The Bekos Family Story

Jeff Bekos speaks with emotion about the day his family’s life changed forever. It was July 5, 2013, 7:45 am, at their home in Doylestown, PA. He was in the kitchen with his 13-year old daughter Hailey, who was off for the summer and volunteering at an animal rescue. She was sitting at the table reading a local news story to her dad. “Suddenly, her voice and words became slurred,” he recalls. “At first I thought she was kidding around; then I thought she was having a stroke.” He drove her to the emergency room and waited with wife Liz to find out what was happening to their daughter. Within minutes of arriving at the hospital, Hailey had her first of many seizures.

A subsequent spinal tap showed that Hailey’s white blood count was extremely high. She was transferred to Children’s Hospital of Philadelphia (CHOP) the next day. The physicians diagnosed her with a rare and life-altering disease that attacks the immune system, Anti-NMDA Receptor Encephalitis. It is a rare but acute form of encephalitis, an anti-immune disease that attacks the nervous system. The disease destroys brain cells to the point that patients cannot speak, walk, recognize those around them, or control their movements. Of the 50 cases that CHOP has treated, Hailey’s was one of the most severe.

The Philadelphia Ronald McDonald House on Chestnut Street opened its doors to the Bekos family just 10 days later, housing them in Room 37. This has been their home throughout Hailey’s illness and hospital stay since July 2013.

Once at CHOP, Hailey began having seizures regularly. She was in a coma for 16 weeks. She stopped breathing and needed a tracheostomy and ventilator to breathe. Her heart stopped 10 times. Recalls Jeff, “We were told that she may be in a coma for 2-3 years; they did not know what to do. With so few cases, they just did not have enough data. Doctors told us to prepare for an ultra-marathon in the desert with one bottle of water.” Philadelphia Ronald McDonald House social worker Helen Reese became a steady source of comfort as the family began its ultra-marathon. “Helen is a very kind and comforting person, helping us in so many ways.” He adds, “The staff here is exceptional; they ease the pain of uncertainty and provide the support that is often missing in a hospital setting.”

The family was in a state of shock. Life as they knew it in Doylestown, just 30-miles away, went on hold as Hailey’s medical team worked to stabilize her condition. She did not respond to the treatments she received, including plasmapheresis, intravenous immune globulin with high doses of steroids, and chemotherapy. “Seeing your child go through something like that is a parent’s worst nightmare,” says Jeff.

The Bekos family would spend their days at CHOP, then come home to the Ronald McDonald House and talk with other families who were going through their own medical crises. “The other families understand what we are going through; we support one another. The families and staff have been the only stable part of our lives for the last 200+ days,” he adds.

Even in a coma, Hailey seemed to be advocating for her own recovery. Around Thanksgiving, she pulled out her tracheotomy. The medical staff was scrambling to put the tube back in; however, her vital signs were good. After a bronchoscopy that week, the doctors felt that Hailey did not need a tube to breathe. This was a turning point in her recovery. A few weeks later, Hailey pulled out her feeding tube. After lengthy discussions with the medical team, the tube was permanently removed. The next step was to aggressively wean Hailey off of heavy doses of various medicines. The medical team agreed to an aggressive plan. Says Jeff, “This was when we saw significant turns in Hailey’s recovery. She began to come out of the coma, and we could see small parts of her old self coming back.”

Hailey also began an aggressive physical, occupational, and speech therapy regimen. Her determination and independence kicked into high gear to the delight of her family and medical team. To date, Hailey has met or exceeded her physical and occupational therapy goals. She will continue to need aggressive speech therapy. She pushes herself hard and is highly focused and determined to beat her disease.

“The other families understand what we are going through; we support one another. The families and staff have been the only stable part of our lives for the last 200+ days.”
Dear Friends,

This year, we are honored to be celebrating an important milestone for the Philadelphia Ronald McDonald House—our 40th anniversary. On October 15, 1974, the first Ronald McDonald House was founded in Philadelphia, thanks to the vision of co-founders Dr. Audrey Evans and Jimmy Murray, and to the support of many other dedicated individuals who were instrumental in the opening of the first House. This dream not only led to the creation of the Philadelphia Ronald McDonald House, but also the creation of more than 330 Houses in 58 countries and regions around the world.

Since opening four decades ago, we’ve continued to grow and enhance our services for families of seriously ill children here in Philadelphia, expanding from a single, seven-bedroom House on Spruce Street in 1974 to a multi-program organization providing a range of holistic offerings to thousands of families in 2014—all because of the commitment of dedicated friends like you.

Just last year, we added two new bedrooms at our Front & Erie House, bringing the total number of families served per night to 65 between both Houses. We also opened our Hospitality Kiosk at St. Christopher’s Hospital for Children, extending our reach to families on the critical care units. Plus, we kicked off new wellness programming including our Healthy Breakfast Program at Chestnut Street and Art & Music Therapy Program at Front & Erie.

A glimpse at last year’s statistics—featured in this issue on pages four and five—truly drives home the need for these expanded services and highlights why the vision of our co-founders continues to be so relevant forty years later. As you’ll see, we had over 2,300 family stays from 46 states and 20 countries in 2013; unfortunately, there were even more families—nearly 2,900—we could not accommodate. This increasing demand, far beyond our current capacity, is why we’ve decided to actively pursue expansion plans for our Chestnut Street House this year to make sure that even more families have a place to call home when facing their child’s illness. Stay tuned for more details as our plans progress.

2014 is poised to be an exciting and pivotal year for the Philadelphia Ronald McDonald House, and we look forward to having our wonderful community of supporters join us every step of the way. We have a series of special events planned for the upcoming months, culminating with our 40th Anniversary Celebration at the Simeone Museum on October 17. We hope that you will be there to help us celebrate the past forty years of supporting families while we look ahead to serving more families in the future. On behalf of all of the children and families who have come through our doors since 1974, we thank you for all of your support in making the last four decades possible.

Warm Regards,

Marlene & Susan

Did you Know?

That three of the top 10 largest donations in our history came from individual bequests?

These wonderful individuals helped ensure the success of the Philadelphia Ronald McDonald House with their thoughtful planning.

If you wish to explore how you may have a lasting impact with the families we serve, it would be great to hear from you!

Lawrence Jacobson, Director of Leadership Giving, would be delighted to take your call at (215) 387-8406, ext 425, or lawrence@philarmh.org.

The Bekos Family Story cont’d

After a 7-month stay at CHOP, Hailey is now living at the Chestnut St. House with her parents, while continuing to receive treatment at CHOP on a hospital outpatient basis. “It’s been a great transition for her to come back with us after treatment,” says her dad.

“The Philadelphia Ronald McDonald House has been so wonderful and kind. Our story, as horrific as it is, is not unlike what so many families go through here every day. As much as we’ve received, we want to give back. We’ve met some really great people and made some friendships that I know will be long-lasting.”

Hailey is making medical history. At a recent donor breakfast at the Philadelphia Ronald McDonald House, she stood and smiled broadly, shaking hands with poise and grace at those who were there to hear her story and cheer her on. Her prognosis is good, and her family and doctors hope that she will fully recover.

If you would like to make a difference in the lives of families like the Bekos family, please complete and return the enclosed envelope or find out how you can help online at www.philarmh.org.
The 2013 National Dog Show & Spotlight Therapy Dogs Fundraiser

In November, we were thrilled to host the press conference for the National Dog Show at our Chestnut Street House for the second year in a row. That afternoon, The Kennel Club of Philadelphia introduced the 2013 National Dog Show Therapy Dog Ambassador Team and three newly recognized breeds.

New this year, we kicked off the Spotlight Therapy Dogs fundraising initiative. This unique initiative brought therapy dog owners and local Allstate Agents together to spread the word around the great work therapy dogs do in the community, and showcased how therapy dogs support our families each week. In the end, this inaugural fundraiser brought in over $17,000 for the families staying at the Philadelphia Ronald McDonald House!

The tremendous fundraising efforts were recognized in late November, on the eve of The National Dog Show, with a red carpet reception at the Chestnut Street House and featured an evening of celebrating the great work therapy dogs do in our lives. A special meet & greet with the three hosts of the National Dog Show (Mary Carillo, David Frei and John O'Hurley) also took place at the event.

We would like to extend a very special thank you to Allstate, Lourdes Edlin & her "go dogs", The National Dog Show, Nestlé Purina PetCare, Penguin Young Readers Group, Pet360, The Philadelphia Kennel Club, University of Pennsylvania School of Veterinary Medicine, Vizion Group PR, and all of our amazing individual fundraisers for all of their efforts.

After nearly six months of renovating the existing lounge spaces on the second and third floor of our Front & Erie House, in February two new rooms were completed and opened to accommodate two additional families each night. The two new bedrooms are warmly decorated, and provide our families with a comfortable, homelike environment during their stay. Both guest rooms are fully wheelchair accessible and will help support the growing population of families with children in wheelchairs being treated at hospitals within close proximity to our Front & Erie House.

This renovation has brought the room count at our Front & Erie House to 20 rooms and allows us to serve a total of 65 families each night at both Houses combined.

“We stayed in room 311, one of the new rooms. It was beautiful and very well painted! Love the floors and choice of colors. Very bright and cheerful!”
Guest Family

“We stayed in room 211, which is a beautiful newly created room. It has an awesome open design for patients and families, especially those needing wheelchair accessibility. The room has a well thought out design and lots of lights to fill the entire room!”
Guest Family

Two New Rooms Open at Front & Erie

Thank you to Katie’s Krusaders, the Katie Kirlin Fund, the Lehigh Valley All Stars Football Game, and the Louis N. Cassett Foundation for making the room renovations a reality by generously supporting the capital project.
THE YEAR IN REVIEW 2013

FAMILY STAYS

2,379 FAMILY STAYS

365 LONGEST NUMBER OF CONSECUTIVE NIGHTS FOR ONE FAMILY

93% AVERAGE OCCUPANCY RATE

2,888 FAMILIES WE COULD NOT ACCOMMODATE BECAUSE WE WERE FULL

8.8 NIGHTS IN THE AVERAGE FAMILY STAY

OUR IMPACT

97% Families who agree their ability to stay close by improved their child’s experience in the hospital

97% Families who agree that staying at the House made it easier to access treatment

86% Families who agree that the Family Rooms were a valuable resource during a difficult time

100% Camper’s parents who agree that Ronald McDonald Camp has a positive impact on their child’s well-being

FAMILIES SERVED BY REGION

We served families from 46 states with the majority traveling from PA, NJ, and NY.

TOP THREE HOSPITALS SERVED

The Children’s Hospital of Philadelphia 50%
St. Christopher’s Hospital 22%
Shriners Hospital 20%

TOP THREE SERVICE DEPARTMENTS

Oncology 26%
Orthopedics 24%
Cardiology 11%

DOWNLOAD THE FULL ANNUAL REPORT IN APRIL 2014 BY VISITING WWW.PHILARMH.ORG/ANNUALREPORT
INTERNATIONAL FAMILIES SERVED

We served families from 20 countries including:

- Bermuda
- Curacao
- India
- Singapore
- Jamaica
- Peru
- Spain
- Croatia
- Poland
- Syria
- Dominican Republic
- Puerto Rico
- Uruguay
- China
- Venezuela
- Ecuador
- Uruguay

RONALD MCDONALD CAMP

- Total Campers: 203
- Patient Campers: 132
- Sibling Campers: 71
- New Campers: 53

OUR VOLUNTEERS

- House and Family Room Volunteers: 324
- Volunteer Camp Counselors and Medical Staff: 113
- Family Activities: 509
- Community Service Groups: 95
- Guest Chef Meals: 1,101
- Shuttle Van Trips: 3,640

RONALD MCDONALD FAMILY ROOMS

- Family Rooms at CHOP: 2
- Patient Rooms Served Each Day: 96

HOSPITALITY KIOSK

- Times the kiosk was accessed by individuals: 3,178
- Patient Rooms Served Each Day: 73
- Individuals who agree that the Hospitality Kiosk made it easier to access healthy food and beverages while in the hospital: 95%
Thank You

To All Of The Donors Who Supported Our Share A Night Campaign, Our 2014 Adopt A Room Program, And General Fund Campaigns In Q4 2013.

**$25,000 and above**
The Alice H. & Joseph W. Campbell Fund of the Philadelphia Foundation
Denny Partan and the County Corvette Toy Drive
Ecomedia - CBS
Estate of Robert C. Wells
Kate Kirlin Fund
Kate’s Krusaders
Mr. and Mrs. Alan B. Miller
Philadelphia magazine’s Design Home 2013
Ronald McDonald House Charities of the Philadelphia Region
Ronald McDonald House Charities of the Philadelphia Region

**$10,000 to $24,999**
Ecomedia - CBS

**$5,000 to $9,999**
Philadelphia magazine’s Design Home 2013
Katie’s Krusaders
Katie Kirlin Fund
Ecomedia - CBS
St. Christopher’s Foundation for Children
Reuben and Mollie Gordon Foundation
Mr. and Mrs. Nicholas Karamatsoukas
Jersey Shore Harley Owners Group

goodies for Good, Inc
The Goldenberg Group & People

**$1,000 - $2,499**
Maiden RE LLC
McGrady LLP

**$500 - $999**

**Under $500**

Thank you to all of the donors who supported our share a night campaign, our 2014 adopt a room program, and general fund campaigns in Q4 2013.
We’re So Thankful For...

1 **Volunteer Guest Chefs**

In 2013, over 1,000 home-cooked meals were prepared and served to our families by volunteer Guest Chef Groups. Thank you to all of the groups who contributed meals to our Houses or Family Rooms in 2013. Pictured here is a volunteer Guest Chef group from Salon L’Etoile after preparing a delicious spread for our families to enjoy. To view a complete list of our Guest Chef groups, please visit www.philarmh.org/guestchef.

2 **In-Kind Donors**

During the 2013 Holiday Season, more than 65 Wish List Drives were hosted in support of the families of the Philadelphia Ronald McDonald House. We would like to extend thanks to all of the companies, groups, families and individuals who chose to host a Wish List Drive for our families throughout the year. Pictured here is a group of Coldwell Banker Preferred agents and management team members who collected and delivered many Wish List items and toys in December.

3 **The 2013 Share A Night Celebration**

To honor the generosity and support we receive from our friends in the community, both of our Houses were decorated with thousands of twinkling lights, each representing a donor’s gift throughout the year. Thank you to all of the individuals, organizations, and businesses who helped to give the gift of home to families in need throughout the holiday season. Thank you also to all of the in-kind donors who helped make the event so special.

4 **Adopt A Tree Program**

We would like to thank all of the generous donors who took part in our first annual Adopt A Tree program at the Front & Erie House for their support in purchasing and decorating the House for the holiday season.

5 **Tri-State Tournament of PA Racquetball Association**

We would like to extend our thanks to the Tri-State Tournament of PA Racquetball Association for raising $2,675 through their annual tournament in December, at the Philadelphia Sports Club in Chalfont, PA. Since 2004, the Tri-State Racquetball tournament has contributed over $22,600 to support the families staying at the Philadelphia Ronald McDonald House.

6 **Philly Marathon**

14 members ran for Team PRMH in the 2013 Philadelphia Marathon in support of our families. Together, the 2013 marathon team raised over $21,500 to support our programs. We would like to thank our team for their fundraising efforts! Pictured to the left is Thomas and Amy Cantilina, team members who stayed at PRMH during their daughter’s treatment at CHOP.

7 **2013 Design Home**

Thank you to everyone who supported the Philadelphia magazine’s Design Home 2013. The four weeks of public tours raised over $45,000 to benefit our families. Our sincere appreciation goes out to all of the volunteers who donated their time to make this event possible. Special thanks to Sherry Litwer, Project Manager of the Design Home, for all of her support throughout the event.
Philadelphia Ronald McDonald House
3925 Chestnut Street, Philadelphia, PA 19104
215.387.8406 www.philarmh.org

Address Service Requested
If you would prefer to receive our quarterly newsletter electronically, please email enews@philarmh.org and let us know!

UPCOMING EVENTS

April 6 — Hot Chocolate 15/5K
May 3 — Sixth Annual Plane Pull
May 28 — Phillies Game #1
June 2 — Hit ‘Em for the House Golf Outing
June 4 — Hit ‘Em for the House Tennis Outing & Card Games
July 25 — Phillies Game #2
August 7 — Phillies Game #3

Save the Date: October 17, 2014 — 40th Anniversary Celebration
Visit www.philarmh.org/events for more information on all of these exciting upcoming events and more!