HELPING MEDICALLY COMPLEX BABIES

THRIVE!

Little Heroes League

2019 Annual Report
Mission
We help babies born with multiple health challenges achieve their best life outcomes by providing early life care coordination.
Dear Friends and Supporters:

We are pleased to report that the Little Heroes League is thriving! Your generosity has allowed us to grow and positively impact more Little Heroes and their families. We now concurrently support 37 Little Heroes and their families, up 76% from the beginning of 2019.

Little Heroes are the most medically complex children. The Little Heroes League provides personalized and dedicated care coordination services for these children soon after they are born in order to help them achieve their best life outcomes.

The feedback we have received from the Little Hero families and care providers in the first 18 months of our care coordination service is universally positive:

- Our services are life-altering (and sometimes life-saving) for the Little Heroes
- Our services get these Little Heroes home and keep them home, where they thrive
- The emotional support we provide reduces the Little Hero family’s stress level
- The doctors want their medically complex patients enrolled in the program
- The hospital would like us to expand the program to new areas and new patients
- Most importantly, the Little Heroes are developing and thriving!

Our main focus in 2020 will be to expand the program: increase the number of patients and families; broaden our services to other areas of Lurie Children’s Hospital and other family needs; and to begin to consider geographic expansion.

Our commitment to you is to continue to direct your contributions to the children and families. As the funds from the founders effectively cover all operating expenses, all of your contributions are used for the care coordination services provided to these children.

Our 37 Little Heroes and their families thank you! You are helping them achieve their best life outcomes!

Will Ulaszek
Chairman and Founder
Little Heroes League

Kim Ulaszek
Founder
Little Heroes League

LHL founders, Will and Kim Ulaszek
Dear Friends:

My favorite LHL event is the annual year-end Family Holiday Party. It is a celebration for all those who are part of the LHL family: Little Heroes, families, providers, care coordinators, Lurie Children’s Foundation team, and the LHL charity team.

While we were setting up for this year’s party at the hospital, someone from the team mentioned we should bring mats for the kids to play on. That thought had never crossed my mind as we have become accustomed to having the Little Heroes confined to strollers and devices.

Seeing the little heroes (now another year older) play on the mats as toddlers was one of the most fulfilling experiences I have ever had. These kids are so often defined by their limitations that it is easy to forget they are still just kids. They like to roll and around and play! It showed us how far these Little Heroes have progressed. We are honored to be a part of that growth.

On a sad note, we lost several Little Heroes this past year. It serves as a reminder of just how how fragile these kids’ lives are. I would like to offer my condolences to all the families who lost a Little Hero in 2019.

Despite the sad news, LHL experienced incredible progress over the past year:

- 37 Little Heroes and their families enrolled at year-end
- Surpassed $1.5 million in raised contributions
- Funded an additional care coordination resource
- Kicked off our impressive Associate Board
- Hosted several marquee events that you helped make a success:
  - Orangetheory Fitness and LHL’s 2nd Annual Fundraiser at Commonwealth Tavern
  - “Heroes & Horses” at Arlington International Raceway
  - “Big Hero Charity Golf Outing” at Ravinia Green Country Club
  - “Chutes & Lagers” at Rock Bottom Restaurant and Brewery
  - “FUNraiser II” at Soldier Field
  - Michigan Holiday Brunch at The Lodge Grill & Bar

Kristin Etue, Brenden Etue (Executive Director), Livia (2), William (4), Eddie (5 months)

Thank you to Kim and Will Ulaszek (Livi’s Grandparents) for their ongoing commitment to the success of Little Heroes League.

Thank you to the incredible team at Lurie Children’s, who continue to partner and help us improve our life-changing first-in-country program.

Thank you to our board members who continue to support and shape our organization.

Thank you to our newly formed and highly engaged Associate Board who have brought commitment, energy, and passion to our organization.

Thank you to the incredible care coordination team – who positively impact the lives of the Little Heroes every single day.

A very special thank you to all who believe in us and support our organization. Please know we continue seeing a positive impact on the Little Heroes and their families that we so proudly serve. We are excited for 2020 and to help even more Little Heroes achieve their best life outcomes.

[Signature]

Brenden Etue
Executive Director
Little Heroes League
2019 MILESTONES

May 11, 2019
“Heroes & Horses” at Arlington International Raceway

June 17, 2019
“Big Hero Charity Golf Outing” at Ravinia Green Country Club

August 15, 2019
“Chutes & Lagers” at Rock Bottom Brewery (Associate Board)

September 12, 2019
“FUNraiser II” at Soldier Field

December 20, 2019
LHL Family Holiday Party

December 7, 2019
“Michigan Holiday Brunch FUNraiser II” at the Lodge

April 6, 2019
OTF / LHL Fundraiser II at Commonwealth Tavern

April 24, 2019
Little Heroes League initiates Associate Board

June 8, 2019
Program Family Support Event at Hello! Baby

June 17, 2019
LHL expands care coordination program

Little Heroes League surpasses $1M in raised contributions

December 20, 2019
LHL funds remainder of 2020 program costs

January 2019
21st family enrolled

December 2019
37th family enrolled
WE ARE THRIVING

Our revenues are growing. That allows us to serve more Little Heroes and their families.

EMMANUEL

ZAMORA

ALEXANDER

31% Revenue increase from 2018

76% Increase of enrolled Little Heroes from January to December in 2019
Together, in 2019, we raised $718K

That enabled us to grow our program resources by 33%

That will allow us to impact even more Little Heroes beyond the 37 families

And their medically complex babies that we are helping to THRIVE!

80 cents Of every dollar spent by LHL supports our care coordination program
LITTLE HEROES ARE THRIVING

Our Little Heroes have shown incredible growth in the past year – thanks to the commitment of their parents, caregivers and the care coordination team.
OUR VALUE IS WELL DEFINED

An independent study conducted by Northwestern University identified the value we are providing to the Little Heroes and their families. The information below comes directly from the study.

LOGISTICS

The care coordinators provide continuity for the Little Heroes both inside and outside the hospital.

a) The low care coordinator-to-family ratio of our program allows individualized care for each Little Hero

b) The continuity of care provided by our care coordinators is critical when care is provided across a rotating set of providers

c) Discharge preparation helps the family prepare and set up their home for discharge; and helps them think about long term goals for their child and family

d) Support continues through their inpatient and outpatient journey

COMMUNICATION

The care coordinators improve communication between the patient, the families, the doctors, and all other care givers.

a) The care coordinator facilitates communication between the family and the care team

b) Consistently and immediately respond to calls/texts

c) Facilitate care across many providers

d) Outpatient providers appreciate care coordinators as a resource for medical information

e) The patient families have one number to call for help or advice when issues arise

FINANCIAL SUPPORT

Our program helps families manage the financial burden of a medically complex child and their care. When families express a financial need, care coordinators directly find funding or resources.

- Rent, utilities, food transportation, holiday gifts
- Access to hospital funding
- Government assistance programs

EMOTIONAL SUPPORT

The care coordinators provide vital emotional support for our families and their Little Heroes.

a) Care Coordinators speak up for parents; but more importantly, encourage parents to advocate for their child

b) Families feel supported as they navigate the emotional challenge of having a medically complex child in the NICU

c) Training sessions help the families feel less overwhelmed and help them manage their child’s care

d) Little Heroes League provides a sense of community
They came in, they said, "don't worry about it, just relax, we'll show you how to do this." They saw I was just so confused and dizzy like this is too overwhelming for me right now, and they just came in, took over and helped me be more calm to be able to assist with it.

I'm unemployed at this time... it was hard for me to try to pay for light and gas... so any resource that I really needed, they [care coordinators] were able to pull out a list of resources for me that were close and convenient to me due to not having any transportation at the time.

They made something that I felt in my heart and in my mind that it was gonna be a really tough road for me easier. Nothing is just thrown at you. They get you prepared.

Before Little Heroes League I would find that I would have one team of doctors and I would come in that following Monday and it would be totally different people and they wouldn't be on the same page as the other ones, so then we would all be like well, "that's not what we were doing."
I love discharges.... We've had a lot of very overwhelmed parents, and it's really cool to see how significant that transformation is. They go from disempowered, terrified, "how the heck am I ever going to do this?" to wheeling their baby out the door in their stroller and they've got everything that they need with them, but they're going home and they're going to do it.

We can't change your medical situation... but what we can do is figure out ways to empower you and give you the skills to be successful.

The doctors actively seek us out for the consolidated view of the patient.
“To be able to have somebody that can really hold their hand through the inpatient process and then connect them to the outpatient / coordinators... is a continuity of support that they otherwise would not have. These are at-risk families that would not make it I believe otherwise in terms of appointments, in terms of care, in terms of training and retraining.”

“By providing that level of support, caregivers are able to focus on their child and interact with them as a parent, which we know is beneficial for their development, so I think we’re creating a situation where we can have a lot more success all around.”

“I would talk to the mom and if there were questions that the mom didn’t know, again because you know it is all medical and even if they were there the whole NICU visit, there are things that are going on in the background, so [the care coordinator would help] find those answers for me.”

“[The care coordinator] is setting up meetings every 2 seconds, calling, emailing. Without that, it would be very difficult. Her communication with the team is what makes it float.”
ZY’AIRE’S STORY
By Zy’Aire (with a little help from his parents)
Read Zy’Aire’s full story on our website.

Zy’Aire
Hi! My name is Zy’Aire and I’m a Little Hero! Thank you for stopping by to read about my journey and the impact that Little Heroes League has had on me and my family.

On Christmas Eve of 2017, I was born. Four months early and weighing just 1 lb 5 oz, my underdeveloped lungs needed support. The doctors immediately put a breathing tube down my throat.

Mom, managing her own medical problems, was rushed to the adult Intensive Care Unit (ICU). Because of her condition, I didn’t get to meet and cuddle with my mom for my first two days of life. Thankfully, dad was able to be there for me.

My First Year
After two days in the Prentice Neonatal Intensive Care Unit (NICU) I contracted “pneumonia.” Which meant I needed a breathing tube. Over the next few months I remained intubated as I contracted another round of pneumonia.

I finally started feeling better and we were ready to go home for the first time. However, when mom grabbed my legs to change my diaper I couldn’t stand it! I was in so much pain! The doctor people discovered I had contracted a scary bone infection called “osteomyelitis.”

This is a life-threatening condition and required transfer to Ann & Robert H. Lurie Children’s Hospital of Chicago for monitoring. Over the next 11 days, I underwent seven surgeries to clean out the infected areas of my bones. All the surgeries required me to be paralyzed and under lots of heavy sedation. As a result of all the cleaning, large chunks of bone were removed, especially around the top of my hips.

Complicating my care even more was the fact that I had been intubated for so many months. The doctors decided it would be best for my recovery if they cut a hole in my neck directly to my windpipe and then hook up a breathing machine (vent). They also decided to add a G-tube for feeding since I had oral aversions.

I can’t imagine how tough all this was for my parents – because I know they were worried I wasn’t going to make it. Also complicating things was my parents didn’t make as much money during this time because they had to spend so much time at the hospital and couldn’t work.

I busted out of the hospital on Oct 16, 2018- at 10 months old. I owe it all to my parents- I got my strength and stubbornness from them!

Home Life
The first day home for any parent of a medically complex kid like me is extremely overwhelming. And it was no different for my parents – as my first night almost ended in tragedy. Water entered my breathing tube and I began choking. Having me at home made things pretty hectic!

Monday through Wednesday is reserved for my therapies (occupational, physical, speech, and development). It’s a lot of work, but these therapies are critical services that help me catch up to where I need to be. Thursdays and Fridays are reserved for appointments which is a mix of pulmonary, nutrition, orthopedics, and my primary care doctor. I have a night nurse Monday through Thursday who watches over me while I sleep. I receive two breathing treatments per day and get fed through my g-tube five times per day. I have an entire room dedicated to all my supplies that includes g-tube and trach equipment and will soon include leg braces and a bath chair!

Little Heroes League
Mom says, “It’s been...Oh my god...finding a pediatrician, keeping up with all the appointments, calling to schedule everything, making sure everything is done. I would have quit my job. Literally. It’s just so much. I tell my care coordinators, Megan, Lisa and Jenny, I don’t know what I would do without you guys. You’re stuck with me forever!”

One of the biggest benefits of HHL has proven to be transition management when tricky babies like me go home. My mom says, “When we first came home, our care coordinators made sure everything was organized and good. They came on the 2nd day home too. “When I had my mental breakdown, Jenny dropped everything she was doing. She brought us food. She came and made sure I was okay.”

For me and my parents it’s really all about consistent and reliable support from the care coordinators. My mom said, “They always call to check in on us. Lisa, our outpatient care coordinator, comes to all the appointments. She cares. She sat with Zy’Aire on the floor and exercised with him. I was able to get up and do some things around the house.”

When talking about one of our care coordinators, mom expressed our feelings so well, “It’s not just a job for her. She’s an angel on earth.”

My Future
Mom and dad are the best. They are so optimistic for me, and my biggest fans. Mom says, “My Mom Goal this time next year, he’ll only need vent at night.” I’m already chatty (it’s a little tough to talk over my trach), but they constantly talk to me because they want me to be as exposed to as much language as a I can. That way when I get this trach removed I’ll be ready to talk their ears off! They’re also hopeful I’ll walk someday. I don’t like putting much pressure on my feet - can you blame me? I spent my first 10 months on my back! But they’re working hard on making sure I get comfortable with weight on my feet. I’m also going through a strict core routine to help me support my head and get that six pack! The sky is the limit for me!
Little Heroes need Big Heroes
2nd Annual OTF and LHL Fundraiser

Orangetheory Fitness (OTF) threw their 2nd Annual Fundraiser in support of Little Heroes League on Saturday, April 6, 2019 - the evening of the NCAA Final Four. Commonwealth Tavern was packed with 105 LHL supporters having a great time while raising funds to support babies born with medical complexity and their families. This has become an annual event and one you don’t want to miss!

Many thanks to the incredible team at OTF and Commonwealth Tavern, with special thanks to Sam Bartlett, Alexis Conway, Aleks Saulys, Fletch Boyle, and the OTF volunteers that made the event a success. Incredible event photography by Danielle Margheret (@daniellemarg).

May 11, 2019 | Arlington International Racecourse, Arlington Heights, IL

Heroes & Horses

Sponsored by the Kreiling Family Foundation, LHL hosted “Heroes & Horses” fundraiser at Arlington International Raceway the day before Mother’s Day. One hundred guests came to the track to celebrate and support all our Little Heroes. It was an incredible day highlighted by great horse races, fancy outfits, an open bar and a gourmet food spread. Thanks to all the guests who attended and supported!

Thanks to all the volunteers (Anastasia Kreiling, Jane Borjon, JT Michalski), sponsors Anthony J. Madonia & Associates, Ltd. and Romano Beverage, and in-kind donors. Event photography by Jordan Myers (@jordanmyersphotos)
Big Hero Charity Golf Outing

LHL hosted our first annual “Big Heroes Charity Golf Outing” at Ravinia Green Country Club the day after Father’s Day. Ninety guests came to the course to celebrate and support our Little Heroes. We were able to provide new ways to help our Little Heroes while meeting new supporters. We also presented a $110,000 check to Lurie Children’s to expand our program by adding a 4th care coordination resource. Thanks to all the guests who attended and supported! Thanks to Impact 365 for producing a great event and to Ravinia Green for hosting! And many thanks to all the volunteers, sponsors, and in-kind donors.

Michigan Holiday Brunch FUNraiser II

Planned once again by Livi’s aunt, Devon St. Louis organized a Brunch FUNraiser for all of Little Heroes League’s (and Livi’s) Michigan supporters. We had over 110 adults and children come out to support our Little Heroes! From pictures with Santa, face-painting, and games for kids, we hope everyone had as much fun as we did.

We would like to thank our amazing event volunteers, our in-kind gift donors, our family members who helped spread the word of the event, the supporters who attended, and the Lodge Grill and Bar for hosting. We look forward to an even bigger event next year!
September 12, 2019 | Soldier Field, Chicago, IL

FUNraiser II

The second annual LHL FUNraiser is officially in the books! And we thank you for helping to make it a huge success! On Thursday, September 12, 2019, we made significant progress advancing our mission during a beautiful fall night at one of Chicago’s most iconic venues - Soldier Field.

Trying to bring the FUN at every even, this year’s event included plenty of it, with celebrities that included emcee Corey McPherrin (Fox Chicago), anthem singer and Chicago icon Jim Cornelison, and keynote speaker and Chicago Bear Pro-Bowler Charles Tillman. We also honored our 2018-2019 Super Hero of the Year, Fletcher Boyle.

Many thank to everyone who helped make the event a success!

We look forward to seeing you at FUNraiser III in 2020 (tentatively scheduled for September 17, 2020).
Chutes & Lagers

LHL Associate Board (LHLAB) hosted their first event at Rock Bottom Restaurant & Brewery in downtown Chicago. Over 100 guests came to support LHL as they played board games, enjoyed live music, raffles, and our specially-made beer, “Livi’s Lagerbier!”

Thanks to the associate board and Rock Bottom for hosting an incredible event. And thanks to all the guests who came and supported our Little Heroes.

October 13, 2019, Chicago, IL

2019 Chicago Marathon

Three members joined the LHL Marathon team this year, and three members finished the Chicago Marathon! The team was a subset of the Lurie Children’s Marathon Team, which came with benefits that included a training program and race day resort access. Contact us if you are interested in joining the 2020 Chicago Marathon team before spots are gone.

December 9 – December 15, 2019 | Felt Women’s Boutique, Chicago, IL

Week of the Little Heroes

Our friends at Chicago’s finest women’s boutique - Felt, once again celebrated our Little Heroes - this time for an entire week! 10% of all sales went to LHL when shoppers mentioned “Little Heroes League” at checkout during the weekend celebration that culminated in a boozy donut brunch on Sunday, December 15th! Thank you to Felt and to all those who shopped and supported!

December 20, 2019 | Lurie Children’s Hospital, Chicago, IL

LHL Family Holiday Party

We love what we do. And we are passionate about doing it. But nothing brings us greater joy than our annual LHL Family Holiday Party. It is an opportunity for all our Little Heroes and their families to get together to celebrate life and milestones.

This year’s holiday party can be said in one word: magical. The day included lunch, games, presents sponsored by ADP Chicago and lots of fun. At least one person from 24 of our families was in attendance. Families spent time together to create bonds that will last a lifetime, and proved that we are not just enabling better outcomes, we are also creating a community.

Having a child with multiple health challenges is life changing, demanding, and stressful. But you would never believe it if you felt the energy at the party! It is rare to experience so much optimism from a group of people facing such difficult situations.

Thank you to the team at Lurie Children’s for throwing this LHL Family Holiday Party. And thank you to the kind folks at ADP Chicago and Gen LeFevour, Alison Girard, and Julie Dix for sponsoring our present drive!
Will Ulaszek is the co-founder (with his wife, Kim) and chairman of Little Heroes League. Most recently, Will was the Managing Director for IBM’s relationship with AT&T. Will has more than 30 years of experience in the telecommunications industry, specializing in sales, marketing, consulting, and alliance formation. Will was a member of the IBM chairman’s Growth and Transformation Team and a member of the Global Leadership Team. He was also formerly Chairman of the Board of the Twin Brook Family YMCA in Schaumburg, Illinois. Will holds a B.S. in chemistry from the University of Illinois and is a Loyalty Circle member of the university. Will currently resides in Chicago, IL, with his wife.

Brenden Eue is the Executive Director of Little Heroes League. His daughter, Liv, was born in 2017 with multiple health challenges, and it is the inspiration behind Little Heroes League. Prior to this role, Brenden was an internal consultant at CBRE specializing in operational optimization and change management. Brenden started his career at The Boeing Company, where he held multiple positions including leading the facilities management strategic outsourcing team and several key site consolidations/divestitures. Brenden earned his BSE in Mechanical Engineering from the University of Michigan and an MBA from the University of Southern California. Brenden and his wife Kristin live in Chicago, IL, with their three children.

Genevieve LeFevour is a trial lawyer who focuses her practice in medical malpractice, employment, general negligence, premises liability and transportation. In 2014, Gen was named one of the “Forty Illinois Attorneys Under Forty to Watch” for 2014 by Law Bulletin Publishing Company. Gen attended the University of Notre Dame for her undergraduate studies and attended Loyola University School of Law in Chicago. Gen attended Loyola Academy for high school where she was a record holding member of the varsity swim team. She was also designated Future Leader of Chicago by the Chicago Community Trust in 1996. In 2011, Ms. LeFevour was chosen by the President of Loyola High School to be a member of the inaugural Young Board of the school known as the President’s Leadership Council. She currently resides in Chicago, IL.

Tracey Kreiling, having been a full-time mom of 5, is proud of her ability to have juggled children, a family business, volunteerizing and event planning during those years. Her efforts have involved non-profits, a restaurant, individuals and corporations. Her philanthropic endeavors have benefitted children’s organizations such as Bear Necessities, Project Ladybug, Chicago Lights, Kids Off The Block and more. Tracey has also supported The ALS Association of Greater Chicago, Ronald McDonald House Charities, Komen Foundation, and others. She oversees the giving opportunities of The Kreiling Family Foundation. Tracey gets great satisfaction helping areas devastated by disasters. There she sets up makeshift shelters, and feeds those in need at the facility. Tracey and her husband live in Chicago, IL.

Pat Eskew is the Consulting Managing Partner for US Industrial Market for IBM. Pat currently serves on the board of Bottom Line Chicago, and is the ex-chair of the Young Leaders Committee for the Economic Club of Chicago. Prior to joining IBM in 2009, Pat earned his BSE in Industrial Engineering from The University of Michigan and an MBA at Harvard Business School. Pat lives in Chicago, IL, with his wife and three children.

Mallory Ulaszek is an entrepreneur with experience in the retail, non-profit and technology. In 2014, she co-founded Presence, a consulting agency that focuses on ideation and operations for start-ups and non-profits, with a focus on process innovation, growth, technology and fundraising. Currently, they include clients such as Ford, Aon, and I-serve in-house business portfolio. In 2015, Presence completed two acquisitions in one week with over 200 sites built in the last 5 years. Mallory has served on the board of non-profit organizations Old Town Merchants and Residents Association (Retail Chair), Pilot Light (Co-President, Young Professional Board), and PAWS Chicago Development Board. Mallory earned her bachelor’s degree from the University of Wisconsin-Madison and currently resides in Chicago.
The Little Heroes League Associate Board is a group of emerging leaders who utilize their time, talents, networks, and resources to support the work and mission of Little Heroes League.

Marisa Sclafani
Co-President

Jennifer Galinski
Co-President

Michael Zicari
Fundraising Chair

Ashley Alfani
Engagement Chair

Noah Placzek
Technology Chair

Mary Antolak
Events Chair

Anastasia Kreiling
Social Media Chair

Mitchell Hill

Caitlin Boyle

Kelsey Krzyston
### SUMMARY OF FINANCIAL ACTIVITIES

#### Summary of Revenue & Expenses (dollars in thousands)

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*Note: 2018 Gross Revenue = $539K; 2019 Gross Revenue = $718K.*

#### EXPENSES

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#### Financial Efficiency Metrics

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1 Represents December only  
2 Does not include $3000 donated to LHL via Lurie Children’s  
3 Does not include $12250 donated to LHL via Lurie Children’s  
4 Does not include $9105 donated to LHL via Lurie Children’s  
5 Includes program funding through 2019  
6 Includes program funding through 2020
Thank you for all your support!

(“Little Hero Livi” artwork by Jimmy Manikas)

www.LittleHeroesLeague.org

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@LittleHeroesLeague