

bonus days

PAGES FOR THE RESILIENT

TAKE A
BREATH WITH
**CALVIN
HENRY**
ON PAGE 32



LIVING LIFE IN
FULL VOLUME

HEALING THROUGH THE ARTS

FROM ER NURSE TO ICU PATIENT
ORGAN DONATION AT THE SCIENCE FAIR
1ST BIRTHDAY TRANSPLANT WISH
+ MORE!



WELCOME TO

bonus *days*



*pages for
the resilient* →



spring

ISSUE 03

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cover photo
Calvin Henry
Photo by Alison Conklin

behind the scenes

The making of our Spring 2025 issue!



Associate Editor Geoff reviewing this issue at the beach!



Copy Director Shelbi laying out the I Spy in this issue, check it out on page 66.



Putting *Bonus Days* together has been an incredible labor of love—from brainstorming stories to photographing inspiring people and bringing each page to life. Every step, from late-night editing sessions to on-location shoots, has been fueled by passion and a deep belief in sharing stories that matter. Seeing it all come together is nothing short of magic, and we're so grateful to be creating something so meaningful.

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bonus days

ISSUE 03 | SPRING 2025

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pages for
the resilient

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I want to celebrate our stories—the strength we’ve shown, the scars we carry, and the incredible things we’ve built because of the lives we’ve lived.

This past year has been nothing short of incredible for *Bonus Days*. Our very first issue won an Anthem Award, a recognition that affirms the heart and purpose behind this magazine. I’ve traveled to Oklahoma, Georgia, New York, and South Carolina to bring this Spring issue to life, meeting extraordinary people and hearing stories that remind me why this work matters so much.

Building a magazine is the most rewarding endeavor I’ve ever taken on, but the momentum keeps growing because of you—our readers. Your support, your social media posts, and the way you share *Bonus Days* with your friends and teams mean everything. It’s even being studied in a college class at Lehigh University, expanding the conversation around organ donation and stories of hope in ways I never imagined. I think Amy Mann, fellow heart transplant recipient, put it best when she read the news “that’s a win for all us transplant recipients and those on the transplant pathway journey.”

Others have walked this road before us, facing similar challenges, and have come out

the other side stronger. They’ve paved the way, creating tools and support to make the journey a little easier for those who follow. Life after any medical journey never looks exactly like it did before, but somehow, it becomes even more beautiful.

I’m always reminded of the saying: *We must know darkness to truly appreciate the beauty of the sun.*

In this issue, you’ll read stories of resilience, like how Heather Rodale turned her healing experience into a foundation to support patients everywhere, and how Calvin Henry refused to give up. I hope you will tear out the beautiful illustration from Dallas Shaw and hang it on your wall. Enjoy reading how Ava has taken a diagnosis and made a platform out of it at such a young age. Have so much fun with the I Spy - we had the best time gathering little treasures to create that.

I want *Bonus Days* to be a place where we find connection and resources: podcasts that make us feel part of a community, helpful tools to allow us to navigate our lives, online support groups, and stories that remind us we are never alone.



You can buy this "I Was Built on Resilience" shirt designed by Edith Gutierrez-Hawbaker at telojurocollective.com



The day Alison picked up 1000 copies of the Autumn issue and packed them all into her Honda CRV!

I’ve caught myself saying, “I’m so excited about this issue” countless times—and I truly mean it. The energy in these pages, the courage of those sharing their stories, the joy in the pump-up songs—it’s all a testament to what *Bonus Days* is about.

Thank you for being here. Welcome to our third issue. Let’s continue to celebrate, support, and inspire each other.

alison conklin

Alison Conklin
Editor-in-Chief
@@bonusdaysmag

Got a story idea?
We’d love to hear it! Email me:
Alison@BonusDaysMag.com

LOSE YOURSELF

EMINEM

SHUT UP AND DANCE

WALK THE MOON

TAKE IT EASY

THE EAGLES

DON'T LET GO

VIVA LA PANDA

I'M NOT OKAY

MY CHEMICAL ROMANCE

CAN'T STOP

RED HOT CHILI PEPPERS

ENTER SANDMAN

METALLICA

PERFECT DAY

HOKU

IT'S ALL COMING BACK TO ME NOW

CELINE DION

VIVIR MI VIDA

MARC ANTHONY

PROMISES

MAVERICK CITY

MY SONGS KNOW WHAT YOU DID IN THE DARK (LIGHT UM UP)

FALL OUT BOY

RUN THIS TOWN

JAY-Z

MAKE A MAN OUT OF YOU

MULAN

Music is such an incredibly personal part of our lives that we connect with every single day. Listening preferences change by mood, activities, whether you’re driving on a long road trip, or trying to keep your toddler occupied in the backseat. There are so many options now to hit your current mood, help change it, and keep your auditory nerves happy. Check out these favorites from the Bonus Days team:

♥ DAWN LEVITT
@DAWNLEVITT_AUTHOR

♥ JOANNE DRENCKHAHN
@NURSEJOJO100

♥ NICOLE CROOK
@BIONICS_HEART

♥ SHELBI STONEBACK

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@ME.ANDMYTRIBE

♥ VANESSA DAUGHERTY
@TRAVELSWITHTRANSPLANT

♥ DALLAS SHAW
@DALLASSHAW

♥ SARAH JAMMER

When Alison was in the hospital in New York City, her husband Geoff created her a playlist on Spotify with some of her favorite songs, as well as songs about hearts.

Scan on Spotify to listen!



Discover this month's curated guide of resources!

Krysalis Kouture: Healing in Style

Paloma Soledad
Survivor/Founder/CEO
KrysalisKouture.com

Paloma Soledad, a fashion designer and three-time stage IV cancer survivor, founded LuxCare to address the challenges of medical treatments with style, comfort,



and accessibility. Drawing from her personal experiences, she created a line of adaptive clothing designed to support individuals managing chronic illnesses and recovery. LuxCare garments are crafted from natural fibers, which are gentle on sensitive skin and free from plastics or metals, making them completely scan-friendly. Each piece is thoughtfully designed with features like chest port access, built-in bralettes, and stylish solutions to camouflage surgical drains and body changes. LuxCare blends practicality with elegance, offering seamless transitions from home to work, school, or medical appointments.

Discover comfort and confidence with LuxCare at [LuxCare-Clothing.com](https://www.luxcare-clothing.com)



Creations by TNTCCP

Etsy Shop by Thuy Nhu Tran

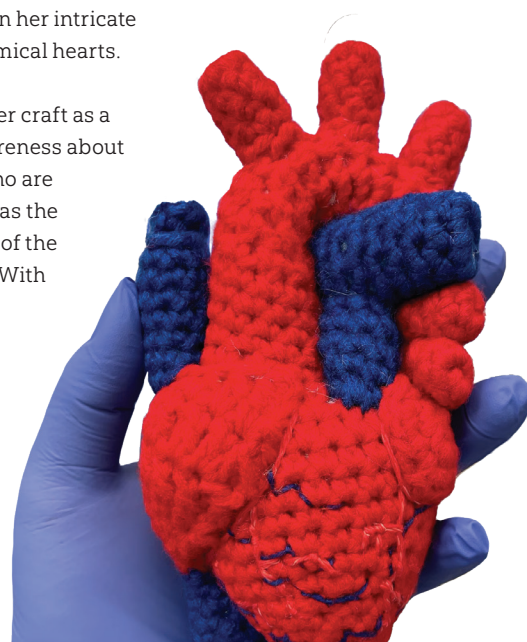
Thuy Nhu Tran is a Certified Clinical Perfusionist, also known as a Heart-Lung-Machine Operator. Her primary responsibility is to support patients' physiological and metabolic needs through extracorporeal oxygenation of the blood during open-heart surgery. This process creates a motionless and bloodless field, enabling cardiac surgeons to operate effectively on the heart.

For Thuy, crochet serves as a therapeutic outlet for managing the stresses of being both a full-time mom and a full-time Perfusionist. After eight years

in the field, she continues to love Perfusion despite its high-stress environment, a passion that is reflected in her intricate crocheted anatomical hearts.

Thuy also uses her craft as a way to raise awareness about Perfusionists, who are often referred to as the "unsung heroes" of the operating room. With fewer than 5,000 Perfusionists in the country, she is dedicated to shedding light on the critical role they play.

She is proud to be part of a profession without which heart surgery would be impossible.



The Second Wind Lung Transplant Association, Inc. was formed in 1995 and adopted the following mission statement, which 29 years later, continues to guide their work.

"To improve the quality of life for lung transplant recipients, lung surgery candidates, people with related pulmonary concerns and their families, by providing support, advocacy, education, information, and guidance through a spirit of service, adding years to their lives and life to their years."

Second Wind is a volunteer driven organization, with no paid staff or central office. It relies solely on private donations to fund its work. It currently receives no government or foundation funding.

Unpacking the Gift of Life

Podcast by Valen Keefer

Discover **Unpacking the Gift of Life**, a podcast that explores the highs and lows of living with kidney disease, chronic illness, and the transplant experience.

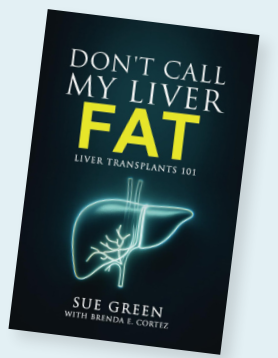
Hosted by Valen Keefer, a passionate advocate, educator, and double organ transplant recipient, the show creates a space to unpack the challenges, triumphs, and perspectives of navigating chronic illness.

Season 1 introduced heartfelt conversations between Valen and co-host Cristen Wathen, a licensed counselor and fellow transplant recipient, offering invaluable insights for patients,

caregivers, and anyone touched by these experiences.

Together, they shed light on the emotional and practical sides of living with health challenges. Packed with compelling stories and actionable insights, this season will continue to offer the community connection and hope.

Whether you're a patient, caregiver, or simply seeking to understand the transplant experience, *Unpacking the Gift of Life* is here for you. Catch up on Season 1 now on Apple Podcasts and Spotify, and stay tuned for an inspiring new season launching in Summer 2025.



Don't Call My Liver Fat

by Sue Green

Fatty liver disease is the fastest-growing disease in America and is also the one that your doctor probably knows the least about. It affects men and women of all ages and usually provides no symptoms until it is very serious.

Liver disease is a poorly understood and managed condition. There are many causes, so it is important to understand how to prevent liver damage. Sue's book *Don't Call My Liver Fat* will give insight and answer many of your questions. It also shares the stories of two women who had liver transplants as a result of the disease. Their personal experiences include a living donor transplant and deceased donation, along with how to navigate pre- and post-transplant issues.

Sue Green is a nurse with an MBA from Rice University and has clinical expertise and high-level consulting experience in healthcare having run acute care hospitals for most of her career. Sue developed liver cancer and cirrhosis with very few symptoms and was told she needed a liver transplant to survive. She had a living donor transplant in 2021.

You can find her book on [amazon.com](https://www.amazon.com) or ask your local independent bookseller.

You can connect with Second Wind and its mission through these channels.

AirWays: a publication devoted to information regarding lung health and transplantation. In addition to articles from medical professionals, AirWays contains personal stories from lung transplant recipients and their caregivers outlining the challenges they faced throughout their transplant journey.

2ndwind.org: It includes information about Second Wind programs, Lung Transplant Centers in the U.S., stories from transplant recipients, information on nutrition, caregivers, and many other topics.

Email Support Group: Second Wind maintains an online support group of subscribers

with an interest in lung health that is open to the public. Questions, comments, and experiences are posted in an email type format. All you need to do is send an email to tnate1254@gmail.com if you wish to be added to the group.

Facebook: Second Wind maintains a Facebook page where lung transplant patients and their families can share information and support.

Membership is open to all, and since the COVID pandemic began, membership dues have been waived. To become part of Second Wind, go to [2ndwind.org](https://www.2ndwind.org)

Young Voices: Big Impact

Ava Jo Thompson

PHOTO BY JODI CHAPMAN

While other 8th grade students are presenting their science fair projects about moldy bread, fruit batteries, or magnet power, Ava Jo Thompson had a more unique subject—the importance of organ donation. Bonus Days is excited to share portions of her project that she presented to 6th and 7th graders at her school in Michigan.

“Younger students I feel are more likely to listen to me because I’m someone of their age but also they aren’t afraid to ask questions and not know things like adults. Raising awareness for this topic is life-saving.”



I was diagnosed with Autosomal Dominant Polycystic Kidney Disease (ADPKD) when I was 6 years old. PKD is an extremely rare kidney disease that causes cysts to form within the kidneys, limiting the kidney’s ability to function. Many medical professionals will never see a case of PKD during their career. Eventually, my disease will progress, causing me to need a kidney transplant to survive.

PKD is a hereditary condition, meaning it is passed down from family members. My grandfather aged out of the transplant list and died of liver cancer. My grammie has PKD and was the first person in my family to receive a kidney transplant. My grammie received her kidney 7 years ago from my aunt. The kidney is still working well to this day!

My personal experience with organ donation and transplantation has allowed me to understand the incredible life-saving and life-altering gift of organ donation.

She presented to her classmates: My goal is to spread awareness and encourage conversations around the importance of eye, organ, and tissue donation within our community! I aim to educate and advocate for organ donation in Michigan and beyond. No one should be forced to donate, but I hope that by educating our local community, I can spark conversations around the importance of organ donation and the life-saving impact it can have on a person’s life.

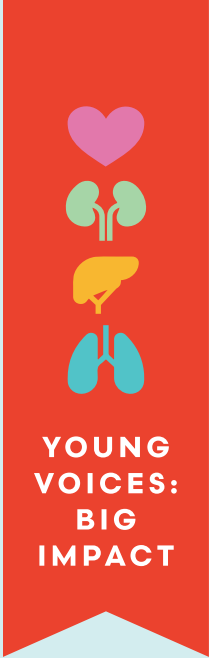
In a few years, you will likely get a driver’s license at the DMV. During that process, you will be asked if you want to be an organ donor. I hope to inspire you to think about that decision before making it.

My biggest plan right now that I would absolutely love to do is host a community night about organ donation and transplantation because Michigan is a majority state for organ donation so I want to put emphasis on the work that we have already done. [tu](#)

PKD FAST FACTS

- 600,000** People in the US have PKD
- Teal** Is the color of the PKD awareness ribbon
- 5%** Of kidney transplants are related to PKD

FOR MORE PKD INFO VISIT THE PKD FOUNDATION



CHECK OUT SOME OF AVA'S PRESENTATION ON ORGAN DONATION!

What Can Be Donated

- Lungs:** The survival rate of transplanted lungs is over 65%.
- Livers:** 70% of transplanted livers last more than 5 years.
- Pancreas:** The average length of time for a transplanted pancreas is over 10 years.
- Intestines:** To date 100,859 intestinal transplants have been done in the world.
- Tissues:** 1 in every 20 Americans will benefit from a tissue donation.
- Corneas:** Can improve a recipient's sight for over 20 years.
- Hearts:** 70% of transplanted hearts last more than 5 years.
- Stomach:** Transplants that include the stomach usually include multiple abdominal organs and are called multivisceral transplants.
- Kidney:** Transplanted kidneys can improve the recipient's life for 10-15 years.
- Blood and Bone Marrow:** Can be donated from living donors multiple times.



Types of Donation

- Deceased Donation:** When a person passes away, they or their family can choose to donate their organs to someone in need.
- Living Donation:** A living, healthy individual donates an organ, part of an organ, or tissue to a recipient. Organs and tissues that can be used in living donation include the kidneys, liver, bone marrow, and blood products.
- Vascularized Composite Allografts (VCA):** VCA donation refers to tissue donation. Advancements in transplantation have allowed for facial reconstruction and transplantation as well as limb transplants.
- Pediatric Donation:** Certain diseases cause children to need organ transplantations. Pediatric donation includes size matching the organ to the child to ensure success.



FEATURED ARTIST

Chloé Temtchine

A Journey of Courage, Resilience, and Music

Chloé Temtchine is an award-winning singer, songwriter, speaker, and the visionary behind *Super Brave*, an interview series showcasing inspiring stories of children and adults navigating life with chronic illnesses. Her own journey, however, is as powerful as the stories she shares.

In 2020, Chloé faced a life-altering battle. After 12 years of living with Pulmonary Hypertension (PH) and Pulmonary Veno Occlusive Disease (PVOD), her condition culminated in a cardiac arrest. She spent four days in a coma, nearly a month on life support, and ultimately underwent a life-saving double-lung transplant.

But Chloé's story of resilience began long before her transplant. In 2013, at the height of her career, she was

preparing for a world tour and collaborating with Grammy-nominated Greg Camp of Smash Mouth. Suddenly, she was rushed to the ER with congestive heart failure. Diagnosed with the rare and severe condition of Pulmonary Arterial Hypertension (PAH), she was given days to live. Defying the odds, Chloé restructured her life around five key pillars: nutrition, exercise, mindset, creative expression, and time with loved ones.

Despite singing with a paralyzed vocal cord and relying on her portable oxygen tank, lovingly nicknamed "Steve Martin," Chloé continued to create and inspire. She released four albums, including *Be Brave*, which saw over 150,000 downloads in its first 90 days. Her music career flourished alongside her advocacy, earning



her accolades such as the Avon Award for "Best Song" and numerous recognitions for her inspirational tracks, *Be Brave* and *Breathe*.

Chloé's transplant marked a new chapter in her life, expanding her mission to include advocating for PH awareness and organ donation. She launched the Chloé Temtchine Foundation (TCTF), with initiatives like *The Smile Tour*, where she performs for pediatric patients across the U.S., spreading hope and joy. Her foundation also supports her *Super Brave* series, which empowers children facing life's toughest challenges.

Chloé has performed on *Late Night with David Letterman* and *The Doctors* and has been featured in outlets like *The Huffington Post*, *LA Weekly*, and *The New York Post*. She's also worked alongside Grammy-



winning songwriters such as Toby Gad (John Legend, Beyoncé) and Sasha Skarbek (James Blunt).

Through music, humor, and compassion, Chloé Temtchine continues to transform adversity into empowerment. Her unwavering message of resilience shines as a beacon of hope, proving that life's greatest challenges can inspire extraordinary achievements. To learn more about her music, upcoming *The Smile Tour*, or her advocacy work with *Super Brave Kids*, visit her website and follow her on Instagram. [@chloetemtchine](https://www.instagram.com/chloetemtchine) [chloetemtchine.com](https://www.chloetemtchine.com)



GRATITUDE spotlight

WITH Sarah Jammer

WHAT'S ONE SMALL THING THAT BRINGS YOU JOY EVERY DAY?

Music!

It has been a constant source of joy in my life for so long! There is always a song to help process whatever emotion I am feeling and sometimes singing is just what is needed to cheer me up!

WHO OR WHAT INSPIRES YOU TO KEEP GOING ON TOUGH DAYS?

My twin daughters.

The three of us have been through so much during this journey together and they are the most resilient and strongest little mamas I've ever met. They consistently remind me that we just need to keep moving forward and everything will work out in the end. We just need to trust in God.

IF YOU COULD GIVE YOUR DONOR OR THEIR FAMILY A MESSAGE, WHAT WOULD IT BE?

Thank you.

Thank you for giving a new mom a chance to live a beautiful new life with her husband and daughters. Thank you for allowing me the opportunity to watch my daughters achieve milestones and grow. Thank you for keeping my husband from becoming single. I thank you from the bottom of my heart for this new chance at life.

At 33.5 weeks pregnant with twins, I felt something was wrong but couldn't pinpoint it. On June 24, 2024, after my weekly iron infusion, I fell into a critical state, later diagnosed with Acute Fatty Liver of Pregnancy—a rare condition requiring immediate delivery. After naturally delivering my daughters, Evelyn and Cecilia, on June 25, I didn't recover and was airlifted for an emergency liver transplant, which saved my life on June 28. Waking up days later, I was overwhelmed by gratitude for my second chance at life, but also devastated by missing the first ten days with my daughters and the unexpected journey into transplant recovery. These six months have been a challenging blend of gratitude, grief, and resilience, teaching me to embrace my "Bonus Days" and the strength within me.

WHAT'S A FAVORITE "BONUS DAY" SO FAR?

Christmas morning!

WHAT'S YOUR GO-TO COMFORT ACTIVITY OR TREAT?

Coloring with alcohol markers.

WHAT'S YOUR FAVORITE WAY TO CELEBRATE MILESTONES?

Being with my family!

DO YOU HAVE A MANTRA OR QUOTE THAT KEEPS YOU GROUNDED?

I'm a big Disney fan and *Mulan* is one of my favorite movies:

The flower that blooms in adversity is the most rare and beautiful of all. 🌸

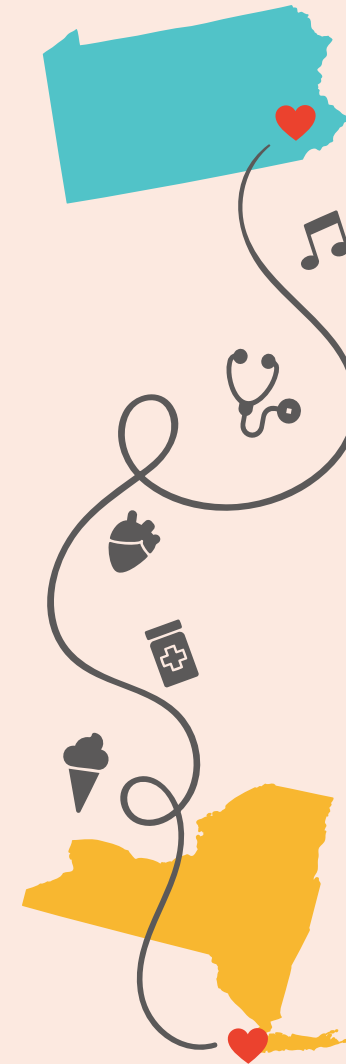


TRANSPLANT LIMBO

BY
DR. ALIN GRAGOSSIAN

@A_CHANGE_OF_HEART_BLOG

In 2019, I received an urgent heart transplant due to familial dilated cardiomyopathy. I had no idea that I had carried a genetic defect that would decide my fate at age 30.



ALIN ♥
LUCY

EVERYTHING HAPPENED ALL AT ONCE.

I had finished medical school a few years prior and was on the fast track to becoming an Emergency and Critical Care attending physician. New York City was calling for the next chapter of my training, and life felt like a highlight reel: celebrating milestones, indulging in amazing dinners in Center City Philadelphia, and soaking in all the beauty around me.

Over the course of a few weeks, I began having shortness of breath and a cough that just wasn't going away. Suddenly, I felt like I couldn't breathe. One thing led to another, and I found myself in a hospital bed, being told that I was critically ill and in cardiogenic shock. I was diagnosed with genetic dilated cardiomyopathy that led to end-stage heart failure. And the only available treatment – a heart transplant.

Fast forward 6+ years and here we are today. I'm so grateful for my organ donor Lucy and her family. I recently got a follow-up echocardiogram- something I do regularly- to make sure my heart is still functioning like it should. I do blood work from time-to-time to make sure that medication levels are satisfactory and electrolytes are within normal limits.

I remember soon after I got my heart transplant, a friend asked me, "But, you're okay now, right?" And at that time, it was such a funny thing to be asked.

What exactly do I consider myself? Am I sick? Am I "OK" now? Yes, I am fine. But I have the potential to not be fine very quickly. Every day is this mix of gratitude and uncertainty. I can't take the gift of Lucy's heart for granted—it's given me a life I wouldn't have had otherwise. But I also can't forget that I live with an immune system ready to pick a fight with it if I'm not careful.

WHAT IS THIS LIMBO THAT I LIVE IN?

My meds are non-negotiable and I'm devoted to a daily routine. My life is peppered with doctor's visits that remind me I'm walking a tightrope. It's an existence where you're always grateful but hyper-aware.

And let's be real, sometimes it's hard to answer when people ask, "How are you?"

Because there's a whole spectrum between "great" and "falling apart." I'm fine—for now. But my fine might not look like your fine, and that's okay. This experience has taught me that resilience—a word that I really dislike using—isn't a one-time thing. Instead, it's something you build daily, moment-by-moment.

And maybe that's the point: learning to carry life's contradictions while still moving forward. [tb](#)



Steven Coffee II aka "Deuce"



Born in late September 2012, Steven Coffee II, affectionately known as "Deuce," is a testament to resilience, hope, and the importance of patient advocacy in medicine. His journey began with challenges that no family could have prepared for, such as diagnostic errors, and not being seen as a partner in his own medical care. Yet, his story is one of triumph over adversity.

At birth, following his newborn screening labs, Deuce began showing signs that something was wrong—low glucose levels, high bilirubin numbers, and poor feeding, all alarming signs to his parents—but their concerns were dismissed, and he was deemed normal by the smaller hospital. In reality, the signs he displayed were, in fact, classic signs of galactosemia. This rare metabolic disorder prevents the body from processing galactose, a sugar in human and animal milk. This oversight led to a rapid decline in his health, culminating in liver failure at the tender age of only two months old.

Throughout Deuce's experience, his father, Colonel Steven Coffee, trusted his parental instincts and pushed for answers. Still, he encountered a medical system that dismissed his concerns and was anchored in misdiagnosis and bias. He was repeatedly reassured that Deuce's condition was minor, and even when

signs like a swollen mass on his son's leg emerged, they were misdiagnosed as fatty tissue or a swollen lymph node. It wasn't until Deuce's health reached a critical point in late November 2012 that the severity of his condition was finally acknowledged.

Rushed to MedStar Georgetown University Hospital, Deuce was diagnosed with fulminant liver failure caused by galactosemia. At just eight weeks old, he underwent a life-saving liver transplant, making him the youngest successful transplant recipient in the United States at the time.

Deuce's recovery was a testament to the power of medical innovation, a dedicated healthcare team, and his family's unwavering love and advocacy. Inspired by their challenges, his father became a passionate international advocate for patient safety and

continues emphasizing the importance of the partnership between providers and patients in healthcare. He co-founded the World Health Organization's US chapter of Patients for Patient Safety and works tirelessly to ensure families like his receive timely and accurate diagnoses and are treated as partners in their loved one's care.

Today, Deuce is thriving as he approaches his thirteenth birthday. He is a happy, energetic boy who loves playing video games, doing tricks with his yo-yo, hanging out with his friends, and creating new adventures with his family. His story reminds us of the importance of perseverance, trusting one's instincts, and making sure your voice is heard even in the face of uncertainty.

Through Deuce's journey, his family hopes to inspire others to advocate for their loved ones and to promote better communication between patients, families, and healthcare providers. Deuce's story is not only about survival but underscores the need for active partnership and reminds us to cherish each day and the wonderful gift we have in life. [ht](#)

Transplant Teenz
@transplanttzz



My Favorites

TV show: *Big City Greens*

Movie: *Sonic 3* (all *Sonic* movies)

Video game: *Gorilla Tag on VR*

School subject: History

Food: Any type of noodles

Sports team: LA Lakers

Dream job: CEO of a vegan or dairy free bakery

If you owned a restaurant what would you name it?

Sweet Treats

If you had to eat the same snack everyday what would it be?

Double Stuf Oreos





Dallas Draws

Dallas Renee Shaw is an internationally recognized fashion illustrator, author, and creative director with over 15 years of experience in the design and lifestyle industry. Her whimsical watercolor renderings have defined the aesthetics of prominent fashion houses, including Chanel, Oscar de la Renta, and Kate Spade. Beginning her career at Walt Disney Animation

Studios, Dallas later founded her eponymous company, collaborating with brands such as Dior, Christian Louboutin, and Four Seasons Hotels. In 2017, she authored the best-selling book *The Way She Wears It: The Ultimate Insider's Guide to Revealing Your Personal Style*.

dallasrenee.com
@DallasShaw



RIP THIS PAGE OUT
AND HANG IT UP!





Hypertrophic Cardiomyopathy Association®

Home for the Bighearted Since 1996

Support, understanding, and real conversations—right at your fingertips.

Meet the HCM patients leading our monthly online support groups and find your community.



LISA SALBERG

Founder of the Hypertrophic Cardiomyopathy Association, Lisa educates, advocates, and supports other patients based on her experience with HCM. She received a heart transplant in 2017. Lisa has published three books on HCM and several peer-reviewed journal articles and spoken internationally on HCM. She has appeared in TV and print interviews advocating for patients' rights, research, and raising awareness of HCM.



LISA VECCHIONE

Lisa was diagnosed with HCM at the age of 31, after she had broken her nose at work and went to her doctor where they noticed she hadn't had a physical exam in a while. After she was diagnosed, she had two ICD placements and tried many different medications. Eventually Lisa had a heart transplant in 2022. Lisa credits the HCMA for offering her the guidance and support she needed. Now, Lisa is co-host of the pre-transplant discussion group with Dawn Levitt.



DAWN LEVITT

Dawn ended up at the doctor's office or Emergency Room often due to severe asthma which left her winded and dizzy after physical exertion. She was diagnosed in 2003 after passing out in gym class, Dawn refused to take the doctor's "no" for an answer and researched HCM and found the HCMA. She has two heart transplants and is now host of the pre-transplant discussion group with Lisa V.



KAREN KLIMCZAK

Karen had no family history of HCM, but kept passing out during physical exertion. With help from the HCMA, Karen received an ICD, and received a heart transplant in 2020. Now Karen is the co-host of the transplant pathway online discussion group, and she hopes to support others along their transplant journey and life's path.

The HCMA was founded in 1996 as a 501c3 nonprofit organization. The HCMA is the pre-eminent organization providing support, advocacy, and education to patients, families, the medical community, and the public about hypertrophic cardiomyopathy and all thick heart muscle disorders while supporting research and fostering the development of treatments.

Learn more about The HCMA at
4hcm.org



JAXON, 8 MO.

ARABELLA, 8

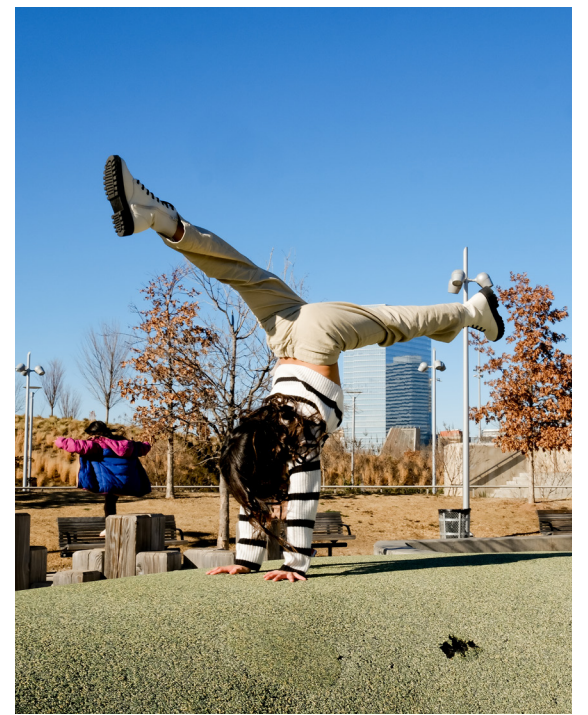
AVALYNN, 6

JOHN, 3

A First Birthday Wish

WORDS BY
MADDIE MARRIOTT

PHOTOGRAPHY BY
ALISON CONKLIN



A typical first birthday has all the usual components: a smash cake, party hats, and a pile of presents. In April of 2022, the Rhoades family had only one birthday wish for their son, John: a match for a liver transplant.

At just one month old, John was diagnosed with biliary atresia, a rare liver disease that causes blocked bile ducts. This, coupled with an earlier diagnosis of an MCAD deficiency causing difficulty breaking down

certain fatty enzymes, had plagued his first month with concerning symptoms including jaundice, lack of appetite, and a distended abdomen.

The diagnosis was terrifying for his parents Taylor and Ashley who had never heard of the disease before.

"When you get this kind of news, you go right into research mode," Taylor says. "You look at percentages,



“ We had to be really careful with him and play with him softly

says Arabella, Taylor and Ashley’s oldest daughter, who was six at the time.

“I remember my mom crying a lot and hugging him,” Arabella continues. “My dad would hold my mom when they cried together. I also remember all the medicine he had to take. I even learned how to prime his milk through his feeding machine.”

juggled caring for their two older children and finding a new job and house closer to the hospital, plus staying on top of John’s care, they had two false alarms for a viable liver. One of which even sent them driving from their home in Oklahoma to Texas Children’s Hospital in Houston.

It put stress on all parts of their lives and forced them to be apart for long periods of time: Ashley with John at the hospital and Taylor often at home with their daughters.

“It was really hard because we had to go our separate ways a lot of the time at this juncture in our lives and we had always been a team in decision-making,” Taylor says. “Being at the hospital, Ashley had to take the lead with all of that, which was different for both of us.”

“We were trying to control every situation that we could because we were in survival mode,” Taylor continues. “After John’s last admission to the hospital, we sat in our garage and really opened up to each other. We started saying that maybe we just needed to let things go and let God handle it for us. The following Monday we got the call.”

There was still a chance that he would need a liver transplant within a year, and that became the Rhoades’ reality when John’s condition continued to worsen in the following months.

“He got really sick on us,” Ashley says. “He has always been such a happy baby and slowly that started to go away. You could see it in his eyes and the way he carried himself. His body was getting tired and smile was turning into tears. This is what I remember the most.”

Periodic fevers sent John repeatedly into the hospital which was over an hour and a half away from the Rhoades’ home. While Taylor and Ashley

you look at life expectancy of someone with this disease. You just try to find the feeling that your child is going to be okay. The unknowns are what scare us.”

“I just remember relying on my husband,” Ashley said of Taylor. “The whole day, all I could think was: is my child going to die? I was in fight or flight. I couldn’t even think about researching Biliary Atresia and I just kept going to him with questions.”

Doctors acted quickly. They told Taylor and Ashley that John would need a Kasai procedure, during which they would take a piece of his small intestine and connect it to the liver to help drain bile.





“
It was the best gift he could have gotten for his birthday.



The call, which came in the early morning two days before his birthday, meant that a liver was finally available for John.

Within a day, Taylor and Ashley carried John into the operating room for the four-hour procedure which was so successful that the surgeon greeted them afterward with only three words, “Everything went great.”

Since then, John has been able to live as a “typical little boy.”

“He is thriving,” Ashley says. “He started playing soccer, he tried out for a baseball team, he’s a big brother now, he loves his big sisters.”

Now, Arabella can play with John without worry. “I like playing on the trampoline, playing hide and seek, and playing tag with him,” she says.

“He just does everything he’s supposed to do, and that’s the amazing part of it,” Ashley continues. “I thought I was going

to lose my baby, and now he’s three and he’s driving me crazy, but in such a good way.”

John’s medical journey continues as he and his family navigate an immunocompromised life. “We know there are going to be bumps along the road that land him back into the hospital,” Taylor says. “That’s just the next step of our journey that we’re figuring out with John as we go.”

Ashley shares the family’s ongoing story on Instagram @me.andmytribe where she brings light to the underdiscussed occurrence of pediatric liver disease. She has recently partnered with BAREinc.org, a non-profit dedicated to research on the treatment and management of biliary atresia.

During Liver Awareness Month in October, she called for adding biliary atresia to the newborn screening list to help families get crucial diagnoses earlier.

“Early detection and treatment are crucial for improving outcomes,” she writes in her caption. “Let’s spread awareness, support research, and advocate for those affected by liver disease.”

There’s one member of the Rhoades family who isn’t quite tired of liver talk- Arabella wants to be a liver transplant doctor.

“I want to be able to help kids, too,” she says. “They’d get to go home, spend time with their family, and not be sick anymore. I want to give them a miracle like John’s doctor did.”

@me.andmytribe



Hi friends!
My name is Caroline Laubach, and I have a heart transplant.

I received my heart three years ago after going into organ failure from a genetic heart condition I did not know I had called left ventricular non-compaction cardiomyopathy. While on life support I had a spinal stroke, leaving me paralyzed from the waist down. A few months after my transplant, I wound up with a form of post-transplant lymphoma. But this is not about that!

There have been countless times where I felt like my body fought me constantly. It felt as if there was nothing reliable about my life- nothing solid I could depend on. There I sat freshly paralyzed, in my inpatient rehab room with my month old heart transplant. I began adding songs to a playlist that I called "These Boots Are Made For Walkin' " after the Nancy Sinatra song. It quickly became a range of lullabies, songs of rage, of hope, of deep rooted sadness. Most of all, it became something sacred that I could depend on to understand me when it felt like no one did.

I've always loved creating different playlists, mostly with niche themes (the stranger the names the better). Ever since being hospitalized, my love of music has become even more

integral in my life. If you ask any of my family members, they'll tell you I always have an airpod in! I consider the music as one with my blood at this point. I'll be quite frank; some songs may seem very random or repeated, but they are weirdly purposeful on each playlist.

There are a decent amount of "breakup" songs as well- I think I've always felt that in a lot of ways I had to "break up" with my old self, with my old life that I had before chronic illness and my transplant. Maybe you feel the same, and I hope in some way these songs will help you find a pathway to less loathing like they did for me! If not, I hope you find comfort in them, some fun in them, some release in them.

Here are a few playlists I created, organized by category of emotions because sometimes you just need something oddly specific. I will apologize in advance for the sheer amount of Taylor Swift songs on these, I just couldn't help myself!

From my heart to yours, I hope you enjoy them!

@just_rollwith.it

LIFE IN FULL VOLUME

WORDS BY
CAROLINE LAUBACH

PHOTOGRAPHY BY
ALISON CONKLIN

PHOTOGRAPHED AT
FOX & FINCH STUDIO

@foxandfinchstudio



59
SONGS
3 HOURS
30 MIN.



MY FAVORITE SONG:
GREEN LIGHT, LORDE

*I'm waiting for it, that
green light, I want it*

This playlist is for the people who can see the thing that they want. It's so close to their reach that they can reach out their arms and almost feel it. It's for longing, for determination. For cautious hope. When things go wrong, it almost feels hard to trust the ground beneath your feet. If you feel you can't step, then take leaps instead, the universe will catch you regardless. This is about learning to have hope either way.

My favorite song on this playlist is Green Light by Lorde (it also served as inspo for the title). It quickly became one of my anthems that I would scream sing in the bathroom (sorry mom)!

SCAN THIS CODE ON SPOTIFY
TO LISTEN TO THIS PLAYLIST:



71
SONGS
4 HOURS
19 MIN.



MY FAVORITE SONG:
NEW ROMANTICS (TAYLOR'S VERSION), TAYLOR SWIFT

*Am I free? I think
I am! I am!*

This one feels like the moment you look at the clear blue sky and feel the warmth of the sun on your face after a period of bone chilling harshness. It's for feeling the wind in your hair that whispers you've made it. Even if the feeling is momentary, it's here and you love it.

Honestly it was kind of hard to pick my favorite song on this playlist- so I'll give you my top two! I love "New Romantics (Taylor's Version)" by Taylor Swift and "Oh, What A World" by Kacey Musgraves. "Oh, What A World" was the song my mom and sister listened to on the car ride home the day I got my heart transplant. I cannot listen to it without happy crying out of pure thankfulness.

SCAN THIS CODE ON SPOTIFY
TO LISTEN TO THIS PLAYLIST:



56
SONGS
3 HOURS
50 MIN.



MY FAVORITE SONG:
SUN BLEACHED FLIES, ETHEL CAIN

*Someday this will make
sense, just not yet*

This one has what it feels like to wallow. Sometimes we have days or weeks or months or years where we feel stuck in this bog of heaviness. This is your reminder that it's okay to feel sad or depressed. When you feel your body has betrayed you, it's valid to feel however you do about that. Close your eyes and give yourself a hug. Take five slow, deep breaths. Someday it will all make sense I promise you, maybe just not yet, and that's okay.

This was another playlist that was hard to pick one favorite song, but I would have to say "Sun Bleached Flies" by Ethel Cain takes the cake. There's something about it that was so haunting and resonated deep in my chest.

SCAN THIS CODE ON SPOTIFY
TO LISTEN TO THIS PLAYLIST:



music is THERAPY

Art and music are profound tools for fostering healing and well-being within the human body. They have the unique ability to transcend barriers, touching individuals of all ages and abilities in meaningful ways. Music, in particular, has been shown to have a powerful impact on both the mind and body. It can serve as a mood enhancer, helping to alleviate feelings of stress, anxiety, or depression, and can play a crucial role in physical rehabilitation, such as overcoming muscle weakness or improving coordination. Additionally, music therapy has been proven effective in addressing speech and language difficulties, providing individuals with new pathways for communication and self-expression, anxiety, improving sleep quality and it can be used to help people cope with grief and illness.

What makes music especially remarkable is that it is processed throughout the entire brain, engaging multiple regions simultaneously. This comprehensive engagement not only stimulates cognitive function but also fosters emotional and physical resilience. When paired with visual arts, such as painting or sculpture, the therapeutic potential expands even further, allowing individuals to explore creativity, process emotions, and build confidence. Ultimately, art and music offer a universal language of healing, capable of transforming lives and bringing comfort, inspiration, and hope to those who need it most.



KATHY PURCELL
MUSIC THERAPIST
@THERAPEUTICARTSGROUP



MARATHONS, FIRST BREATHS *and Lattes*

COFFEE & CONVERSATION WITH

Calvin Henry

WORDS AND PHOTOGRAPHY BY
ALISON CONKLIN



I sat at a marble table at Cafe Intermezzo in Atlanta waiting for Calvin Henry. It was a Saturday morning and I had just flown into town the night before. It was cold. I was bundled in a puffer jacket and hat and I found the one chair under the heater that hung from the ceiling as it slowly pushed hot air in my direction. I had talked to Calvin on the phone, exchanged a few emails and texts, but this morning I was excited to be able to meet him in person.

He walked into the restaurant equally bundled, looking sharp, and greeted me with a big smile. He sat across from me and I didn't know it at this moment but I was about to have a conversation that would forever stay with me.

Calvin ordered a latte and that sounded good so I ordered a decaf one. We sipped our cups and warmed our hands with the heat from the mugs.

"So you had a double lung transplant twelve years ago?" I asked. In truth it was the most I really knew about Calvin.

I heard so many wonderful things about him from Brooke Iarkowski, who introduced us, but he doesn't have social media so I couldn't seem to find much more on him other than a few short stories. He shared that he was about 37 when he noticed he wasn't feeling well.

I'M A *stubborn* GUY.
I JUST KNEW I WANTED TO *Live*
AND I WASN'T GOING TO *Give up* UNTIL SOMEONE
said yes.



At first there were little things like getting winded easily, which eventually progressed to coughing up blood. The latter symptoms were what pushed him to go to the doctor where he was diagnosed with idiopathic pulmonary fibrosis, an end stage non-cancerous lung disease that causes scar tissue to form on the lungs. It is very rare and his case is not genetic.

Once diagnosed his condition rapidly declined. He shared that he had been brought back to life and near death many times because of his failing lungs.

We paused there for a moment each taking sips of our lattes. "There is no cure for it and a double lung transplant was my only option," he shared. Calvin went on to tell me he was evaluated at ten different lung transplant centers but due to the potential risk that came with one of his underlying conditions, esophageal dysmotility, he was denied at each one. "They believed the risk wasn't worth the benefit of receiving the lung transplant." - each one telling him no - that unfortunately he

was not eligible for transplant. It wasn't until he went to his eleventh transplant center that the answer changed.

"What kept you going after each denial?" I asked.

He smiled and said "I'm a stubborn guy. I just knew I wanted to live and I wasn't going to give up until someone said yes. I just set off heading to each center and kept going until I couldn't go anymore."

His tenacity led him to Houston Methodist where they said yes to listing him. "I celebrated twelve years two weeks ago," he beamed. He went on to share how hard the early days of recovery were. The rollercoaster of the first year - sometimes one step forward just to take two steps back. I listened in awe of him and his story.

"What did taking your first breath feel like?" I asked.

He laughed a little and shared that he hadn't trusted it. He had been on oxygen for so long that when he was asked to take his first breath after surgery without

any assistance he reached for the oxygen anyway out of instinct.

It was the doctor who said, "You won't need that. You can breathe freely now. You have healthy lungs".

"I remember coming out of the hospital without a breathing tube. I had been on one for over a year prior to surgery and suddenly because of my double lung transplant I was able to walk out without one."

"Now being twelve years out, what would you tell yourself who was sitting in your hospital bed two days post transplant?" I asked.

Calvin looked at me for a second before responding with "No one has ever asked me that before."

I smiled at him and shrugged.

"My response to the doctors telling me that I needed a double lung transplant was 'let me hang on, let me hang on for as long as I can without a transplant until it's almost too late.' But now twelve years later - oh my goodness, it's like an awakening.

NOW TWELVE YEARS LATER—OH MY GOODNESS, IT'S LIKE AN *Awakening!*





“You know Alison,” he said, “I am only sitting at this table talking to you because of two reasons: I believe so passionately about *organ donation* and I want to make sure that people know and understand how it changes lives.”

Calvin's TOP MOMENTS

Being able to run the Olympic Marathon course (Marathon Pour Tous) during the Paris Olympics in between the professional men's and women's races was a definite top 10 moment. The entire atmosphere of the games, attending the Olympic events and closing ceremony, and soaking in the atmosphere of Paris during this time was great.

Some others in no particular order:

- Leaving the hospital after transplant and breathing on my own without an oxygen tube in my nose.
- Running the Houston Half Marathon, the 1st after my transplant.
- Seeing and spending time with my partner's grandson when he was 1st born and watching him grow year by year.
- Spending evening reflection time on Bathsheba Beach, Barbados, where my mother grew up.
- Returning to Peru and hiking to near peak level of Vinicunca (Rainbow Mountain) at 16,500 feet elevation after being evacuated from the same area by ambulance 10 years earlier because I was suffocating due to lung damage.
- Attending L'International des Feux Loto-Quebec (world's largest fireworks competition).
- Running the Puerto Rico Tropikal Half Marathon.
- Going to the 2018 MLS Cup and watching Atlanta United win the championship.
- Traveling to Gibraltar, grabbing a car, and driving up the scenic Mediterranean coast to Spain and exploring the country.

Future Goals:

Currently registered for the 2025 Great North Run, UK (world's largest half-marathon), I'd also like to complete the 5 day Inca Trail Peru hike within the next couple of years, and I'm targeting running all 7 World Marathon Majors.



I have been able to get back to running, back into salsa dancing, and scuba diving. All of these things are part of my life now because of my donor. So if I could go back twelve years in time and tell myself anything it would be to do this sooner! Don't be afraid of having the transplant."

I felt my eyes prick with tears. I understood this feeling. Remembering how terrified I was when I heard "transplant" was my last option.

"I think less than 1% of the entire world has ever run a marathon and I knew I wanted to be able to do that. I had loved running before I got sick and post transplant I wanted and craved the challenge. My team told me to make a list of all the things I wanted to be able to do after my double lung transplant. And guess what - I have done all of them."

A full fledged tear rolled down my cheek. I swiped it away hoping Calvin didn't notice. I simply said, "It is beautiful that you are part of that 1% of people who have run a marathon."

"It's been great continuing to make memories with family and friends post-transplant. For extra motivation, my transplant coordinator asked me to put together a list of the top 3 activities that I wanted to do post transplant. So the marathon running, salsa dancing, and scuba diving were things I'd done regularly before I became ill that I've loved being able to do since. I've also returned to weightlifting and playing basketball. I've competed as a transplant athlete and am a bronze medalist (basketball) and also on the Athletics Advisory Council for the World Transplant Games, as well as a multi-medalist in table tennis (Silver),

badminton (Gold), and ballroom dancing (Gold) in the Transplant Games of America.

I'm a big sports fan and so it's been great to attend a number of live sporting events like Atlanta United, Miami Dolphins, or Florida Gators games. Walking the grounds during a recent Masters Tournament was a highlight for me as a long-time golf fan.

I've always loved traveling and I am thankful that receiving the transplant has restored my ability to continue regularly doing so. My favorite trip has been to Mallorca, a historic island with a tough to match mix of scenery."


"A little over three years ago, there was a promotional conference and they were selecting 3,000 people from around the world to celebrate 1,000 days before the Paris Olympics. As part of it, you got to run a promotional race with Eliud Kipchoge, who is generally known and is regarded as the best marathoner in the world. I got one of the entries, which was crazy! So I trucked it over to Paris and I ended up running this race. It was definitely one of my top 10 life moments and this promotional race won me an entry to run the marathon event during the 2024 Paris Olympics."

Calvin is still an avid runner, participating in multiple half-marathons a year. He has spent his bonus years fiercely advocating for organ donation, speaking at conferences, sharing his story, and mentoring other transplant patients and as a member of AST's Transplant Community Advisory Council. He also promotes advocacy as a member of the HRSA Patient Affairs Committee and on the Board of Directors for Transplant Recipients International Organization (TRIO).



"You know Alison," he said, "I am only sitting at this table talking to you because of two reasons: I believe so passionately about organ donation and I want to make sure that people know and understand how it changes lives."

I nodded and said, "If it weren't for two people saying yes to organ donation, neither of us would be here right now, meeting, and sharing our stories."

We finished our lattes in quiet reflection before stepping outside into the cold to take photos. My time with Calvin was nothing short of a gift - one I've carried with me every day since. It's a powerful reminder that every encounter holds the potential to leave a lasting impact. In the end, life isn't about seeking blessings but about becoming one in someone else's story. 



HOPE HEALS

WORDS BY MICHAEL SOLE PHOTOGRAPHY BY ALISON CONKLIN

Hope is a powerful weapon.

This phrase consistently ran through my head since my diagnosis began in July of 2022. I first heard this phrase in the movie, *The Hunger Games*, and it reminded me of my faith and how hope and faith are so interwoven with each other. It even reminded me about how Viktor Frankl survived the atrocities of the Holocaust as discussed in *Man's Search for Meaning*. Without hope all was lost and there was no reason to live.

Unfortunately, this is a thought that often visits us when we are facing harsh conditions, one that is involved with the transplant process. What is my quality of life? Will I ever get a donor? What if the surgery goes wrong? These are all questions I asked myself

frequently after realizing that I had a chronic illness and that my liver was slowly failing.

September 28, 2023 I call my Hope Day. That was the day that my donor called to let me know that he was going to be able to give me a portion of his liver for a liver transplant. I broke into joyful yells and tears. I recall telling him (probably more likely yelling), "You have just given me hope!"

Up until that point, I was losing hope day-by-day with each donor that was disqualified from the process and each day seeing myself deteriorate both physically and mentally. I didn't like how I looked, I was exhausted constantly, nauseous frequently, and had jaundice. I kept telling myself

each day though that if I lost hope then I lost me, and I can't let that happen. Admittedly, I was running quite low after a year of fighting off those thoughts.

What a selfless act of my donor to give me a new life. He was going to literally change my life. You couldn't bring me down after hearing that news, I was on cloud 9. It is beautiful to think about how medicine can let one human help another with such a procedure as this. Although it is also quite a large philosophical jump to think that another human's organs are inside of you as well.

October 31, 2023, was the day it happened. I remember walking down the hall and seeing the OR team prepping

It is beautiful to think about how medicine can let one human help another with such a procedure as this.



ZEST FOR LIFE

I woke up about a day later feeling a new

I was full of so much hope of what could be after this procedure... I could be the "old Mike". I would regain my freedom and get back my personality that everyone knew me to have.

However, as I laid down on the table and the nurses put the cold AED pads on me I began to stare into the fluorescent light and hope quickly became dread. What if this doesn't go well? What happens if I don't wake up?

Immediately, I began to tear up, and a nurse came over to rub my hand and soothe me. The last thing I remember is my surgeon Dr. Emond saying to the nurse, "Thank you for doing that with Michael, today is a special day for him, and we are here to make that happen."

I woke up about a day later feeling a new zest for life. Energy flowing through my veins and feeling as if I saw the world through different eyes. This is what hope feels like.

Immediately, friends and family noticed a difference in my eye and skin color. I no longer had jaundice and grey colored skin; I had clean pure eyes with radiant skin. After several days of being in the ICU at New York Presbyterian, I was transferred a few floors up to the transplant suites.

Then something arose within me that I would have never expected throughout this whole process, someone asked if I wanted to see my incision. I quickly wanted nothing to do with seeing the incision. It scared me to think about knowing how big it was and that it traveled all the way across my abdomen. I also didn't want to

see what had happened to my body. I glanced down briefly and caught a look and was immediately disgusted with myself and didn't want to look again for as long as I could.

Ultimately, a few days later it was time to start to shower and learn how I would conduct my activities of daily living once I was discharged from the hospital. I still didn't want to look or touch my incision. I felt as if

everything from my chest down was no longer me and was ugly.

It was such a struggle to have so many moments of gratitude followed by moments when I could not explain why I was scared to even look at myself, when I should be celebrating myself. It made me feel guilty that I could not celebrate the gift that I had waited so long for and the amazing procedure the medical staff had performed on me.

Simultaneously, I was also struggling with how I thank everyone who supported me on my GoFundMe and especially my donor. There was no way I could financially repay them and there are no words that I can find that could express my gratitude to my donor.

One recurring theme that I had several people tell me was that I needed to live a good life to show people that they invested



MICHAEL AND HIS LIVING DONOR, JON BECKER, THROW OUT THE FIRST PITCH AT A YANKEES GAME.

their time and money into the right person. Secondly, was to give back and help others who might be in a similar situation. My first step in that process of showing people how thankful and grateful I was for them was to love myself and accept my new body and my scar. That moment was filled with many tears of joy thinking of all of those that helped me along the way, but also a feeling of emptiness that I could not find a way to thank them as well.

In the following weeks to months, I saw the incision scabbing over and healing day-by-day. I felt similarly to it— each day I was learning how to get back on my feet and stay active, trying to get back to the person I was prior to my health issues. Then one day it came to me (as I was cleaning it after a shower) that I had been caring for my incision with just as much care as I was for my mental health, and I began to love myself again a little bit more. This scar was not ugly, but this scar was beautiful. It represented the hope that I gained from my donor. It represented the hard work and care for the surgeons, as it healed it represented my new life.

The scar now runs like a quiet whisper across my abdomen, a bell curve shape etched by my surgeon's steady hand. It reminds me of the journey of life. The highs and lows. The periods of hope and despair. My scar is unique and at the end of it when you think it is finished, it starts an upward trajectory.

It is safe to say I wear my scar with pride now and let it tell a story of hope, how my best friend saved my life, and the delicate balance between life and death. My scar has taught me many things, but most importantly— that hope is stronger than fear. [lu](#)

This scar was not ugly. This scar was





*from first
responder
to first
priority*

WORDS BY
DAWN LEVITT

PHOTOGRAPHY BY
ALISON CONKLIN

Joanne Drenckhahn

ER NURSE · MOM · HEART TRANSPLANT RECIPIENT

Joanne Drenckhahn served as an emergency room nurse on the front lines of the Covid Pandemic in New York. She cared for each patient who came through the doors into her ER, sometimes tenderly holding their hands to comfort them when their own family members could not enter the hospital to be with them.

Always big-hearted, she volunteered to help others, raising funds for another nurse who required a liver transplant, never thinking that she would need a transplant of her own one day.

Raised on Long Island, Joanne's vibrant nature filled the room as she spoke about her time in high school. It's not surprising that she was a cheerleader as enthusiasm radiates from her.

After graduating from high school, she attended college with a major in journalism, but midway through her journalism program, Joanne switched to nursing school. Her first job after graduation was as an oncology nurse in a chemo infusion center in the Bronx, followed by her return to Long Island to become an ER nurse.

"Not that I didn't love oncology, but I loved the pace of the ER energy. The whole vibe.

I became an ER nurse in October of 2004. I love the emergency room. I love the action. I love the chaos."

Joanne met her husband, Steve, a police officer, in 2011. They both worked night shift and spoke the same language of daily life and death crises. They were a perfect match.

Joanne and Steve married in 2016. Their first son, Logan, was born in August of 2017, followed by their second son, Gavin, in February of 2019. The growing family moved into their dream house in December of 2021. Life seemed like a fairy tale, until tragedy struck in 2022.

"My father passed away in June of 2022 from complications of non-Hodgkin's lymphoma and Parkinson's. I feel like he was definitely my angel through this whole thing. I felt his presence a lot."

Joanne's life was about to take another tragic turn. When she arrived at work on August 1, 2022, she felt unwell. She had never contracted covid throughout the pandemic, and she thought she might have the virus. After a rapid test showed negative results, she clocked in for work. She felt increasingly worse as the day wore on but insisted on finishing her shift.



I LOVE THE PACE OF THE ER ENERGY.
I LOVE THE ACTION. I LOVE THE CHAOS.

Shortly after she got home from work, her husband found her sprawled on the floor in the living room.

"I came home and had a 103 degree fever. My husband came down from putting the kids to bed and he was like 'What are you doing? Take Motrin and go to bed.' The next morning, I still had the 103 degree fever. So, I drove myself to the emergency room where I work. They swabbed me for covid again. They did an EKG of my heart because my heart rate was fast, and it showed that I was possibly having a heart attack. I was completely in shock. All my friends were there. They assured me I was going to be okay."

"We went down to the cath lab, and they said, 'Your heart is good, your heart is perfect. You have a virus, and it seems to be attacking the heart muscle,' so it was a viral myocarditis. They said, 'We're sending you to the ICU for a couple of days for some antibiotics.' That night, I got significantly worse, and my EF, my ejection fraction, started to go down and they decided to put a balloon pump in the next day."

The balloon pump clotted and didn't work. Doctors removed it and tried another which also didn't work. Just days after her initial trip to the ER, doctors told her that she needed to be placed on a ventilator and have an Impella pump inserted

because she was in persistent ventricular tachycardia and her ejection fraction had dropped to only 15 percent.

"I begged them not to put me on the ventilator. It was August. I remember it was August 5th and my son's birthday is August 17th. The last thing I said to my husband before being put on the ventilator was, 'please give our son an epic birthday.'"

He said, "His birthday is not until August 17th. You're being ridiculous, you're gonna be fine." And I said, "No, please. You promise me you'll give him an epic birthday if I'm not here," and he was like, "okay, I promise."

Twelve hours after doctors placed Joanne on the ventilator and inserted the Impella device, they placed her on ECMO (extracorporeal membrane oxygenation) to keep her brain and organs perfused.

Steve took on the job of making her medical decisions. Previously, she had handled the medical care in the family. Her nursing friends stepped in to help guide him toward the care she needed. With his insistence, Joanne was transferred from her hospital on Long Island to NYU in New York City on August 6th.

For a week, doctors at the larger hospital tried everything they could to restore her heart function and wean her from the ventilator, but they were unsuccessful. At the end of that week, the transplant surgeon approached her husband.

"He said to my husband, 'We've done everything. Her heart is no longer beating. She's being kept alive by machines. We have to put her on the transplant list.' On the 13th they placed me on the list as status 1A - top priority."



THE LAST THING I SAID TO MY HUSBAND
BEFORE BEING PUT ON THE VENTILATOR WAS

*please give our son
an epic birthday.*

Steve got the call the next day, August 14, at 9:00 at night, that a heart was available. Surgery took place on the night of August 15th into the morning of the 16th.

"We consider the transplant date the 16th because the new heart went in around 2:00 a.m."

Joanne remained on the ventilator for another week before she woke up to a multitude of complications.

"I was paralyzed. I was unable to move, couldn't lift my arms, couldn't lift my legs, couldn't feed myself. It was terrible. I had to learn how to walk again. How to eat again, how to do everything again."

"They had me on high dose pressors because they didn't know if my brain was perfusing, and due to the pressors, my fingers and my feet became necrotic. I developed gangrene, and I lost the tips and parts of all 10 fingers. And I lost half of my left foot and all the toes on my right foot. I couldn't have those surgeries until after I recovered from my transplant, so I had to have one limb at a time, six weeks apart. I had four separate surgeries after my transplant."

While Joanne recovered in the hospital, her entire community rallied to help her family.

Steve's mother moved in to help him with the children, while friends coordinated meals and fundraisers. Friends and neighbors came together to fulfill Joanne's last request before being placed on the ventilator, giving her son an epic 5th birthday party.

"There were at least eighty people at my house. They had clowns. They had characters dressed as Spider-Man. They had all the food delivered. They donated all the food. The clown people wouldn't take any money. Since my husband is a retired police officer, every police car in our local area did a drive-by parade. Every fire truck did a drive-by, and they stopped and let the kids get on. I saw videos of the party and my son was so happy."

The early months were admittedly challenging navigating not only a heart transplant but adapting to her life with amputations. "I would hold it together during the day, and then at night, when I was unable to do simple tasks for myself and my husband would care for me I would do nothing but cry. It was so hard for me to see a way forward."

As she worked tirelessly with a physical therapist, she began to have little wins.

"The day I got up the stairs, I cried. I hadn't seen my kids' rooms in five months. Just being able to sit on their beds and look at their things was overwhelming. It was a milestone—one that reminded me how much I had lost, but also how far I had come.

I just wanted to feel independent again. The day I got in the car for the first time after everything, I announced, 'I'm driving to Starbucks!' I didn't know how I would grab the cup with my hands, but I figured it out.

That moment of independence felt so good, even if it was short-lived. For every ten steps forward, it felt like I took two steps back with each new surgery, but those moments of freedom kept me going."

Joanne is now two years out from her transplant surgery, and she has adapted to her new life. Insurance delays forced her to find workarounds for her missing fingertips until she received approval for her doctor's requests. By then, she said that she had become so used to the methods she had implemented that she preferred her own improvisations.

Over time, she discovered various tools to help her make up for the lack of manual dexterity that accompanied the loss of her fingertips. She has found things such as tacky paper which helps her pick up small items better than the prosthetics offered through medical suppliers. She has activated her iPads and iPhones to be speech enabled making communication easier. Through a period of trial and error, she has developed routines and tools which aid her in

performing her activities of daily living and acting as mom for her two boys.

"My boys know that how I am able to do things might look different than what it was before everything happened, but they see me showing up everyday to be there for them. I am grateful to watch them grow up and I am proud to show them that life doesn't need to end just because it goes in a different direction than anticipated. I work hard to be here and I am proud of that."

Unable to return to her previous job as an ER nurse, Joanne now works part-time as a substitute school nurse in her son's district.

She gives back to her transplant community by serving on the NYU Langone Patient and Family Advisory Council (PFAC).

"I want people to know that your life after transplant can be just as full as your life before. You just have to navigate it in a different way. Some days, I almost forget that I had a transplant, except that I have to take my medicine twice a day. I'm still the same person. I try to just live my life like I did before, and you don't have to make your transplant the focus of your life. Every day I wake up and I'm grateful for the fact that I got the transplant and I am able to live this life."

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Growing up these were my favorite cookies. As a child my grandma would make them with me and let me do the icing! When I made them for my boys they instantly fell in love with them. It's now a family tradition to make them together and the boys always do the icing and sprinkles!

grandma's LEMON COOKIES

Ingredients:

3 eggs
1/2 cup milk
1/2 cup vegetable oil
1/2 cup granulated sugar
2 tsp lemon extract
3 cups all-purpose flour
6 tsp baking powder

Directions:

1. Preheat the oven to 350°F.
2. In a large mixing bowl, combine all ingredients and mix until a smooth dough forms.
3. Drop rounded spoonfuls of dough onto a greased or parchment-lined baking sheet.
4. Bake for 8–9 minutes, or until the edges are lightly golden.

5. Remove from the oven and allow the cookies to cool completely on a wire rack.

Lemon Icing Ingredients:

3 cups confectioners' sugar
1 tsp lemon extract
1/4 cup milk or water

Directions:

1. In a medium bowl, whisk together all ingredients until smooth.
2. Spread or drizzle the icing over the cooled cookies.
3. Allow the icing to set before serving or storing.

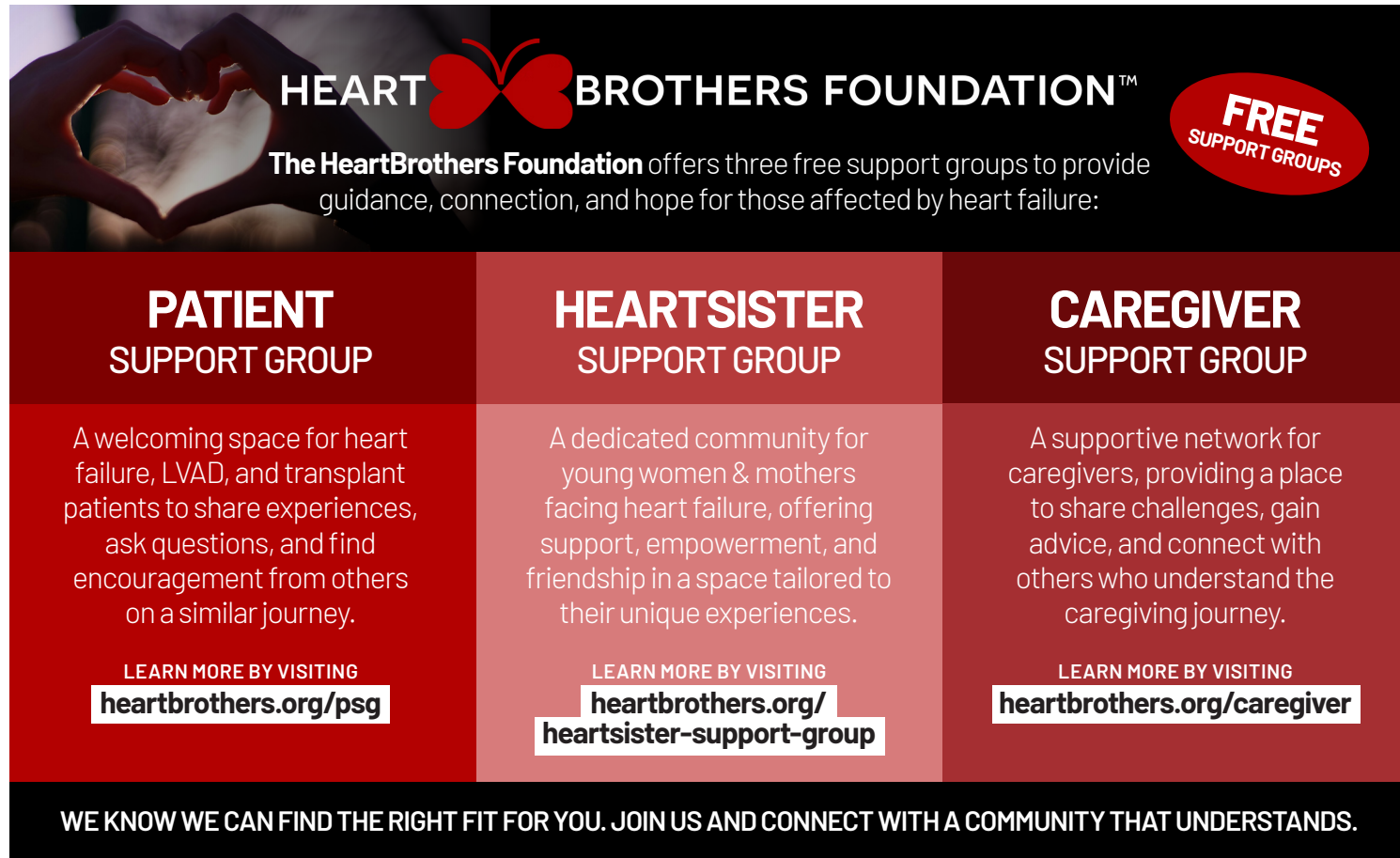




THE TRANSPLANT COLLECTIVE

The Transplant Collective brings together Nonprofit Organizations, resources, and advocates to bridge the gap between Living and Deceased Donors, those in need, and Transplantation. Through connection, compassion, education and collaboration, we strive to save lives, offer hope, and create a more accessible path to organ donation.

JOIN THE COLLECTIVE
transplantcollective.org



HEART BROTHERS FOUNDATION™

The HeartBrothers Foundation offers three free support groups to provide guidance, connection, and hope for those affected by heart failure:

PATIENT SUPPORT GROUP

A welcoming space for heart failure, LVAD, and transplant patients to share experiences, ask questions, and find encouragement from others on a similar journey.

LEARN MORE BY VISITING
heartbrothers.org/psg

HEARTSISTER SUPPORT GROUP

A dedicated community for young women & mothers facing heart failure, offering support, empowerment, and friendship in a space tailored to their unique experiences.

LEARN MORE BY VISITING
heartbrothers.org/heartsisiter-support-group

CAREGIVER SUPPORT GROUP

A supportive network for caregivers, providing a place to share challenges, gain advice, and connect with others who understand the caregiving journey.

LEARN MORE BY VISITING
heartbrothers.org/caregiver

FREE SUPPORT GROUPS

WE KNOW WE CAN FIND THE RIGHT FIT FOR YOU. JOIN US AND CONNECT WITH A COMMUNITY THAT UNDERSTANDS.

Crispy Almond Meal Chicken Parmesan

by Rachel Kofsky

This balanced version of a family favorite is a weekly staple in our house. It also happens to be gluten free for any gluten free/celiac families. The almond meal adds a nice texture while also adding in protein, fiber and Vitamin E compared to standard bread crumbs. In our house we prefer chicken thighs but feel free to use white meat chicken breasts if you prefer. When you are looking for a satiating but balanced choice during a cold winter night – look no further!



Ingredients:

- 1 lined baking sheet
- 2 mixing bowls or plates
- 1 package of chicken thighs (or 2 if you have a larger family)
- 1 tbsp salt
- 1 tsp garlic powder
- 1 tsp onion powder
- 1 tsp dried oregano
- 1 tsp dried parsley
- 1 tsp pepper
- 2 whole eggs
- 1 cup blanched almond flour (you may need more depending on how much chicken you use)
- Parmesan cheese (shredded or grated)
- 1 package mozzarella
- 1 box of any pasta of your choice
- 1 jar of pasta sauce, store bought or homemade
- Fresh basil (optional)

Directions:

1. Open a package of chicken and pat dry with a paper towel and set aside.
2. Preheat your oven to 400 degrees.
3. Set up your baking sheet either as is or lined with tin foil (parchment paper is a no with broiling we learned this the hard way) and spray with any oil of your choice.

4. In one bowl – crack and whisk two eggs, in the second bowl put herbs, seasonings and almond flour. Mix together.
5. One piece at a time, cover chicken in egg batter then in almond flour mixture and place onto a baking pan.
6. Bake chicken for 30 minutes.
7. At the 30 minute mark, take out the baking sheet and using a spoon spread pasta sauce on each piece, then layer slices of mozzarella cheese and parmesan on each piece.
8. Change oven temperature to Broil and place chicken back into the oven.
9. Boil your water for the pasta.
10. Monitor the chicken for 5-10 minutes until the cheese is melted.
11. Plate chicken on top of pasta – you can add some fresh basil on top if you like. It's dinner time!

Grandma's Chicken Soup

by Rachel Kofsky

Nothing feels like home and comfort more than a warm bowl of chicken soup. We make chicken soup every Sunday in our house – inspired by my Mom's chicken soup I grew up loving. Using bone broth as the base makes it even more nourishing and high in protein – the vegetables provide fiber and the ginger and turmeric add just a bit of zing of flavor and some anti-inflammatory support.

Ingredients:

1 large pot
1 whole chicken
6 large carrots
6 stalks celery
1 pat butter
1 half white onion
1 garlic clove
1 peeled piece of ginger, keep whole (about the size of your thumb)
1 tsp turmeric
1 handful fresh dill
1 handful fresh parsley
3 quarts chicken bone broth
Salt and pepper
2 cups of white rice (instant or any variety you choose)
Lemon (optional)

Directions:

1. Prep your veggies first—cut up and peel your celery and carrots. We prefer larger chunks in our house but you can chop finely if that's your preference.

2. Finely chop or grate garlic and onion.

3. Turn the stove on medium heat and add a pat of butter to the pot, add in veggies with a sprinkle of pepper, add in garlic and onion. Sauté for 10 minutes or so until the onions are becoming clear.

4. Add whole chicken to your pot – make sure to remove any giblets that might be inside the cavity.

5. Add bone broth until the chicken is completely covered.

6. Add a piece of ginger, then add turmeric, parsley and dill.

7. Bring the pot to a boil. Once boiling, turn down to medium low.

8. Let soup simmer for 1-2 hours.

9. As soup cooks, prepare rice (either via rice cooker, microwave, etc).

10. At the 1 hour mark, use tongs to take out the whole chicken into a separate bowl and use tongs to take the meat off the bones.

11. Add chicken meat back to the soup pot.

12. Scoop rice into a bowl and ladle soup on top.

13. We add our salt at the end – season to your taste!



Rachel Kofsky

MA RD CSP CLC LDN
LEAD DIETITIAN, PEDIATRIC PULMONARY
CHILDREN'S HOSPITAL OF PHILADELPHIA

Rachel Kofsky MA RD CSP CLC is a Registered Dietitian who has worked with children pre and post lung transplant since 2015. She currently is the nutritionist for the lung transplant program at the Children's Hospital of Philadelphia. She has a Master's Degree in Health Education from the University of Alabama and has certifications in pediatric nutrition and lactation. She's been working with children since she graduated from Penn State in 2012. She started her career at Maria Fareri Children's Hospital, then worked for many years at Morgan Stanley Children's Hospital @ Columbia. Over the years she found herself specializing in pediatric lung disease including cystic fibrosis. She takes pride in helping families and their children find joy and balance in food especially when going through the transplant journey.

Rachel's passion is meeting families where they are and finding nourishing choices that fit into the day to day routine. As a newer mother herself, she relates to families trying to "do it all" and feels her empathy has made her a true partner with the families she treats. She grew up in Westchester County, NY with a Mom who reinforced the "all food fits" mantra. Nothing was off limits which she appreciates herself now as a Mom and dietitian. She finds value in helping families navigate all the food information that surrounds us today amongst the ever-changing social media climate.

She's a dietitian who is passionate about building a relationship with her families that is trusting and practical. She encourages family to focus on what matters most to them throughout transplant – and to always keep in mind quality of life.

She currently lives on the Main Line outside of Philadelphia with her husband and two year old daughter. They spend their weekends enjoying the Philly food scene, traveling to the Jersey shore or the Catskills, and visiting all the local farmers markets. 🍷

The Connection of Healing, Art and Music

BY HEATHER RODALE



IT ALL STARTED IN 2004 WHEN I LOOKED OUT THE WINDOW.

Recovering from melanoma cancer treatment, I could see the East River from my hospital window in New York City – but as I walked the hallways, I discovered that not everyone had the same view. But I never realized how that view would change the trajectory of the rest of my life.

After I recovered from cancer surgery, my doctor said I could go back to work. My body might have been “healed” but my mind was not. I was worried about my future as a single mother with 4 kids. My doctor said “Just go live your life.”

I was now living with a chronic condition. As a result, I suffered a deep depression unsure how long my life would be. I wanted more time with my kids since I felt they only knew me as a mom but not as the person I had grown to be.

I wanted more time to share how I coped and recovered from my ups-and-downs in life as I knew their life would not be immune to hardships like mine.

On one of my darkest days, a coworker gave me the names of two life coaches and said, “Call one today.” I worked with one coach for six months who helped me find joy in my life. She asked me to let go of everything in my life that was not joyful. Over 3 months, I let go of almost everything except my kids and my home. After a process of mind mapping, or joy mapping, I put back what brought me joy. Healing Through The Arts was born from that work.

Art was a recurring theme in my exploration of personal joy. My mother was an art teacher. Both my grandmothers were artists. Even if art was not our primary career, it was part of our life.

We learned as children that art was fun, whether participating, viewing, or experiencing what other artists created. It was not dependent on being an expert at it. And often when you are stuck with a problem at work, it helps to stop and get creative to uncover a new solution.

I began to explore opportunities in my community. I attended concerts, art workshops, learned art journaling, created mandalas, and collected inspirational quotes to use in my art.

When I was doing art, I had no pain. My mind began to focus in positive directions. The thought of how long my life would be was replaced by how can I enjoy today?

In researching the benefits of art and health, I discovered the work of Dr. Roger Ulrich PhD who found that patients who looked out to a view of trees went home from the hospital at least one day

sooner than those who looked out to a brick wall. The patients with a view of nature needed fewer doses of pain medication. This is how I felt with that view of the East River. I felt calmer, though I didn’t think as much about it then.

Research continued to show that patients with access to views of nature or nature art, were less stressed, needed less

pain medication and were more hopeful and optimistic about treatment options. The calming and healing benefits of nature and art, also extend to caregivers, both family and hospital staff.

I knew the naturescape that I stared into, that helped me, could help others when they had a view of something less inspiring outside a hospital window, sometimes it was even a brick wall.

Art can be a window of hope when a real window did not exist.

Why is Art Needed in Healthcare?

Art helps people think about something else other than their pain. As the art emotionally draws the viewer into a picture, it can be a welcome distraction from the pain of recovery and boredom.

Art shows that life is beautiful and opens the mind to new possibilities by creating optimism. Familiar scenes bring back memories. Unfamiliar ones can create a sense of wonder or desire to want to see more.

Art helps us see how we are connected and similar to others, across cultures and history. Mothers have always cuddled their children, pets are adored, and landscapes provide beautiful vistas and places of comfort.

Art lasts longer than we do. It helps us leave a legacy and message for the future.



here there's life, there's hope. It is a deep truth. However, hope is the inverse: "Where there's no hope, there's no life."

Humans are hoping for a better future; we live very largely in our anticipations. The things we know are coming and we look forward to. If the light of hope goes out, life shrinks to mere existence, something less than life was meant to be. This is a fact that must be accepted.

The light of hope goes out when it shrinks to mere existence, something far less than life as meant to be.

was a Headmaster's conference boys' school, one of England's educational elite, and amid its quite brilliant faculty of instructors the holar who stood out was a man we called Bill (his name's back of course), the headmaster. When I studied Greek and Latin classes at Oxford, I met up with a tutor who could hold a candle to Bill or could teach me as much as Bill had taught me. He was a cleric, a man in who had retreated from the faith and become a Buddhist.

Decades later, chatting with one of my former colleagues, I asked after he'd then retired and, as I knew, in his early nineties, he reply to my question based on a recent visit, ranis (I seem to recall it words): "He's very low. I asked him what he was doing these days; all he would say as, "Waiting for the end." remembering the sharp-edged, upbeat vigor of Bill's mind in his heyday, I felt very id for him. Buddhism, as we now, does not target hope. There was a long-lived man, brilliant in his day, now withering rather than blossoming as he aged. Is that the best one can hope for?

ope At the End of the world, Hope springs eternal in the human breast," declared Alexander Pope in his usual pompous way, but that is not the story. For the first half of people's lives, spontaneous

hope does indeed spur them forward. Children hope to do those things that they do not do things. They have money; new clothes hope for a good income, a good life to live, and so on.

Quality children, established couples hope for the day when their children will be off and they are free to do as they please. What if they are not? What if they are not? What if they are not?

The Bible, however, speaks directly to it, setting before us a destination that reaches beyond the horizon. It is not a destination of money, but of a life that is not defined by the things of this world.

The metaphors are mixed a bit blurry, but the basic meaning is clear. Whatever God's work of putting us in our resurrection bodies may involve, and that is more than we can imagine at present, it is not going to be impoverishing but enriching. It will not feel frustrating or disappointing. And it is already here.

It can be said in position of the resurrection, or rebirth, that await us, which is pictures he as installing in the new house that is here for our home? Not much, it can be admitted, and the positive things are negatives really the ideal new house in the world, everything works perfectly and nothing malfunctions, and in our resurrection bodies it will be the same. Jesus, risen, remained recognizable, so can be sure that when we "further clothed," the same will be true of us. So we should know each other and have in that knowledge.

habiba

In 2011, the first Hope & Healing Juried Art Show for high school students was held with the idea of supplying art to hospitals and healing facilities.

As a teacher, I had worked with every level of student except high school. I figured I could get the best quality work for free from high school students and I knew student artists were getting no recognition as programs were being cut and funding going to sports. I also knew as a mother that high school students are often lost in thinking about their career and if I could open a door of opportunity to them it would be rewarding. It was not just encouraging them to pursue art, but the act of thinking creatively which is needed in business and many professions.

When the high school students continued to college and asked to keep participating, the college category was added. They were invested, and we also needed more art. Today, two student participants have become art educators and teach this to their high school classes, extending this show's reach far beyond one student, one year at a time.

After students donate their original art to HTTA, we hold a gallery show in the Lehigh Valley to showcase their hard work. During the show, local practitioners can give us their wish list of art they want for their offices and spaces. After the show all the art is available and donated free of charge.

After 14 years we have placed over 1000 pieces of art in more than 40 hospitals, clinics, doctors' offices, mental health offices, nursing facilities, and any healing facility that wants uplifting and hopeful art to inspire their patients and staff.



PHOTO BY CHRISTA NEU

Your brain can't tell the difference between visualization and experience, so visualize the best.

We have seen through the inspiration statements that students supply for this art show that they are healing as they are helping others. They have spoken of dealing with chronic conditions, loss, depression, bullying, and loneliness to name a few. One teacher told me she had no idea her students were both suffering and healing until she included our project in her classes.

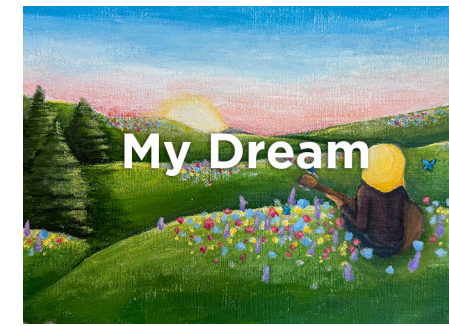
In 2015, I met musician Jim Brickman who composes and plays calming piano music. I shared with him that his songs and my student art would be a perfect combination for Healing Art & Music Mini Meditations. He loved the idea and gave me permission to use his music.

He also introduced us to other musicians who joined the project as well. One of those was Olivia Newton-John.

For a recent concert in my hometown, Jim asked us to create a new meditation with a song he had written years ago with Olivia. It was intended to be a duet but at the time they did not have a partner for her in the song. While going through old cassette tapes in early 2024, Jim found the recording of the song "My Dream". Technology now allows her voice to be lifted from the cassette and be partnered with Il Volo, an Italian pop trio. View this special Mini Meditation on HTTA.org, along with 16 others, and enjoy the calming music and inspiring art.



HEALING ART MEDITATIONS, COMBINING CALMING MUSIC AND INSPIRING STUDENT ART, CAN BE STREAMED AT HTTA.ORG





When I started Healing Through The Arts, I had no idea how far it would reach or how many people it would help. I knew it had helped me and I found nothing else like it. It took courage to be brave at creating something new, and including smart people who could help me with my weaker areas of production, like technology.

Now it is a balance of finding time to work and time to create my own art. I've been a caregiver most of my life helping other people. This is just one way I can continue to care-give others as well as myself.

Healing Through The Arts

Allentown, PA
Where those who are healing find strength, hope, and inspiration through the arts.

HTTA.org
@Healing.Through.The.Arts



Not everyone has practice being creative. Here are a few ideas which can be done by anyone and from anywhere:

- Color in coloring books or coloring pages, it can be very meditative.
- Listen to music. "I am always more creative with music playing," Heather says.
- Declutter and organize. Can anything be repurposed or made into art?
- Read that pile of books you have not had time to tackle before.
- Look online, including on Pinterest, for new creative ideas or projects.
- Search for creative quotes and write your favorites on colored cards, decorating them with drawings or stickers and placing them where you can see them often. Kids can do this too.
- Help others who are struggling by sending notes or calling them. It helps to know we are not alone when we can't be with others.



Throughout my career as a surgical oncologist, I dedicated myself to providing the most advanced cancer care. However, I soon realized that "healing" encompasses far more than just medical expertise. A cancer diagnosis leaves an indelible mark, and the journey to recovery can be arduous. We often erect mental barriers to regaining our lives – feelings of guilt, self-blame, or a sense of impending doom. Words, both spoken and written, often

fall short in alleviating these deep-seated emotions. This is because these "feelings" are actually complex emotions that reside beyond the reach of our conscious minds.

Non-verbal, visual communication, as expressed through the arts, has the unique ability to circumvent these mental barriers. Art can offer profound comfort and healing where words fail. It took me years to fully appreciate the validity of this concept, both for my patients and in my own personal journey.

I encountered Heather Rodale over a decade ago and wholeheartedly embraced the integration of her Healing Through The Arts (HTTA) program into our cancer center, and subsequently, throughout our entire hospital network. Soon, patients began expressing their gratitude for the presence of art in the waiting rooms. It not only provided a momentary distraction from their anxieties but also had a palpable positive impact on their well-being. The program's expansion throughout the hospital yielded similar positive feedback from nurses in recovery rooms and on hospital floors. These benefits extended beyond patients to our hospital staff as well. Heather Rodale's program also enriches our broader community, undoubtedly producing similar positive effects.

Beyond the immediate benefits, HTTA possesses a more subtle and profound impact. Those involved in creating, experiencing, and interacting with the art are all reaping benefits far greater than they may realize. Philip Yenawine, the Director of Education at the Museum of Modern Art in New York, has extensively documented the multifaceted benefits of art, demonstrating its profound impact on individuals of all ages, extending far beyond aesthetic appreciation.

-DR. LEE RILEY

Retired Oncologist, Now Full time Artist
@leebrileymd
leebrileymd.com

YOU GET TO *Live!*

Jamie Lane

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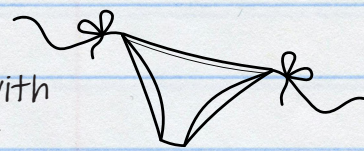
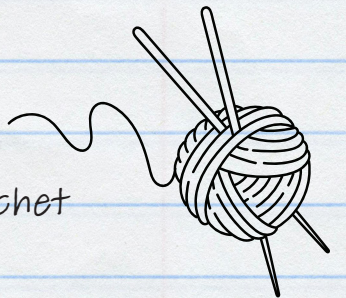
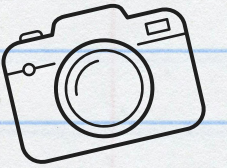
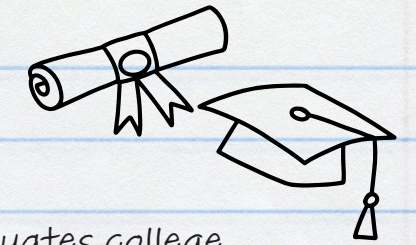
PHOTOS BY SCOUTJPHOTOGRAPHY



Polycystic kidney disease has wreaked havoc through the maternal side of my family my whole life. When I was 23 years old (I will be 55 this year!), my mother had a brain aneurysm right in front of me and passed away from the severity of it. Since then, I have had many things I have wanted to live long enough to experience, knowing I would need a kidney transplant at some point just like my uncle and aunt, and my brother. What I didn't know was that I was going to be the first person in my family with Polycystic Liver Disease as well and that was the transplant I needed first.

In July 2023 my daughter saved my life by donating 70% of her liver to me, and in March 2024 a friend donated her kidney to me. It was after this transplant I finally could start living my life again. In just that short time, I have already been able to do so many things I've had on my dream checklist and can't wait to finish off this list and some! 🍷

- See my daughter return to play college soccer.
- Watch my daughter cross the stage as she graduates college.
- See my son get a job aligned with his love for photography and creative side.
- Be there for my daughter's final college soccer game after coaching her and watching her play soccer for 18 years.
- Marry the love of my life after 7 years.
- Finally decorate our house we have lived in since 2021 but have been too busy with all of my medical stuff to do.
- Open back up my yarn shop and get back into the knitting/crochet world because it makes me happy to be with my creatives.
- Get involved with patient advocacy at my hospital if my immune system ever behaves enough for me to be around people more.
- Turn my Transplant Journey Blog into a book. I have been through SO much.
- Go to Mexico and wear a bikini and not care about my stomach scars from two transplant surgeries.
- Travel more with my husband. He has never been to Europe, and I would love to be able to take him to Italy.
- Speak with medical students about my experiences over the years with different hospitals and doctors and tell them what's important for them to remember as they embark on their new careers.
- See our children fall in love and get married.
- One day have grandchildren!! I need little babies to knit for.





ALISON'S FAVORITE CARD GAME

I love this game because everyone is working together for one common goal rather than competing against each other. One of my most memorable times playing was on a ferry ride coming back from a day spent in Friday Harbor in Washington State. The 6 of us kept losing and after countless rounds, we finally won. Our cheers were so infectious that everyone else also on that ferry cheered right along with us. My two sons and husband Geoff and I always play as our go to game and I even played it while waiting in the hospital for my heart transplant. It just takes one deck of cards and is easy to understand. I hope you love it as much as I do! Enjoy the challenge and the joy of working together to win!

Objective

Higher or Lower is a fun and collaborative game that can be played solo or with others. The goal is to correctly guess whether the next card drawn from the deck will be higher or lower than a face-up card on the table (just like the game show Card Sharks). Players work together to successfully use all the cards in the deck before running out of cards to guess from.

What You'll Need

- A standard deck of 52 playing cards (no jokers).
- At least 2 players (though it can also be played solo).

Setup

1. Shuffle the deck thoroughly.
2. Lay 12 cards face up in a row on the table.
3. One player acts as the dealer and holds the deck face down, ensuring the cards are not exposed to anyone else and themselves.

HOW TO PLAY THE GAME

1. Start the Game

The first player chooses one of the face-up cards on the table and guesses whether the next card in the deck will be higher or lower.
Example: "I think the next card will be lower than this King."

2. Flip the Card

The dealer flips the top card of the deck and places it face up.

3. Check the Outcome

If the guess is correct, the card from the deck is placed on top of the chosen pile on the table.

If the guess is wrong, put the card from the deck face down on the pile in question and the pile used for that guess is no longer available for any future guessing.

4. Next Turn

The next player chooses any remaining face-up card on the table and makes their guess.

5. Winning the Game

The game is won when all cards in the deck are used up and placed on the table.

If no more face-up cards on the table can be used for guesses, the game is lost.

Card Values

Cards are ranked from lowest to highest:
Ace (1), 2, 3, ... 10, Jack (11), Queen (12), King (13).

Special Rules (Optional)

Ties: If the next card is the same value as the chosen card, the guess is automatically incorrect.

Example: If you guess "higher than a 5" and the next card is a 5, it's wrong, and the card is placed face down on the pile.





your favorite bonus days

Every bonus day is a great day but we asked our friends what some of their most memorable bonus days were and their answers are beautiful. This is what it is all about, so please keep them coming!



Prior to returning to work full time, I wanted to celebrate my health and all my progress with my closest friends. This is me 4 months post heart transplant, at a rooftop in NYC.

Joanne Matibag

There is a special place behind our family cabin in the Black Hills of South Dakota that we all call "The Top of the World." When I was young, we would hike up here and toss balsa wood airplanes off the edge. I hadn't been able to hike it since I was a teen. My parents, kids, husband Matt and I hiked it in 2023 after my heart transplant. It has so far been my favorite bonus day.

Amy Bilka-Skillbred



I am the spouse of a heart transplant recipient who has lived almost 69 years with HCM. The spouse perspective is unique from the recipient's, so I look for relatable stories.

We have a 4-year-old grandson who adores his Papa. After the transplant, he had to wait months before he could really spend time with him. But on the day Papa came home, we squeezed in a

quick visit for a hug to hold them over until they could be together again. It was a precious moment.

This Halloween, we continued our tradition of dressing up together. Last year, little Michael was Spiderman, and Mimi and Papa were Dorothy and the Scarecrow. This year, we joined the Nintendo crew—Papa as a Mushroom, Mimi as Yoshi, and Michael as

your favorite bonus days ❤️

Bowser. It was a wonderful day of fun and memories.

Time together is so precious, and making memories with this little guy (named Michael after his Papa) is our top priority. We don't know how much time we have, but we want Michael to have memories to treasure forever.

Karen Helles



My two favorite bonus days were the day I got a new puppy and the day we walked in the Heart Walk on my 5 month heartiversary! I always wanted a dog, but before my heart transplant I could hardly walk myself let alone a dog! Finally getting a pup and being able to actually walk in the heart walk were two things I had dreamt about for a long time!

Tara Wasserman

One of my favorite bonus days so far was 12/25/24, when I danced and laughed with my 2-year-old son, Easton, at Disney World. As we spun around and around, I couldn't help but think about the people who saved my life, and how Easton wouldn't be here if it weren't for them. I'm grateful for each and every bonus day!

Heather Baker



I got my transplant in January of 2022. Since then I have been able to travel, try new things and see new places. This summer I went to Kona, Hawaii for the first time and it was healing.

Abigail Richter



This is a picture of my 16 year old daughter, Gianna, and me kayaking on Lake Lure in Chimney Rock, NC. It was about 10 months after my kidney transplant. It was the first trip I had taken and the first time to Chimney Rock. Being on the water with my favorite girl, doing something we love, in this beautiful place that was lost during Hurricane Helene has made this one of my very favorite bonus days so far, but in all honesty, they are all pretty amazing!

Tina Loveland-Smith



One of my favorite bonus days was when our oldest son and his teammates won the 4A Baseball State Championship last year!!! Our son plays baseball for the same high school his uncle and dad both played baseball for which made winning this title even more special! It was a night filled with smiles, screams, laughter and tears! A night I am SO thankful I was here for!!!

Brittany Howard



One of my favorite bonus days was being able to walk my daughter down the aisle on her wedding day. Nearly seven years post heart transplant, my donor's family made sharing this memorable and even more special.

Greg Oaster



As a proud heart transplant dad, I can't help but cry as I reflect on my bonus days—days I wasn't sure I'd ever get to see. Watching both of my kids graduate from college was more than just a milestone; it was a blessing beyond words. Seeing both of them play football together on the same field, side by side, was a dream come true. Both of my sons, living out their dreams—it's more than I ever could have hoped for.

Gynoveil Henry



Because of my donor I was able to become a first time father in June of 2024. My second blessing.

Alex Sundberg

My favorite bonus day was traveling to London & going to the Taylor Swift concert with my mom this summer! None of it would have been possible without all 3 of my amazing donors!

Carly Kelly



Share your best bonus day!

We love to hear about your bonus days! Please send your name, a short description and a photo to Hi@BonusDaysMag.com to be considered for a future issue of *Bonus Days Magazine*.

@bonusdaysmag



We are so glad you're here.

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