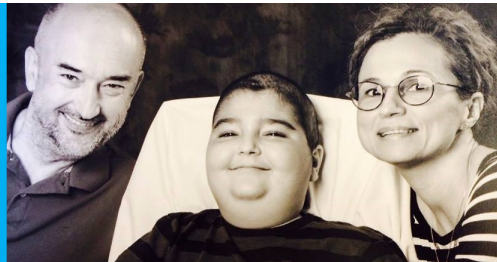


Family to Family:
What I wish
I'd known
about HLH



Thank you to our community of supporters who have made our outreach and this book possible.

HLH Center of Excellence
www.cincinnatichildrens.org/hlh

Family to Family:

*What I wish I'd known about
Hemophagocytic
Lymphohistiocytosis*

Dear Parent,



HLH can be a scary world. We are very sorry that this disease has struck your family, but by virtue of the fact that you are reading this book, you have found the right experts to care for your family. The team you contacted in Cincinnati is the best you will find anywhere.

HLH is a very difficult disease, there's no denying that, but survival IS possible. There are many survivors, and there are even HLH survivors who THRIVE, but only with the right combination of medical care, diligence, support, and optimism.

Arm yourself with knowledge and positive energy, and keep moving forward. Never look back, never ask why or say "poor me," but always forge forward and try to help all of the others on this journey with you. It takes a village to get through this crisis; look around you and help the others. Accept help from some, and return the favor by helping the other families. By helping others, you will take the focus off of yourself for a moment, find a second of relief from your stress, and re-energize yourself with positive energy. Read as much as you can, starting with these materials. Constantly research and learn about the medical issues, stay positive, and stay strong. Best wishes and may there be a higher power protecting you and your family.

Stay the course,
Ann Flaherty, RN, BSN
HLH/BMT mother

From our HLH Family to Yours,

Treatment for a rare disease, like HLH is incredibly isolating. No matter where you are, facing a rare disease changes you, your perspective and the way that you experience the world around you. The advice in this book was gathered during a family conference from a group of experienced families who have faced an HLH diagnosis. Many were treated at Cincinnati Children's, but not all.

What you will read on the following pages is advice from real families, based off of their actual experiences facing HLH. The pictures in this book are of real HLH patients who have become part of our greater HLH family. This booklet was created to help those starting out on the journey, so that they may be more prepared and know that they are not alone. We express our sincere appreciation for the families involved in this project, as there is nothing more powerful than kind words from a family who has already trodden the same path, to one who is just beginning it.

**To reach the HLH Center of Excellence
at Cincinnati Children's,
call 513-803-3872 or email HLH@cchmc.org**



Annual HLH Conference: Family Session, 2015

My HLH Story



Now in high school, Jennifer raised \$800.00 for HLH through a fundraiser at her school in 2015.

Jennifer presented the funds to Dr. Jordan at the annual HLH conference for physicians and families at Cincinnati Children's Hospital Medical Center.

Today Jennifer describes herself as a regular 17 year old in high school and says you'd never know she was diagnosed with HLH when she was 8, unless she told you. Like many patients, Jennifer's illness started out of the blue.

On a normal day, while at dance camp, she began to feel feverish and sick. After that, she only remembers bits and pieces. "I was never really scared, just tired and felt sick, but I also had lost all track of time". She was admitted to the hospital where she was diagnosed with HLH and a CMV infection.

Jennifer was inpatient for several weeks, and on a ventilator for over a week. Jennifer's family leaned on their faith, and a great team of doctors to get through this terrifying time. Slowly, her disease improved with steroid treatment, and happily Jennifer did not need a bone marrow transplant.

We asked Jennifer how she feels about her experience today:

"I would be a different person if this moment had not have opened my eyes. I have grown more thankful for the people in my life. I have become more conscious of others and their feelings, because we do not always know what hardships they may be facing. I now know how precious life is and try my hardest to live it the best way I can."

Finding Answers....



Ask Questions. I wish I would've asked more.

Keep a **notebook** with your questions and notes. I kept a 3 ring binder to track all of my child's medical information.

Pay attention to the medicines your child is being given, **it's ok to ask** what someone is giving your child.

It's also ok to ask staff if they have **washed their hands**. Keeping your child free of germs is important.

No one loves your child as much as you do. You are your child's best advocate.

If you are planning an inpatient admit, ask for *a list of items that you should bring.* Ideas include favorite blankets, movies, toys.

Ask about *visitor rules,* so that you can know ahead of time and plan accordingly. Don't assume that all units have the same rules.

Ask for the *contact information* of your nurse care manager or a person who you can reach when you have questions. Keep it handy.





Ask the Child Life division to help you plan activities or special things for your child while you are in the hospital.

Talk with your child about things other than being sick. *Remember, there is more to your child than their illness.* Help them to remember this, too. It will give you quality time together and will make good memories as well.

Ask about other supports that are available to you in the hospital. There are social workers, PT, OT, Speech, possibly music therapy or holistic health.

Every situation will be completely unique. I felt like I was a parent and a nurse and sometimes a doctor.

Ask for help from your team when you need it.

Ask to review things when you aren't sure.

Phrase your questions on a point scale. It will help you to gain perspective.

“Where is my child on a scale of 1-10?”

Ask about *genetic testing* and if other family members should be tested for HLH genetic mutations.

Find out if your child will need a bone marrow transplant. Ask how *donor matching* works.



Finding Your Way...



“HLH treatment is a marathon, not a sprint.” Plan for the long term.

Check the sources of the information that you find online to be sure they are reputable.

Use www.carepages.com, social media or a blog to keep family updated instead of repeating yourself over and over.

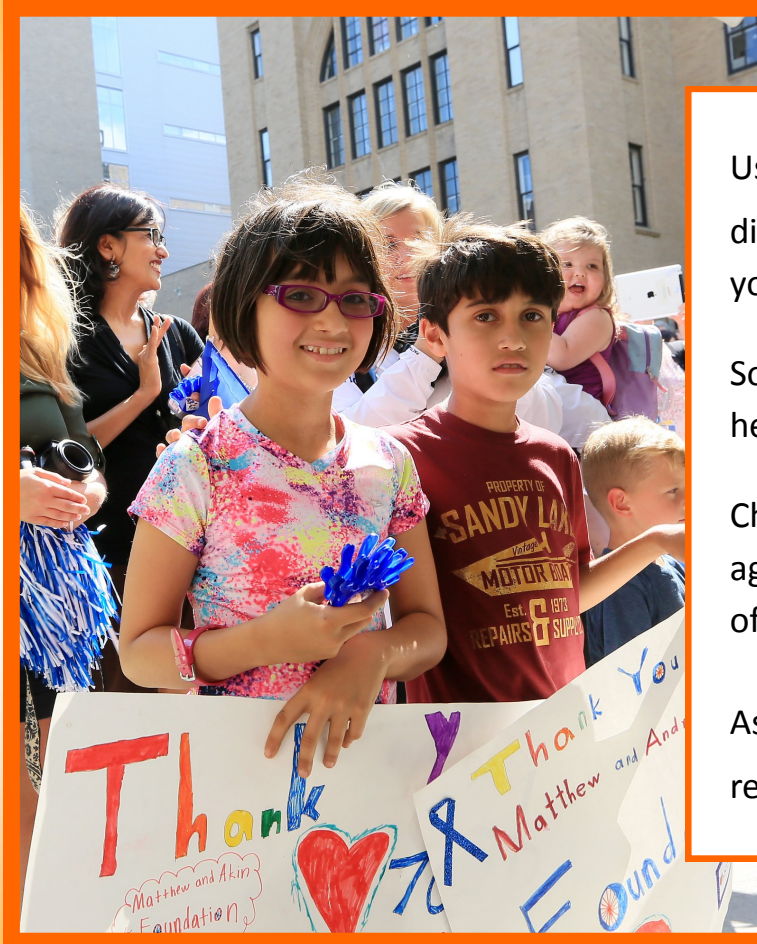
Figure out how to make your life work with these changes. Can you work remotely from the hospital?

Be proactive about insurance denials, call your insurance company and ask questions about your coverage.

Connect with others families, those who have been out a few years, they will give you hope.

Ask your child's *friends* to keep in touch. It's important for your child to have a sense of connectedness to those who love and support them.





Use the *Family Resource Center* for discounted hotels, computer access, and finding your way around town.

Some hospitals have a concierge service that can help with errands.

Check with your insurance plan if you have coverage for daily needs or hotels while receiving out of town treatment.

Ask the *social worker* about additional resources that might help with expenses.



Don't be afraid to ask for help,
both physically and emotionally.

*People usually ask to help
and so take them up on it!*

Have one person in charge of
laundry, one in charge of meals,
one in charge of taking the kids
to after-school activities, one in
charge of taking out the trash.
Ask some one to pick up your mail
or have it forwarded.



Start a *wish list* for family and friends to help with. You could even do it online.

- Books, toys, or other items for your child
- Online movie subscription
- EZ pass for traveling toll roads to appointments or pre-paid gas cards
- gift cards for the cafeteria
- Restaurant gift cards for places nearby
- Stamps, writing supplies
- Drawing or other hobby supplies to help your child pass the time

Take care of yourself.

This cannot be underestimated.

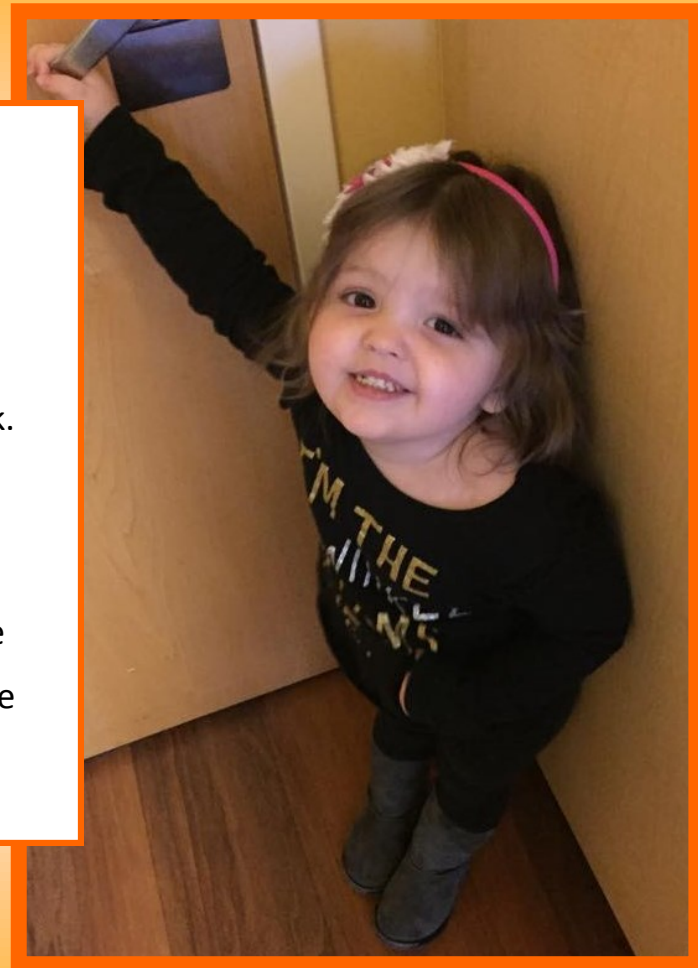
Find a routine that works for you.

Take a few minutes to get lunch, read, or take a walk.

Step outside for a while.

Don't isolate yourself. Talk with other parents.

Find a support system that fits you: online groups, emailing friends, or calling home. Make the time to do this, it's important.



Finding Perspective...



“I’d wish I’d known about the physical changes involved with steroids and treatment.”



Steroids can cause weight gain, hair growth, high blood pressure, moodiness (may cry a lot), and high blood sugar.



**Feeding tubes help
with eating.
Children get used to
them quickly and they
make giving medications
easy.**

*The physical changes you
see in your child during
steroid treatment do not
last forever.*

Ava, after treatment, 2015

Ava, during BMT, 2014

Success!

Alex was transplanted for HLH as an infant at Cincinnati Children's, has graduated high school and attends Wake Forest University.



Alex pictured above with his parents in 2015. He is a Matthew & Andrew Akin Foundation scholarship winner, which is designated specifically for HLH patients.



Alex during treatment in January 1999, above.



Alex after treatment in August 2000.

My HLH Story

HLH happens most often in children, but adults can get it too. Most adult doctors are not experienced in treating HLH because it is so rare and that is how a 36 year old can end up in a children's hospital!

Aaron had an autoimmune disease called mixed connective tissue disease for a few years when he became ill with a fever, weakness and body aches. Aaron was admitted to a hospital in New York, where things got worse. He developed the signs of HLH in his blood (low counts, high ferritin) and his organs began to fail. Aaron was on a ventilator and needed dialysis. Aaron's loyal and well-named brother Happy was at his side advocating for every effort to be made to help Aaron.

Aaron's doctors conferred with Cincinnati and started treatment for HLH. After 6 weeks in New York, Aaron transferred to Cincinnati for treatment and fit in very nicely in a children's hospital!

The good news is that Aaron continued to get better and he is now, home, his organs are all working just fine and he is off all HLH treatment. Happy rode in the "700 miles for Hope" HLH fundraiser in honor of Aaron and his courage in winning against this tricky disease!



Finding Hope...



Know that there will be times of uncertainty.

The journey is long, much longer than I had thought it would be.

Pick your battles.

Take things one day at a time.

Small goals are good.

Read survivor stories.

Find *inspiration* around you.

These moments count too.

Think about what kind of coping skills work best for you. What about your spouse, or your child, how do they cope?

*Everyone copes differently,
and recognizing this helps.
You have to let people cope in the
way that works best for them.*

I wish I'd have known how much stronger, not only myself, but my child would be for going through it all. *You are stronger than you know.*



There certainly are no guarantees in life but putting yourself with the *experts* surely increases your odds.

With a diagnosis as rare as HLH, the volume of patients treated in a center and thus the amount of *experience* a medical team has, matters immensely .

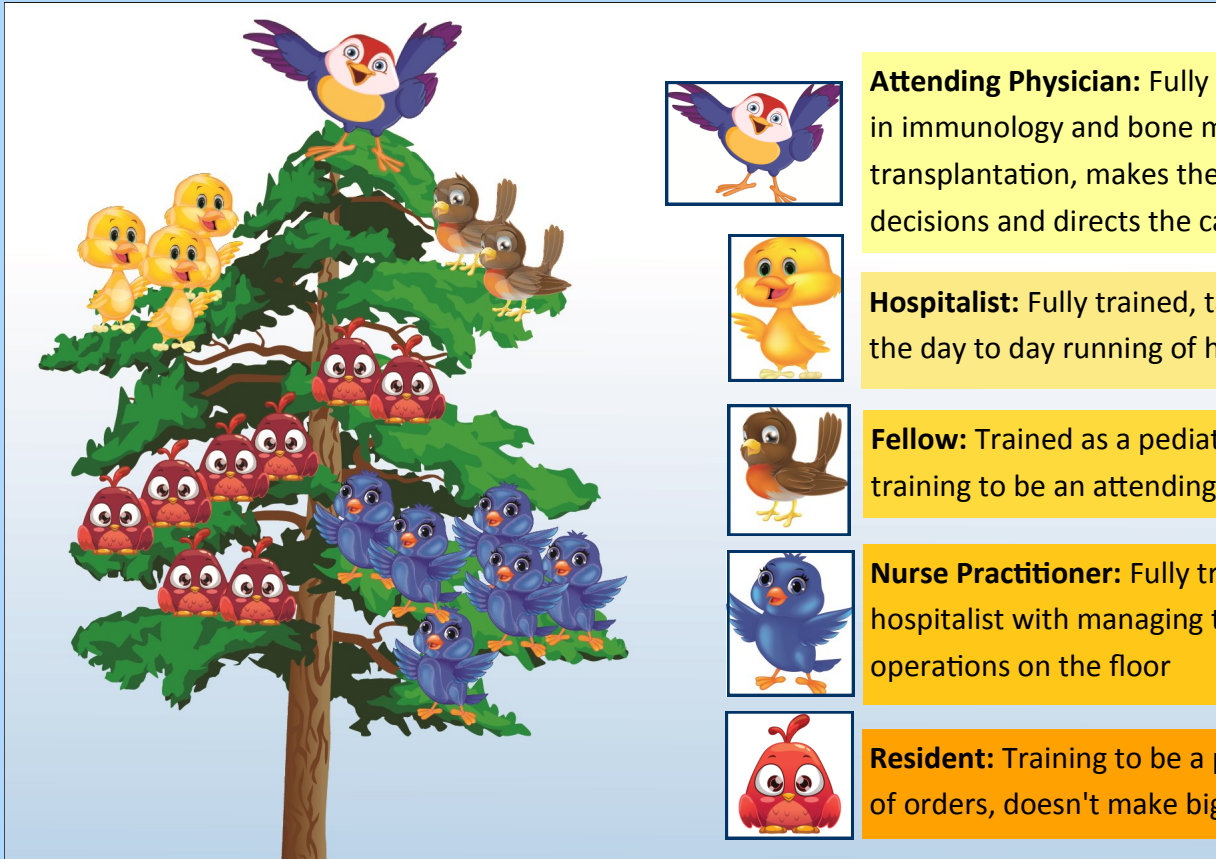




I'd wish I would have known the sheer staggering numbers of *platelets* and *transfusions* and procedures that there would be in those first few months.

I wish I would have known what a *roller coaster ride it would be*, doing poorly, doing well, worse again, and then better.

Finding Who's Who amongst doctors



Attending Physician: Fully trained in immunology and bone marrow transplantation, makes the big decisions and directs the care plan



Hospitalist: Fully trained, takes care of the day to day running of hospital floor



Fellow: Trained as a pediatrician, now training to be an attending physician



Nurse Practitioner: Fully trained, assists hospitalist with managing the day to day operations on the floor



Resident: Training to be a pediatrician, takes care of orders, doesn't make big decisions

A hospital has many specialized physicians, departments and services.

Each may play a role in your child's care.

See the following pages to see how they can help.



Finding the help you need

There will be many members on your child's care team. It can be overwhelming, and hard to know who does what.

Here we describe key players that may be important in your child's care.



Social workers are trained to assist with stressful situations and problems that can arise during a hospital stay with a chronically ill child. They can help you find resources to deal with your child's situation.



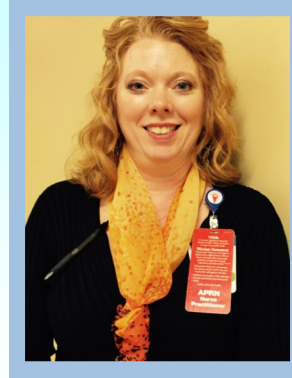
Nurse Care Coordinators

are experts in bone marrow transplant, and coordinate outpatient care. They help you navigate the hospital system and will be your primary point of contact long term. Get to know them quickly!



Attending Physicians

are pediatric specialists with extra training in immunology and bone marrow transplantation. They lead the team of doctors and direct the care plan. They supervise and teach hospitalists, fellows, & residents.

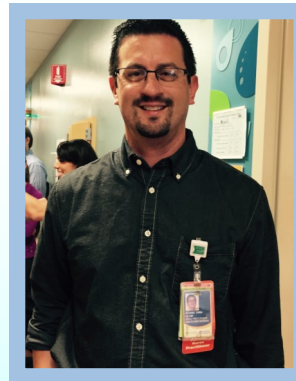


Clinical Managers:

The unit leader for each patient care area. Clinical managers are the overall charge nurse of patient services on the inpatient floor and can help with major problems in your child's day to day care.



Hospitalists are fully trained medical doctors. Hospitalists take care of the day to day running of the hospital floor. In many hospitals, Hospitalists are available 24/7 and will be there to check your child immediately if there is anything wrong.



Advanced Practice

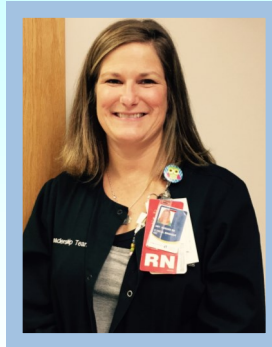
Nurse: Nurse practitioners (APN) and clinical nurse specialists are registered nurses who have completed graduate-level education and board certification. They provide care in a specialty area in collaboration with doctors.



Inpatient Care

Coordinator or Discharge Planner:

Coordinates care on the inpatient unit and facilitates discharge planning, including follow up care needs.



Charge Nurses:

The charge nurse oversees the nurses on the unit for a particular shift and are the family's first resource for any difficulty with nursing care.

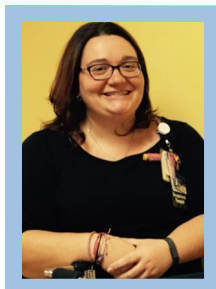


Registered Nurse (RN) :

Nurse who has graduated from a college-level nursing program and has passed a national licensing exam. You will have a registered nurse assigned to your child's care 24 hours a day.



Physical therapists (PT) are trained in working with children who have critical illnesses, they use cutting-edge techniques to improve a child's motor skills, strength, and endurance.



Occupational therapy (OT) helps children learn skills and participate in activities for successful, independent daily living.

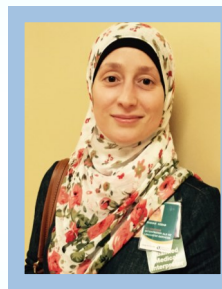


Speech-language pathology services include comprehensive evaluations, consultations, parent counseling, and treatment for children with communication or feeding / swallowing disorders.



Unit Secretary

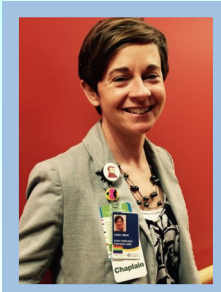
Unit Secretaries help keep the unit running smoothly. They are a good source of information about the unit.



Interpreter Services Trained and qualified medical interpreters are available to help non-English speaking families. Having a medical interpreter ensures that the communication between you and the hospital staff is complete and accurate.



Psychologists provide behavioral assessment and care to help your child cope with the rigors of acute and chronic health conditions.



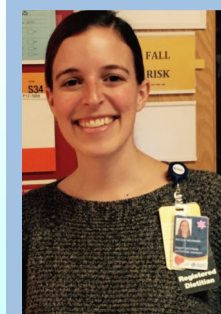
Pastoral Care:

Chaplains provide spiritual guidance to people of all faiths or simply emotional support for families who are struggling with a child's illness.



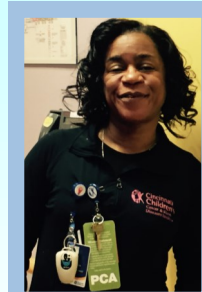
School Teacher:

Certified teachers are here to help your child with school concerns during hospitalization.



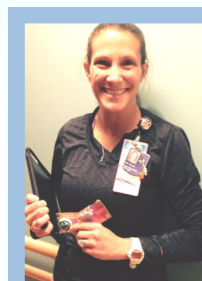
Registered Dietician:

Coordinates the special diet and nutrition therapy your child may need.



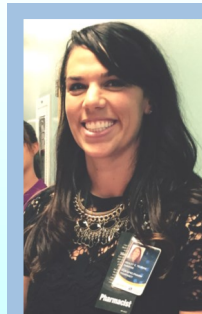
Patient Care Attendees (PCA)

perform basic care services, such as checking temperature and blood pressure, assisting with feeding and bathing, and responding to call lights. PCAs work under the supervision of nurses and doctors.



Child Life:

Child life staff hold masters degrees and work with you and your child to reduce anxiety during procedures and hospitalization. They introduce books, toys, and educational play that can help your child cope with their medical care.



Pharmacist:

The Division of Pharmacy works with the care team to deliver medication safely and effectively.



Pain Management:

Fully trained consultative team that helps to manage pain and other uncomfortable symptoms. This team is made up of physicians, social workers and a nurse practitioner, all dedicated to providing comfort, care and support. This care focuses on enhancing quality of life for the child and family and minimizing suffering.

Financial Counselor: If you are worried about paying your medical bills, financial counselors are available to help.

Music Therapy: Music therapists use music to help your child meet treatment goals and cope with stress, fear and anger. Music therapy is based on research, and music therapists are board certified through the Certification Board for Music Therapists.

Integrative Medicine: Holistic Health staff use safe, proven, complementary and alternative therapies integrated with traditional medical treatments and are able to teach children effective ways to reduce stress, pain, discomfort and fear or anxiety.

MAX

The Angry Macrophage



Meet Max the angry macrophage in our cartoon that explains HLH in a child friendly way.

See the video on our website at:

<http://www.cincinnatichildrens.org/service/h/hlh/about/>

Or search for Max the angry macrophage on youtube

**We sincerely thank all of the families and children
who generously extended their time,
thoughts, words and pictures to this book.**

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Liza and Alex Green

Aaron Peterson

Kristin Akin

Ann Flaherty

To learn more about the HLH Center of Excellence
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