



Aloha

From Our House to Yours

www.RonaldHouseHawaii.org

Newsletter of Ronald McDonald House Charities® of Hawaii

January 2012



A Family United

Having one of your children stricken with leukemia is challenging and frightening enough, but imagine what it must be like to have two of your children both coming down with the disease almost within a year of each other. If it were you, how would you react? How would you cope with having your world turned upside down - twice? One could only hope to handle it with as much poise and purpose as the Spence family is mustering right now.

Originally from Mililani, Dan and Elaine Spence relocated to Hilo in 2008, when Dan accepted a position with a water bottling company there. Then, in 2010, just as the couple and

their four children, Jordan, 19, Elexis (Lexi), 16; Angelina, 13; and Danielle, 10, were starting to settle into a comfortable routine in their new home and schools, everything suddenly changed. It changed when their doctor uttered the word "leukemia." Lexi was diagnosed with acute myeloid leukemia (AML), an aggressive form of blood cancer, as she was beginning her sophomore year at Hilo High School.

At first the family was in shock. "It's something that happens to someone else's kid, not your own," Dan mused. But soon, he took charge, and came up with a strategy to give Lexi the best chance to get well. It involved great sacrifices by the whole family, as they all moved temporarily to Oregon, near Doernbecher Children's Hospital, to be with Lexi during her bone-marrow transplant and treatments. Lexi's sisters

enrolled in school there and Jordan, a college freshman, transferred to a university near Portland. Dan had to go back and forth to Hilo, tending to his job there.

Lexi's treatments and follow-up care in Oregon lasted more than nine months. To keep the family together up on the mainland, Dan and Elaine used all of their savings and retirement funds. It took an emotional toll on everyone too, but they managed to get through it. Lexi's AML went into remission, she grew her hair back, and they all began to dare think about returning to the happy routine they had enjoyed together in Hilo. But it wasn't meant to be.

In November 2011, about two months after getting back from that unexpected and unwanted adventure, unbelievably, Angelina was diagnosed with leukemia too. It was a different type than Lexi's called Acute lymphoblastic leukemia (ALL). The Spences again found themselves facing difficult challenges and needed to rearrange their lives to stay close to Angelina, who is still in the early stages of her lengthy treatments on Oahu. They are currently staying together at the Ronald McDonald House, continuing to draw strength from each other. "This

time around it's both easier and harder," Dan said. "It's easier, because we know the routine and what to expect. On the other hand, we've stretched our resources as far as they can go." It is also harder for them to hide the

strain they all are feeling.

Like her sister Lexi, Angelina is growing up faster than she probably should be. She still dreams of traveling to places like Paris and New York, becoming a chef and having her own restaurant someday, but through her experiences, she has developed a burning desire to help others. Lexi has come through her treatments feeling the same way, and the two, along with Danielle, have made plans to start a non-profit dedicated to helping kids with cancer and their siblings. Of course, Lexi would also like to do something with her singing. She has sung with Alicia Keys, performed the

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Surrounded by love. Angelina (center) with mom Elaine, dad Dan, and sisters Danielle and Lexi at the Ronald McDonald House.

Wish List

Gift Cards

- Wal-Mart
- Costco
- K-Mart
- Target
- Sam's Club
- Longs Drugs
- Supermarkets
- Gasoline gift cards
- Prepaid phone cards
- Movie Tickets
- Taxi Service

Household Items

- Paper towels
- Ziploc bags—gallon
- Garbage bags (yard & kitchen)

Food Items

- Flour
- Sugar
- Cooking oil
- Fresh fruits & vegetables
- Frozen meals (microwave)
- Individually wrapped snacks
- Assorted canned goods

Miscellaneous

- Rolls/sheets of "Forever" postage stamps
- Xerox paper (8.5 x 11)
- Office supplies

Message from our President



Jerri Chong

2012 marks 25 years of having Ronald McDonald House in Hawaii! Sometime this year, we will also surpass 10,000 families served since opening, and reach 100,000 room nights provided. Big milestones to be sure, but statistics don't even begin to tell the real story of "The House That Love Built." All of these families have their own unique story and have traveled their own distinct paths. Most will never be the same following their experiences with a seriously ill child. We are just so glad that in some way we may have made their journeys less burdensome and provided emotional and practical support when they needed it the most.

The organization has flourished over the years because we have constantly been able to gauge our community's changing needs — and then been brave enough to make important, proactive changes along the way. Because of increasing requests for our services, we grew from one Ronald McDonald House to two Houses totaling 17 guest rooms available each night, and we have added our in-hospital respite facility, the RMH-Family Room, to assist families spending all of their time at the hospital with their child. This little slice of the Ronald McDonald House receives nearly 9,000 visitors each year.

Originally, the Ronald McDonald House was for parents only, as children's serious illnesses were all treated inpatient. But as medical techniques and tools changed, such as outpatient cancer treatments, micro-surgery and non-invasive surgeries, organ transplant protocols, etc., and many seriously ill children started to be treated on an outpatient basis, we evolved into a home-away-from-home for entire families. Now, as we reach our 25th anniversary, we are extending our hand to reach out to as many of our families as we can. How wonderful it is to be able to reconnect and hear about how they are doing 5, 10, 15, 20, even 25 years after staying at the House. With today's social media tools it has never been easier to stay in touch. Reach us through our Facebook page, Twitter, or our new website — and be sure to watch for us at a shopping mall near you this year. We'll be having 25th anniversary events featuring Ronald McDonald himself at malls on Oahu, Kauai, Maui and the Big Island! Of course, we would not have been able to serve families all this time if not for so many wonderful, caring community partners, such as you. The contributions come in many different forms, from folks dropping their change into a collection box at any McDonald's to local foundations making investments in the community through RMHC-HI. Your support is what makes this House a home, and on behalf of all the children and families that you have touched, thank you so much!

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national anthem at a professional soccer game in Oregon, and sang for the 900 people in attendance at the RMHC-HI Gala last November, which was her second performance following her treatments.

"The whole experience has brought our family closer," shared Lexi.

"And we don't take things for granted anymore. We really appreciate each other," added Elaine.

As tough as things are, the Spences have found a place to nest on Oahu at the Ronald McDonald House. "You folks went out of your way to accommodate our whole family, making sure that we were taken care of," said Elaine. "Everybody is so friendly. They make you feel comfortable. Like at Christmas, all the kids got presents and that made them happy and made them smile."

Dan credits the Ronald McDonald House for helping to take care of the family's day-to-day things. "It's really taken the burden off of me as the father. So basically, we can wake up, eat and go to the hospital. There are some really good people at the Ronald McDonald House--whether it's staff or other families staying here. Instead of feeling so isolated, we've met some new people. We have made some bonds, and it keeps our spirits up."

Although fighting through severe nausea every day and seeing her hair fall out, Angelina is very aware of people offering their assistance. "It's nice when you receive the help," said Angelina, choking back tears. "It's why Lexi and I want to have our foundation to help others. It makes you

have a good day. When I see people helping me, I want them to be happy because they are making me happy."

The family wants everyone to know how important bone marrow drives are and is encouraging the public to join the bone marrow registry. "It could save a life," said Dan.

There's more information about donating bone marrow on Lexi's website, www.bonemarrowforlexi.com.



Angelina, Lexi and Danielle woke up on Christmas morning at the Ronald McDonald House to find presents under the tree with their names on them.

www.ronaldhousehawaii.org -- it's all new!



Our newly redesigned website is up and running! It's easy to navigate, and it is chock-full of information about the organization, our programs, the families we serve, and the community heroes that make it all possible — our supporters and volunteers.

On our new website, it is easy to access our past newsletters; see photo galleries of our facilities and events; read stories about some of the heroic children

and families that have stayed with us over the years; sign up for our e-mail list; make a donation; contact us; view our current Wish List; check out our calendar of upcoming events; and do many, many other things.

Please take a few minutes to look around at www.ronaldhousehawaii.org. Tell us what you think.

Home for the Holidays!

The holidays can be difficult for families that are far from home and away from many of their loved ones. Cancer and other serious conditions don't take holidays off so you will always find families staying at the Ronald McDonald House on Christmas. But they know that they are not alone. Thanks to our compassionate community, these families find themselves bathed in yuletide spirit and strengthened by many gestures of caring.

It was a special Christmas 2011. From Don & Marion Murphy's annual toy drive and Christmas celebration for RMHC-HI; to the House Christmas party; to the delights of Christmas morning and day, families shared all the things that make the holidays special. See more Christmas photos on the Ronald McDonald House Hawaii Facebook page.



2011 RMHC-HI Share A Night Gala

Honoring the Honolulu Star-Advertiser and President/Publisher Dennis Francis
November 20, 2011
Sheraton Waikiki Hotel

Nearly 900 people "Shared the Night" on November 20th at the 6th annual RMHC-HI Gala, honoring the *Honolulu Star-Advertiser* and its president/publisher Dennis Francis. Mr. Francis has been supporting RMHC-HI for nearly 20 years, and helped create the "Buy a Paper, Help a Child" program, that both the *Star-Advertiser's* predecessors, the *Honolulu Star-Bulletin* and the *Honolulu Advertiser* took part in. Without missing a beat, the program continued when they joined to become the *Honolulu Star-Advertiser*.

The concept of Buy a Paper, Help a Child is a simple one that generates significant revenue for RMHC-HI. Anytime a newspaper is sold in a McDonald's Restaurant, a portion of the purchase price goes to RMHC-HI. This partnership has generated almost \$2 million through the years.

The crowd was treated to a wonderful program, emceed by Guy Hagi, weather anchor for the HawaiiNewsNow team. Entertainment was provided by Brian Robertshaw's Stardust with Jennifer Hera, along with vocalists Rocky Brown, Kristian Lei, Nick La'aa and current Judd Hillside guest, 16-year-old Lexi Spence. Here are just a few photos from the Gala, which grossed over \$400,000. As you can see, a great time was had by all!

To view additional photos, please use this QR Code or visit the Ronald McDonald House Hawaii Facebook page.



After receiving his award from RMHC-HI, Dennis Francis (second from right) posed with (l-r) Jerri Chong; RMHC-HI Board Chair Richard Rand; Hawaiian Airlines' Peter Ingram; and Bank of Hawaii's Peter Ho.



Vocalists Rocky Brown, Kristian Lei, Nick La'aa and Jennifer Hera joined Brian Robertshaw's Stardust for a medley of Broadway tunes.



Some of the RMHC-HI families in attendance posed together at the entrance to the ballroom.



Her leukemia in remission, 16-year-old Lexi Spence of Hilo shared a song with everyone.



Dave and Fiona Kennedy



Victor Lim, Kitty Lagareta, Leilani Keough, Blossom Tyau, Joanna Sullivan, Dennis Francis, Lynn Ariyoshi, Dr. Lawrence Tseu, and Charlyn Honda Masini



Cancer patient Jilienne Prutch of Maui warmed many hearts that night. Here she is with Honorary Co-Chair Peter Ho.

Mahalo to Our Shining Stars

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The Westin Ka'anapali Ocean Resort Villas • The Westin Princeville Ocean Resort Villas • Tiffany & Company
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Left to right, Ernie Fukeda, Patrick and Debbie Lim, Curtis and Karen Gushi.



Jay Higa, Jerri Chong, Iris Suehisa, and Wade Nakashima



Ron Nagasawa, Dennis Francis and David Black

COMMUNITY SUPPORT

Mahalo!



RMHC-HI's Candace Asam-Lopez accepted a donation of \$1,094 from OC-16's Dave Vinton. The contribution was the proceeds from their Annual High School Volleyball Classic.



Randy Grubb and Beth Phelps of Walsh Construction visited the House to offer their help. Here, they are posing with RMHC-HI's Terri Chong and Nikee Wainit, and toys that they brought.



Meghan Dung sold personal items to donate more than \$500 worth of gift cards and Wish List items.



Jackie Margolese, a Family Room volunteer, created "Coasters 4 A Cause" and raised more than \$300 to buy items for the Family Room.



Lyle Moody, President of the General Contractors Association visited the Judd Hillside House to present RMHC-HI with a \$21,665 donation from the Association's members, and a big stack of Wish List items. Terri accepted on behalf of kids like Robert, Frankie and Taylor, shown here.



For many years, Mary and Bill Kendall have been donating home-made blankets for families staying at the Ronald McDonald House.



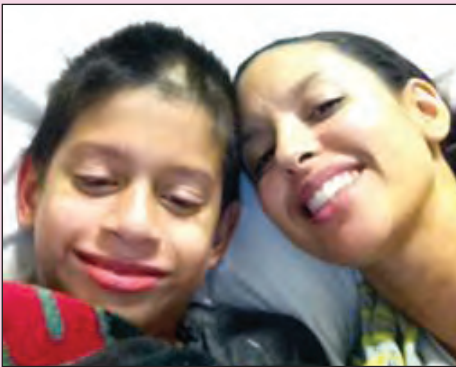
Members of the Ancient Order of Foresters Court Camoes 8110 made a holiday contribution of \$350 and other useful items.



RMHC-HI's Gene Davis was invited to share the Ronald McDonald House story at the West Pearl Harbor Rotary Club this month. Here he is (black aloha shirt), posing with some of the club members.

An unexpected turn in the road

Jenn and Matthew Marin were in the middle of a much anticipated family "staycation" at a vacation home in Kailua-Kona. Matthew's parents were visiting, and it gave the family a chance to enjoy each other in comfortable surroundings. "Actually, it was just a couple of blocks away from where we live," said Jenn, as she began to describe the day their nine-year-old son Sebastian suffered a stroke while playing in the pool with his brother Devon, 11, and sister Hailey, 4. "I went upstairs for a moment to get something for Haley, and I heard



Here are Sebastian and Jenn in the hospital following his stroke.

the kids screaming that Sebastian was hurt. When I got to him, he was lying next to the pool and screaming in pain like I had never heard a child scream before."

As they readied for a trip to the emergency room, Sebastian

went unresponsive and they proceeded with new urgency.

Doctors in Kona couldn't be sure exactly what was wrong with Sebastian, but they knew he had to be sent to Oahu, and fast. It was specialists in Honolulu who determined that Sebastian had been stricken by a Hemorrhagic stroke caused by an AVM or Arteriovenous Malformation. He was paralyzed, and he wasn't able to talk or respond. Heartbroken but determined, Jenn never left his side, continually talking to him and comforting him. Matthew, who manages a restaurant in Kona, also came as soon as he could get away and stayed for as long as he could.

But soon Jenn realized that living at the hospital was wearing her down and it wasn't helping Sebastian if she became sick or exhausted.

"Thankfully, I knew of the Ronald McDonald House and decided to give it a try since it was so close to the hospital," said Jenn. "Being here has definitely helped us, it's been huge. It really is like a home environment. I didn't know how much I needed this place."

Sebastian has made great leaps. He had to learn to move his arms and legs again, to walk and talk again - and he has. "Physically, he is coming back well, but he still needs work on his cognitive abilities," said Jenn. "He's still having trouble with his short term memory, but we are so proud of him."

"Bash," as family and friends call Sebastian, is currently receiving special cognitive therapy at a Hospital in California. They hope he can come home to Hawaii soon, but in the meantime, Jenn is there, right by his side.

Before they left, Jenn recorded a short video clip to let supporters of Ronald McDonald House know how much staying here has meant to her family. Please use this Smartphone QR Code to see it, or click on Jenn's picture on our website's home page at www.ronaldhousehawaii.org.



Jenn Marin: "Thank you for having the Ronald McDonald House."



Here is Sebastian shortly before his stroke.

Ways to Support RMHC-HI

- ♥ By direct cash donations to RMHC-HI, P.O. Box 61777 Honolulu, HI 96839-1777
- ♥ By incorporating RMHC-HI into your estate planning
- ♥ By naming RMHC-HI as the recipient of your own company's matching gift program or its corporate support
- ♥ By donating real estate, stocks, bonds, securities, etc., to RMHC-HI
- ♥ By putting spare change in the RMHC-HI collection boxes, located near the cash registers inside all McDonald Restaurants and most drive-thru windows
- ♥ By providing in-kind donations and professional services for the Ronald McDonald Houses and Family Room
- ♥ By volunteering your time to help at the Family Room or Ronald McDonald Houses
- ♥ By buying the *Honolulu Star-Advertiser*, *West Hawaii Today*, *Hawaii Tribune-Herald*, *Garden Island*, *Maui News*, and *Guam's Pacific Daily News* inside a McDonald's restaurant
- ♥ By using McFun-Raiser coupon booklets for your school or organization's fundraising campaign
- ♥ By purchasing a Happy Meal or Mighty Kids Meal at any McDonald's restaurant in Hawaii and Guam during the ongoing Happy Meal=Helping Families promotion
- ♥ By attending or contributing to RMHC-HI special events such as the Golf Classic and Gala



Volunteer Spotlight



by Michael Ahakuelo, Volunteer Services Manager

We shine the volunteer spotlight on an extraordinary young gentleman who has gone through more trials and tribulations in his life than most of us will ever go through. Jarek Barnett is a Ronald McDonald House Family Room Volunteer, but back in 2006-7 he was a patient right there at Kapiolani Medical Center for Women and Children (KMCWC). Near the beginning of his senior year at Mililani High School, Jarek suffered a stroke and spent a month in the Pediatric Intensive Care Unit (PICU) at the hospital.

While he was in the PICU, and during the additional seven months Jarek spent in the hospital, his father Louis was able to utilize the Family Room. "I could see that the Family Room was a convenient place for my father because it relieved some of the stress for him and he wasn't that far from me if I needed him," explains Jarek.

Jarek's health became very fragile in February 2007, and the family

learned that he needed to go to UCLA Medical Center in California to receive a heart transplant immediately. According to tests results he only had weeks left to live.

When Jarek and his father arrived, doctors almost immediately found a match for him and within 22 hours the transplant was completed.

At this point wheelchair bound, Jarek returned to Mililani High School in May 2007 and had the opportunity to walk with his fellow classmates for graduation ("Roll with them," he jokes). He enrolled at Leeward Community College and studied liberal arts, then transferred to Honolulu Community College in spring 2011 where he is pursuing an Associate's degree in Human Services.

But incredibly there is more. This past summer, Jarek was hit by a drunk driver near Ala Moana Boulevard and spent several days in Queen's Hospital with a broken nose, internal head

Volunteer Jarek Barnett, on duty at the RMH Family Room.



bleeding, fractured cheekbones, and face scrapes from the pavement.

But having had a stroke, a heart transplant, and being the victim of a hit and run accident hasn't deterred Jarek from becoming a positive force in the world. "I volunteer at the Family Room because I want to help others the way my father was helped here," he says. "It feels so good to go home knowing that I was able to help someone just by talking to them and sometimes sharing my story of my challenges, if they ask."

We applaud Jarek's sprit and determination and we are proud to have Jarek as part of the RMHC-HI Ohana.



Mahalo for your support!
www.RonaldHouseHawaii.org

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