to buy meals all the time. You don’t have to worry about cooking or preparing anything. You just come to relax and it’s one less thing you have to worry about.” In 2003, a dedicated committee, headed by Mary Redle, was formed and thus began the community outreach needed to sustain and enhance the nightly meal program. These committee members approached area restaurants, delis, groups and individuals to educate them on the program and ask for their needed assistance. When Don McCardle joined the group in 2005, the donations boomed.

Since then, the program has taken off! Currently, over 40 restaurants, delis and caterers from the area contribute to our program. In an average month, 8 - 12 meals are brought in from a local establishment. The rest of the month, meals are prepared by our talented volunteer cooks and groups who use donated goods and groceries. Cooks are told to prepare a meal for up to 50 people each night with most meals consisting of a main course, sides and a dessert.

We use the food program to allow yet another way for our families to remain close together as much as possible. With the burden of grocery shopping and cooking off their backs, families have more time to focus on the treatment and care of their child, not to mention that the meals give added nourishment in a time when their focus is not usually on taking care of themselves.

Knowing first-hand what it’s like to be a resident here and how much a great meal can comfort those in need, Emma Yoder faithfully commits to preparing and serving a full Amish-style meal once a month. Fifteen years ago, Emma’s daughter was treated at Akron Children’s Hospital and during that process, the Yoder family stayed at our House and enjoyed the comforts of having dinner each night. Accompanied by her now healthy daughter and other friends including Anne Casey, their driver, Emma makes sure she gives back to our House by volunteering and preparing one of our most popular (and delicious!) meals each month.

Another big supporter of our nightly meal program is Chick-fil-A in Cuyahoga Falls. This outstanding restaurant has been supporting our organization since 2010 by providing dinner once a month which usually includes chicken strips, chicken nuggets, coleslaw, fruit, salad and dessert. When asked why Chik-fil-A gives to the House, Mike Johnson,

## Want to know how you can help...

Providing our residents with a nightly meal for nearly 30 years has occasionally involved some creative thinking, but it is always made possible by the ongoing generosity of the greater Akron community. Please visit our website, [www.rmhakron.org](http://www.rmhakron.org), to see a list of the individuals and companies who make this happen because of their donations. ***If you would like to donate a meal for fifty grateful people (our wonderful families!), please contact the House at 330-253-5400.***

Chick-fil-A General Manager says, “We feel it’s important to support an organization that really cares. We are all part of one community and it is important that we as a community support one another”.

The rest of 2013 is filled with planned dinners and spots are currently being filled for 2014. A working calendar is kept to make sure not a single day is missed and proper arrangements can be made for delivery, pick-up, grocery shopping and prep. With all these considerations, a nightly meal is estimated to cost \$140.00. Part of the suggested guest \$10/night donation goes to support our nightly meal program. In 2012, only 39% of families were able to contribute anything to their suggested donation. It is the ongoing support of the Greater Akron area that guarantees this meal will always be provided at the House. Therefore, with our current expansion on the horizon, we know that this program will need to continue to grow as well. Our House currently has 20 guest bedrooms and at the completion of the expansion, we hope to get up to 60 guest bedrooms. That’s a lot of mouths to feed! This program has been so successful that special arrangements are being made for the expanded House to have a separate meal prep area and commercial style kitchen. This way, we can accommodate and plan for serving up to 150 people each night through the program.

To help pull off this feat, our House would like to explore more partnerships with additional local restaurants and groups. Our Executive Director, Anne Collins, says, “By providing a meal for our residents, supporters are giving much more than a meal. They are giving a chance for families to be together and ease their struggles. With continued support from the community and by growing our meal donor base, we will be able to keep this program running for many years to come in a House three times as big.”

As of August of 2012, new guidelines for the food program were established to ensure the health and safety of the families who take advantage of the food the House provides. Our House can no longer accept any donations of food prepared by volunteer cooks in private houses. Only food prepared at a licensed retail food establishment can be accepted for donation if delivered directly and within a short period of time and only packaged foods purchased from retail grocery stores in unopened containers or whole fruits or vegetables can be accepted for donation. In addition to these rules, any food item past its expiration date may not be used. The health, safety and well-being of families who stay at our House is our greatest priority when planning our meal program.

There are many ways to get involved in our meal program! We understand that many local businesses, restaurants and caterers have full schedules and are busy running their own organizations, so it helps when these establishments donate gift cards for us



to purchase meals at their stores when we need to. Gift cards to local grocery stores are also a great way to get involved in our meal program to ensure we have the items we need when the time comes for our volunteer cooks to prepare a meal.

In addition to the rewarding feeling of helping families in need, groups, restaurants, delis and caterers can expect to be recognized for their heartfelt gesture. We proudly acknowledge all of our meal donors on our website and encourage friends of the House to patronize these establishments. We also display the name of your group or establishment on the day of the meal in our main entrance and will sometimes add names, pictures and stories of your donation to our social media pages. Check our website to see a full list of our 2013 meal donors!

Community support will be crucial for a successful expansion and growth of our meal program. We encourage restaurants and individuals alike to contact us about getting involved in the program and we thank the many groups, organizations, restaurants and caterers who have given so generously to the families that stay at the House! Help us to keep families together (and fed!) when it matters most.

— written by Stephanie Zelasko

## A Message From Our President, Heather Jalbert

I cannot believe the time has passed so quickly, and as my term as President soon expires and I reflect on all we have accomplished together and all that is soon to come, I can only smile to myself and say WOW!!

These past two years have been as fulfilling and exciting as promised - and the work we do for so many families in need is absolutely unbelievable. As you all know, we here at the RMH have embarked on the most ambitious and significant physical expansion in our history. Our board, our staff and countless volunteers, as well as our many institutional and community supporters, are demonstrating their commitment by giving of their time, talent and treasure as we lean forward to undertake this much needed and highly anticipated expansion of the RMH of Akron. Our capital campaign is underway and we are excited about the future as we look forward to the groundbreaking. When completed, our renovation and expansion of the House will give double our current capacity. This is amazing as we will be able to increase our potential and provide even greater support to our families and allow us to meet our mission and vision promises. Think of it - a sixty-room house. WOW!

While I will be turning over the reins to Steve as our next president in January, I remain committed to the RMH and I plan to continue to serve RMH of Akron on both the capital campaign and Strategic Planning in the years ahead.

Throughout my tenure as President, I have come to know each of you and I remain humbled and amazed by your individual and collective commitment to the house. It has been an extraordinary adventure. To the staff and volunteers, words simply cannot express my thanks for all you do. You are simply the best team ever assembled. Thank you from the bottom of my heart and may God bless.

### Staff:

Anne Collins  
Executive Director  
Meri Skiera  
Volunteer/  
Media Coordinator  
Stephanie Zelasko  
Executive/  
Development Assistant  
Mary Merendino  
Night/Weekend Manager  
Lauri Esposito  
Weekend Supervisor

### Care Cables:

TRIAD /  
Next Level  
Designer  
Star Printing  
Casey Hughes  
Editor  
**Honorary Trustees:**  
William Considine  
Robert Klein, M.D.  
John Shaffer

### Board of Trustees:

Heather Jalbert  
President  
Steve Shriber  
Vice President  
Casey Hughes  
Secretary  
Kim McFarlane  
Treasurer

### Board Members:

Sarah Baker  
John Blickle  
Darryl Fieldman  
Sarah Flannery  
Donna Grigas  
Jeffrey Hord, M.D.  
Luisa Iturriaga  
Don McCardle  
Connie Nolte  
Michael O'Malley

Rosie Perez  
Mary Redle  
John Sloan  
Kristin Susick  
Pamela J. Webb  
Janis Worley  
Dawn Zelich  
John Zoilo

### Who To Call:

For volunteer opportunities, either on a regular basis or for special needs, call our Volunteer Coordinator, Meri Skiera at 330.253.5400. For information on organizing a fundraising event, call Anne Collins at 330.253.5400. If your group or organization needs a speaker to discuss our mission, call Meri Skiera at 330.253.5400.





**RMH Food Program**

Since January of 1985, the Ronald McDonald House of Akron has provided an evening meal for its residents every night – weekend, holidays, snow days, every day, without fail. To read up on our food program and the need for it to grow with the House, check out the “Dinner is Served” article inside.

Love Care Cables in your mailbox? Then you'll love our e-newsletter in your inbox! Send an email to [stephanie@rmhakron.org](mailto:stephanie@rmhakron.org) to start receiving the monthly Ronald McDonald House e-newsletter.

**Ronald McDonald House** 

[www.rmhakron.org](http://www.rmhakron.org)

Check if appropriate:

- My name is misspelled
- My address is incorrect
- I received more than one copy
- I no longer wish to receive Care Cables

Please clip your label and mail to us noting your request.

The Ronald McDonald House of Akron does not share your personal information (i.e., name, address).

Non-Profit Organization  
U.S. Postage  
**PAID**  
Akron, Ohio  
Permit No. 534

**Ronald McDonald House® of Akron, Inc.**  
245 Locust Street, Akron, OH 44302

Return service requested



AKRON

# Care Cables

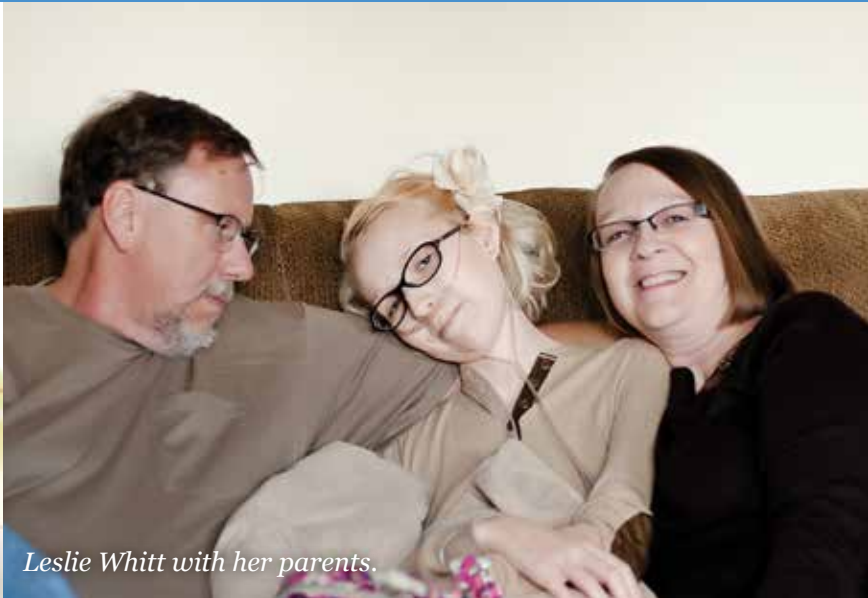
Ronald McDonald House of Akron's Newsletter to Friends

[www.rmhakron.org](http://www.rmhakron.org)

Fall 2013

## The Ties That Bind Us All Together

The families we care for at the Ronald McDonald House are on a journey. Some share only a few days of that journey with us, some months, and some even longer. Inside this issue, read how we help them along that road, whether it is with a welcoming atmosphere, a satisfying meal, or something much more.



Leslie Whitt with her parents.

## PARTY WITH A PURPOSE!

For the past four years, Rick and Pat O'Desky have graciously opened their home to sponsor a holiday party to benefit the Ronald McDonald House of Akron. All invited guests are asked to bring a gift card, Wish List item, or make a monetary donation to the House in return for the chance to enjoy the O'Desky's wonderful spread of holiday food, drinks, and desserts surrounded by the beauty of their private residence.

This amazing event fills our coffers and our shelves for months after the holidays are gone. A very special thank you to the O'Deskys (Pat is Personal Assistant to Bill Considine, CEO of Akron Children's Hospital) and to Two Men and a Truck, who help us with a donation of a truck and drivers to enable us to manage the large amount of donated goods we hope to receive.

