

SUMMER 2025

bonus days

PAGES FOR THE RESILIENT

THE POWER OF CONNECTION

DRAWING STRENGTH | NIGHT SHIFT
A STUDENT'S MISSION

← MEET
DR. KEN SUTHA
ON PAGE 34





WELCOME TO

bonus *days*

*pages for
the resilient* →



summer

ISSUE 04



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cover photo
Ken Sutha, MD, PhD
Photo by Alison Conklin



behind the scenes

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bonus days

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Editor-in-Chief
Alison Conklin

Associate Editor
Geoff Conklin

Art Director
Taylor Van Kooten

Copy Director
Shelbi Stoneback

Graphic Designers
Angela Kilburg
Noelia Ortiz de la Rosa

Contributing Writers
Patrice Morris Ball
Nicole Clement Crook
Geoff Conklin
Susan Gottshall
Dr. Alin Gragossian
Kristin King
Sydney Kurland
Karen Lunt
Madeline Marriott
Nickolas Massar
Gianna Paniagua
Melanie Wickersheim

Contributing Photographers
Jonas Hausmann
Varina Shaughnessy

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I told a nurse, Nickolas Massar, about *Bonus Days* before a single page existed. It was the middle of the night, and I was in a hospital bed—a year and a half after my heart transplant—feeling fragile and unsure of what came next. He stood by my side with a calm steadiness that only the best nurses carry, and I remember saying,

“I think I’m going to start a magazine.”

And somehow, here we are, four issues later.

There’s so much I want to tell you about this Summer issue of *Bonus Days*, I’m not even sure where to begin. But let me start with this: please make the granola recipe. It’s easy, it’s delicious, and as someone who genuinely loves granola, I promise - it’s worth it.

On a much deeper note, I started *Bonus Days* with the goal of making four issues, just to see if anyone else was longing for connection like I was. Turns out, I wasn’t alone. And now? Major institutions are handing it directly to their patients (maybe that’s how it ended up in your hands - shoutout to Penn, NYU, UT Southwestern, and Yale). We’ve grown into t-shirts and greeting cards, and as I was finishing this magazine, I was already deep into working on the fifth.

This issue was an emotional one for me. I had the privilege of connecting with incredible people and hearing stories that will stay with me forever. Visiting Kelly and her family in

Idaho moved me deeply - her strength and her commitment to supporting other families like hers left a lasting impression. Spending an afternoon with Gianna, watching her bring her comic to life with such effortless creativity, was an absolute honor. I’m so grateful this issue gets to share more of who she is. Spending time with Lisa Salberg - who has helped guide me through not just my transplant, but also my first open-heart surgery years ago - was a full-circle kind of beautiful.

And then there’s Nickolas. That night nurse who listened to a half-formed idea in the dark and believed it could be something. It means the world to have him in this issue.

When you read Ken’s story, I hope you carry his tenacity with you on your own hard days. Let Maddie’s spirit and drive find a place in your heart too - she’s a force.

I hope you can feel the strength and love poured into every page. Thank you so much for picking up this magazine and for believing



PHOTO BY JONAS, ALISON'S SON

in this dream of mine. From my own experience, I know just how healing it can be to share your story - and to read others that remind you: you are not alone in whatever you’re walking through right now.

So please, enjoy this Summer issue. Flip through the stories, feel moved by the imagery, color and hand out the inspiration cards, and snack on some homemade granola while you do.

alison conklin

Alison Conklin
Editor-in-Chief
@@bonusdaysmag

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



WE ASKED THE *BONUS DAYS* TEAM...

what would you do with one extra hour everyday *(not spent sleeping)*



I think I would bake or cook something new everyday. It would be something extravagant and shareable!

-Maddie Marriott

I would 100%, no questions asked, have a dedicated self-care hour. We’re talking extra long showers and hanging out in PJs—the best. -*Nickolas Massar*

If I had an extra hour every day, I would spend it reading a book from the huge “To-Read” stack that’s piled up in my home office. -*Susan Gottshall*



-Gianna Paniagua

I would call my loved ones to check in every day. -*Nicole Clement Crook*

I am currently trying to master wheel throwing, but am loving adding colored porcelain to the stoneware and throwing it on the wheel. With that hour of me time, find me in the studio getting messy, getting my creative zoomies out, and trying to learn more. -*Shelbi Stoneback*

If I had an extra hour in my day, I would devote it to being fully present. I would spend that hour walking alongside my husband, Noah—free from distractions, immersed in the beauty around us, and deeply present with each other and the gift of life.

-*Valen Keefer*

If I had another hour in my day, I'd love to dedicate it back to being creative and crafty. I think there is something really healing in creating your own art and giving yourself that time to relax and be yourself!

-*Maddie Flickinger*

I would spend an extra hour a day with my pets. We are getting a Great Dane puppy in a few weeks that we are naming Harold.

-*Alison Conklin*

Discover
this month's
curated guide
of resources!

Cocoplum

Claire Ring
Founder

Cocoplum is a small sunglasses brand I created to use recycled prescription pill bottles, something most recycling facilities don't accept. It started during the early days of COVID when I had a newborn and rarely left the house. With nowhere to go, I became hyper-aware of how much plastic waste my household generated every day, even while trying to minimize it. That realization sent me down an internet rabbit hole, where I discovered Precious Plastic, a global movement focused on small-scale plastic recycling. It opened my eyes to the possibilities of turning everyday waste into something useful.

I began experimenting with different types of recycled plastic and eventually landed on prescription pill bottles. Most curbside recycling programs don't accept them, despite the fact that the plastic is in perfectly good condition. Cocoplum sunglasses are made from 97% recycled pill bottles and 3% colorant using an injection molding process.



I collect pill bottles, shred them, and mold them into lightweight, colorful frames. Each pair is a reminder that recycling can be creative, practical, and fun.

Today, Cocoplum is growing bottle by bottle, pair by pair. I'm focused on expanding into more retail stores, while continuing to build a brand that proves small changes can lead to big impact.

Learn more at Cocoplumco.com
@cocoplumsunglasses

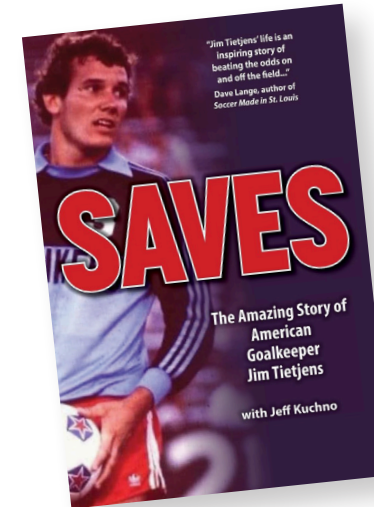
Adulthood Well

Elle Pendrick
Founder

Elle Pendrick is a five-time open-heart surgery survivor who's turning personal adversity into a guiding light for others. With a background in advocacy, she founded Adulthood Well—a business dedicated to empowering people to navigate

surgery and life with chronic illness. Drawing on four decades of firsthand experience, Elle creates practical, relatable, and innovative resources to help people take control of their health and daily life.

Learn more at adulthoodwell.au/book-elle-speaking



Saves: The Amazing Story of American Goalkeeper Jim Tietjens

Jim Tietjens
Author (with Jeff Kuchno)

Jim Tietjens has been called one of the greatest goalkeepers the soccer hotbed of St. Louis has ever produced. A state champion in high school. An All-American in college. A member of the United States Youth National Team. And a professional goalkeeper.

Following his athletic career, Jim transitioned successfully to the business world. As an accomplished sports marketer and sporting goods specialist, he enjoyed successful professional relationships with giants of the sports world - Tony Gwynn, Ken Griffey Jr, Ozzie Smith, Mark McGwire, just to name a few.

But Jim's story is about more than sports. His is a story of

determination, perseverance, and faith. Few have faced the litany of health challenges Jim has seen in his life. From multiple heart transplants to bouts with cancer, Jim has survived a myriad of health issues.

In this book, Jim shares stories of memorable moments with some of the greats in the sporting world. He recounts his numerous operations and rehabilitation efforts. And he honors the life-saving role family, friends, doctors, nurses - and organ donors - have played in his life.

Scars, Stories, and Strength: Reimagining Patient Education

Maria Baimas-George
Author

Hi! I'm Maria Baimas-George, an abdominal transplant surgeon and the creator of The Strength of My Scars (strengthofmyscars.com), a series of illustrated books designed to make medical care less intimidating, more understandable—and dare I say, even a smidge fun?

This all started during my surgical residency at Carolinas Medical Center in Charlotte, North Carolina. On pediatric surgery, I kept seeing the same issue: kids and their families were overwhelmed.

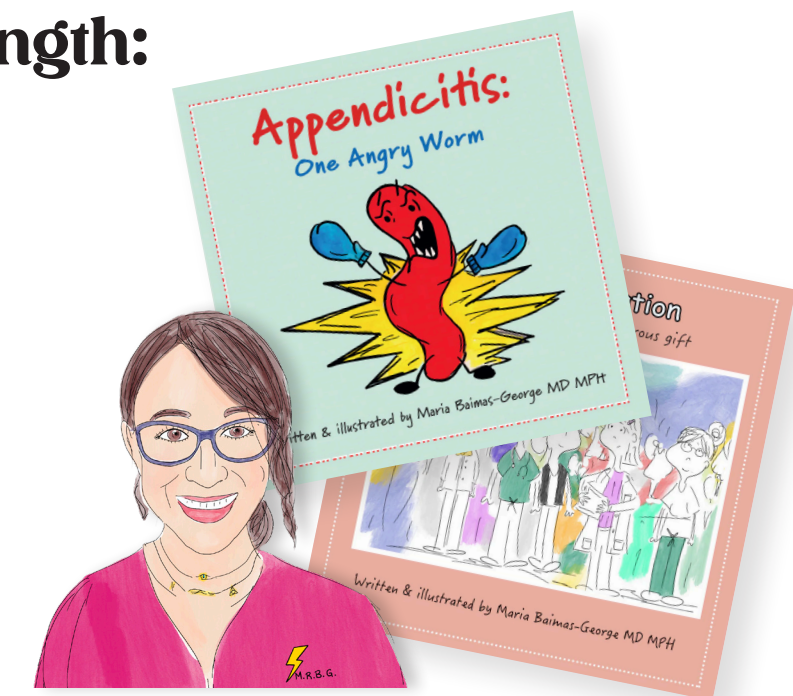
Understandably so, most medical explanations sound like a foreign language spoken underwater - eek! I wanted to fix that. My solution - I did what

any over-caffeinated resident with no free time would do: start writing and illustrating children's books!

Each book tackles a specific condition—from appendicitis to liver transplant—and explains the anatomy, hospital course, surgery, and recovery using simple words, colorful illustrations, and an analogy like an aquarium water filter or a busted car engine.

They're written at a 5th-6th grade reading level but are really for anyone who doesn't speak fluent "doctor." I ran a randomized controlled trial, and found that the books significantly improved understanding, satisfaction, and reduced anxiety for caregivers.

Things snowballed with these results. I created my own website with the help of my sister (she's



the best!) and kept making books. Currently on book #40! Along the way, patients and surgeons started asking for adult versions too! That led to the creation of books for transplant recipients and transplant donors of all ages. And the impact of these books is being studied right now at the University of Colorado.

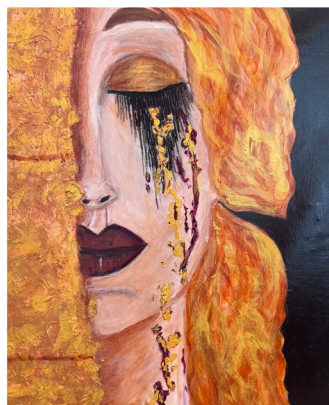
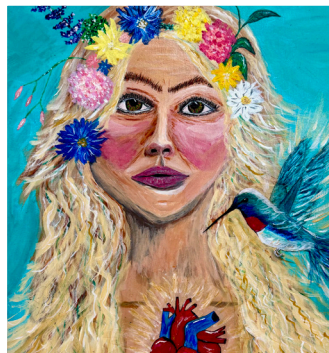
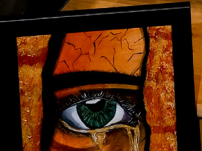
Early results: patients love them, feel less stressed, and actually get what's going on. The most common feedback? "I wish I got this earlier."

So, I'm working to get these books into clinics and transplant centers nationwide. Because every scar has a story—and every patient deserves to understand theirs.

FEATURED ARTIST

Amy Mann

Heart Transplant Survivor | Artist | Advocate



In 2018, I received a heart transplant after living with hypertrophic cardiomyopathy (HCM). I'm endlessly grateful for my donor—a gift that allowed me to witness milestones I once feared I'd miss. I now work in advocacy for heart transplant and HCM awareness and coach others navigating the transplant journey. I know how consuming life post-transplant can be and how easy it is to lose sight of who you are beyond being an organ recipient.

Art helped me remember. Though I had a natural knack for art when I was younger,



I stopped creating after a discouraging experience with a teacher. It wasn't until about 18 months ago that I picked up a brush again, searching for an outlet that had nothing to do with hospitals or health. I joined a small art group, and those weekly gatherings with fellow artists quickly became a powerful source of connection and healing.

My work is deeply personal - often symbolic, often emotional. I paint from experience: the isolation and fear of illness, the beauty of resilience, the journey through trauma and transformation. Some pieces are rooted in my transplant experience, like my portraits featuring anatomical hearts, flowers, and hummingbirds (if

you see a hummingbird, it's a symbol of my donor's presence). Others are spontaneous expressions of emotion, memory, or simply a need to create. I primarily use acrylics and often incorporate mixed media for texture and storytelling.

I describe my style as whimsical, symbolic, and emotionally layered. Art is my therapy, my escape, and my voice. It's how I process the hardest moments - and how I celebrate the most meaningful ones.

My work has been featured in two exhibitions, and my website, where you are able to purchase originals and prints. You can also find my latest pieces on Instagram @2ndheartart.

If you're a transplant recipient or someone living with chronic illness, I encourage you to explore creative expression. Art has helped me reconnect with myself, find peace in chaos, and

build friendships outside the world of medicine.

My journey now lives in every piece I paint. [h](#)

@2ndheartart
2ndheartart.com

Book Corner

by Nicole
Clement Crook

Summer is my favorite time to read. As a teacher, I feel guilt free from responsibilities and love getting a chance to unwind. This is a time I often stay up way past my bedtime to finish a book. My family and I travel to the Midwest every summer so this is an opportune time to enjoy a few good novels whether I'm in a car or airplane. I love having this chunk of time to myself to immerse myself into all the different genres and stories.



A Man Called Ove BY FREDRIK BACKMAN

A Man Called Ove is a story I wish could be scrubbed from my brain and I can read again to experience the magic. This book made me laugh and cry at the same time. Ove is a complex character that is an acquired taste. Once you know him, you can't help but to love him. He gets new neighbors that are constantly in his business, and grumpy Ove doesn't care for it. Until he does. It is a beautifully written story. Easily my favorite book of all time.

I'm going to say it - I fear the movie was just as good as the book. It's Tom Hanks, come on now.

The Paradise Problem BY CHRISTINA LAUREN

I went into this story with no idea what it was about. I just knew I adored *Love and Other Words* by Christina Lauren. *The Paradise Problem* was a book I was captivated by instantly and I couldn't put it down. It's basically a trope of fake marriage but the story behind it is riveting.

The Last Time I Lied BY RILEY SAGER

Riley Sager is a mastermind and his plot twists have your jaw on the floor. This twist I did not see coming. I love a good psychological thriller to disassociate with.

Small Great Things BY JODI PICOULT

My first dabble in Jodi Picoult and it did not fail. I appreciated that she spoke on the healthcare system and how race can be seen. It was incredible, frustrating, heartbreaking, and tragic - all at the same time. The ending felt like a really big hug from Jodi herself. I can't wait to read more Picoult.

The Alchemist BY PAULO COELHO

The Alchemist is a book I recently read for the first time. I will be the first to admit I was missing out. Santiago's journey was inspiring as he grappled with his inner conflicts and overcame all of his obstacles. I connected to it being a chronically ill individual as I have my own obstacles and inner conflicts daily. This fable reminded me that it's your strength, hope, and conviction that helps you follow your dreams. [h](#)

DO YOU HAVE A BOOK
THAT YOU WANT
NICOLE TO READ?

Send your suggestions to
hi@bonusdaysmag.com

Nicole Clement Crook
[@bionics_heart](https://www.instagram.com/bionics_heart)

Drawing STRENGTH

WORDS & PHOTOS BY ALISON CONKLIN

At just 14 months old, Gianna received her first heart transplant. She doesn't remember the moment - how could she? - but her body does. Certain smells, like anesthesia, and small flashbacks have stayed with her in ways that words never could.

Growing up as one of the earliest successful pediatric heart transplant recipients, Gianna learned to live with differences woven into her daily life.

"My mom made it seem normal," she says. "She taught me that being different was just the expectation. And that was okay."

In childhood, Gianna carried medications wherever she went. She missed field trips. She couldn't share drinks with friends. "It wasn't until high school that I realized how set apart I really was," she explains. "People thought I was a snob because I wouldn't drink tap water or have a 3-second rule

with food that dropped on the floor. But for me, it was survival.

Art became a lifeline early on. Hospital stays meant visits to the Child Life Center, where creativity became a way to personalize sterile spaces. "Art and medicine were always tied together for me, it was a way to make the experience mine," she says.

From crafts to painting to sculpture, she found ways to express a world few around her understood. By the time Gianna pursued her MFA in sculpture, art had become not just a lifeline but a profound statement of identity.

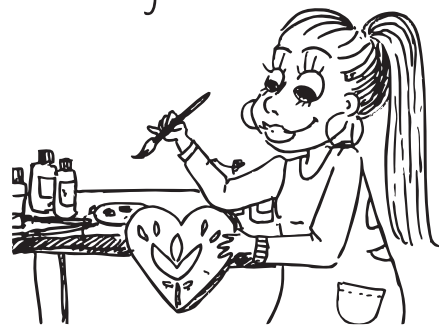
Her work was detailed, labor-intensive, often involving intricate paper-cutting that demanded hours of standing.

"There was only one other woman in my sculpture program," she recalls proudly. But the physical toll was real.



ART & MEDICINE WERE
ALWAYS TIED TOGETHER FOR
ME, IT WAS A WAY TO MAKE
THE EXPERIENCE **MINE.**

Painting for fun



Make Comics



Reading at a hotel bar



Catch up on my Shows



Graduating in 2018 after battling four major medical rejections during school, Gianna felt exhausted.

Art, once a refuge, had become painful.

When she transitioned into a post-baccalaureate pre-medical program in 2019, she set art aside.

"I thought I would be fine stepping away," she says. "But it felt like trying to breathe with only half a lung."

As she battled through coursework and worsening health, Gianna felt a growing void - a missing part of herself she couldn't ignore.

Her MFA thesis had explored the loss of language after medical

trauma - how art could create a new vocabulary for stories too painful or complicated for words.

She had lost that language and she needed it back. It wasn't until 2020, during a class at Columbia University, that Gianna found it again. The discovery of graphic medicine - the intersection of comics and health narratives - changed everything.

"Comics were a way to keep making something," she says. "I didn't want to leave this world without leaving something behind that could help others."

Graphic storytelling offered something sculpture couldn't: immediacy, portability, and a clarity that reached people in a different way.



WHEN YOU MEET ANOTHER TRANSPLANT PATIENT, YOU CAN TALK WITHOUT EVEN EXPLAINING. THAT CONNECTION IS EVERYTHING.

"I could tell stories so they knew exactly what was happening to me," she explains. "Actual people. Actual statements. I didn't have to write every detail - the images and text filled in the blanks."

Even better, comics could be made anywhere - even from a hospital bed.

It wasn't until much later, facing her second heart transplant during the pandemic, that Gianna realized the true emotional power of this new medium.

"The sculptures were abstract. The comics showed the truth and they reached people faster and deeper than anything else."

As she battled heart failure again in her twenties, while simultaneously studying science and preparing for medical school, Gianna was struck by a deep isolation. "I was sitting in classes with future doctors, while my own body was failing," she says. "They didn't realize how urgent it was. And that was devastating."

Her comics became a bridge - a way to capture experiences that words alone couldn't fully explain.

"Maybe I'm not as isolated as I thought," she says. "My comics made people feel seen and that connected us."

Gianna's second transplant was brutal. Recovery was slower and more grueling than anyone predicted.

"I didn't think I deserved another heart," she admits quietly. "But I still felt I had more to do."

It was during that painful recovery that she made a life-

changing decision: to shift away from her original plan of becoming a transplant doctor, and instead use her creative gifts to heal in a different way. "I realized you don't need a medical degree to change lives," she says.

Today, Gianna's work is a hybrid of hand-inked and digital comics.

She creates her *Bonus Days* contributions digitally, but often returns to hand-inking when she wants to reconnect with the early days of her graphic storytelling journey.

Through her comics, her support group for young transplant patients, and her advocacy for mental health in transplant care, Gianna is redefining what healing looks like and what community feels like.

"Transplant is terrifying, uncertain, and deeply personal," Gianna shares. "When you meet another transplant patient, you can talk without even explaining. That connection is everything."

Her current project is a book manuscript that questions if there is redemption for transplant patients with a history of immunosuppressant non adherence using her own narrative as a channel.

Looking back, Gianna wishes she could tell her younger self just one thing.

"Listen to yourself. Trust your body. You're not alone and one day, you'll find your people."

In every page she draws, in every story she tells, Gianna offers something she once needed herself: proof that even in the hardest moments, we can still draw strength. [b](#)



Gianna Paniagua
Graphic Artist
@tragicdarling



Patrice Morris Ball

PHOTO BY VARINA SHAUGHNESSY

Making An Impact

My family and I were thrust into the world of organ donation and transplant soon after my youngest sister, Roberta, learned she would need both a kidney and pancreas transplant. Seeking information about wait lists, we found Donate Life Northwest and a supportive community that understood our fears, tears, and—ultimately—our cheers. Our fears that a donor may never be found for my sister. Our tears that another family would grieve a loss if a donor was eventually found. And our cheers when my sister's kidney and pancreas transplants from an anonymous deceased donor were successful

in 2002. Those were her first, but Roberta has received five transplanted organs overall (two pancreases and three kidneys).

My own role in the transplant community has evolved over the years as my family has been impacted in several ways by organ, eye, and tissue donation and transplant. I donated a kidney to my sister Roberta, my husband Byron died from cancer and donated his cornea, my uncle Rick received a heart transplant, my aunt Glenda was a senior citizen bone and tissue donor, and my uncle Frank received several skin grafts after suffering severe burns over much of his body.

Believing it was an ideal place to educate students about the importance of the donor registry, I proposed a Senior Capstone course which I have been teaching at Portland State University in Portland, Oregon since 2010. When class registration opens each term, the course fills with students from across the disciplines and a variety of majors (biology, pre-nursing, pre-med, marketing, public health, graphic design, and film) eager to learn more about that mysterious designation option on their driver's license or anxious to tell their own story of connection to organ donation or transplant.

The course has evolved over the years, but always includes some history of organ transplants, policy and legislation, myth-busting, impact of televisions and movies, individual personal stories, medical ethics and racial inequities, evolving transplant advances, religious stances, donor chains and vouchers, and because students often ask, we look at developing and future innovations such as drone delivery, 3-D printing, and xenotransplantation.

Above all, I always stress to my students the importance of having "the talk" with family members now, far in advance of any crisis. PSU's student enrollment is 52% BIPOC, and most of my students are from populations traditionally underrepresented in organ/eye/tissue donations and transplants: non-whites and first-generation

immigrants who have rarely had family discussions regarding organ donation. Often these students were raised in homes from cultures that oppose or misunderstand organ donation/transplant based on myths and misunderstandings which we address in class.

I don't know of another such undergraduate class in the USA. When the Spring Term 2025 session wraps, a total of 560 students will have completed my course. Students are required to write a final reflection paper on their new or expanded understanding of organ donation, often writing passionately about the emotional impact of the class. I consider the course a success when I read about their enthusiasm to discuss what they've learned with their families and communities, and I believe the ripples created by this experience are boundless.

"Thank you to Patrice Ball for leading a course that changed my life, and therefore changed the lives of countless families involved in the cases I have worked on at Lifeline of Ohio, first as a Family Services Coordinator (FSC) and now as an Organ Recovery Coordinator."

—Hannah Johnson

Children's Transplant Initiative

WORDS & PHOTOS PROVIDED BY ROSS AND CHERYL WITT

In 2011, our youngest daughter (Kimmy, 12) was diagnosed with a rare genetic kidney disorder called Nephronopthesis. Her kidneys were functioning at 20% and were not going to improve. After 3 months on medications and a strict renal diet, doctors informed us she would need a life saving kidney transplant.

After my wife and I went to get tested, it was determined that I would be the better option. In November I successfully donated my left kidney to Kimmy. Five years later, Kimmy returned from a church camp and informed us it was laid on her heart that weekend that she needed to tell her story and use it to help kids going through what she went through. After much discussion and prayer, we started Children's Transplant Initiative (CTI), a 501c3, as a way to become part of the circle of care for pediatric solid organ transplant families.

CTI formed in December of 2016 and launched with programming six months later. Our first program is called "Hope Lifeline", a mentoring program where our family would come alongside new transplant families to support,

answer questions, and join them on their journey. We now have a number of families CTI worked with that provide the same mentoring, and include heart, kidney, liver, and lung transplant families.

"Donor Awareness" is our second program. We have partnered with several donor advocate organizations in Houston to promote awareness in the community.

Our third program is "Family Assistance", where we provide families with a \$500 Visa gift card to offset some of the expenses that families tend not to think about like parking, food, gas, medicines, and co-pays.

CTI's long-term vision in the beginning was to build a pediatric transplant hospitality house. We knew this would take a lot of time and a lot of money and considered leasing or purchasing a 5-bedroom home for pediatric transplant families to stay and support one another.

In 2018 we met a couple that runs a business in the corporate housing segment, and they fell in love with our mission. They donated two fully furnished 2-bedroom



2-bathroom apartments, including housewares and washer/dryer, located two blocks from Texas Children's Hospital in Houston. They helped with the rent when we opened a third apartment soon after. When Covid hit, people stopped traveling and the company had to stop their assistance. Fortunately, with the help of numerous donors, foundations, and corporate sponsors, CTI was able to maintain and grow our hospitality housing program.

The housing program is called "R" Rooms, a place to rest, relax, and recover. We currently

operate eight hospitality apartments in Houston to support the two children's hospitals, and due to the waitlist, we hope to add a ninth in 2025. Families stay in the apartments free of charge for as long as they need.

To date, CTI has been blessed to provide financial or housing assistance to 320 pediatric transplant families, over \$134,000 in financial assistance, and over 13,000 nights of hospitality stay at our various locations.

@@childrenstransplantinitiative



ENJOY THE MUSICAL STYLINGS OF TWO BEST FRIENDS SOAKING UP THE SUN (WITH SPF) AND PREPPING FOR TRANSPLANT WITH SOME COMEDIC RELIEF TURNED EMOTION.

I had always felt like I would need a heart transplant in the future. So one gorgeous day on the beach years ago, my best friend Casey and I started this heart-themed playlist. We decided it would be played when that time came. And it was.

My dad had a heart transplant 13 years ago. I remember all of the tubes/monitors/ventilator/restraints, and I remember holding his hand in the ICU waiting for him to wake up. But I didn't just have the normal feelings of compassion and fear that most family members have. I also felt like I was watching my future unfold. Knowing that I had the same genetic condition, Hypertrophic Cardiomyopathy- I couldn't help but wonder if this was what was in store for me.

I spent the next 13 years trying to live as much as I could. I didn't know if heart failure was inevitable, but I knew I didn't want to be left full of regrets with no time left to do the things I was most passionate about. I followed my dream to become a pediatric nurse, I traveled all over the world, I watched a lot of beachside sunsets, and I volunteered with organizations that were important to me.

Music followed me to all of those places. I associate specific songs with certain memories: a sunset boat ride in Greece, wind blowing in my hair during a convertible drive in Hawaii, a riverside walk in Portugal, a sunset paella dinner on the beach in Spain. I did all of the things I wanted- until I couldn't. Those songs and memories stayed with me even when "I couldn't."



PLAYLIST Tara Ashley Wasserman @TWASSERGRAM

Spoiler Alert (you are reading *Bonus Days*)- I did need a heart transplant, and on June 1, 2024 I got it. Before my transplant, the last time I was truly able to exercise was 16 years ago. In the years prior to my transplant I struggled to walk at all. Those musical memories stayed with me as reminders of the amazing things I had done, but also what I would be able to do again. Music functioned in many ways: providing those memories, offering comedic relief, distractions, and allowing emotional connection to aid in coping. I'm grateful for each of those purposes served.

Since my transplant, I have been able to walk, breathe, and participate in various fitness classes that I was never able to do before, but always wanted to try. My journey hasn't been complication free (in fact, quite the opposite), with two more surgeries just a month ago. Regardless, I probably don't need to tell you that the difference is life changing.

Now I'm only 10 months out, but you better believe I'm counting down the days until I can travel again. Just like I lived my pre-transplant life regret-free and full of passion, you can count on me using every Bonus Day to its fullest extent.



WAIT (FT. LOOTE)
MARTIN JENSEN



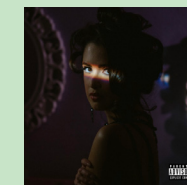
MEDICATION
DAVID WIMBISH &
THE COLLECTION



HEARTLESS
THE WEEKND

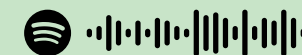


ON TOP OF THE WORLD
IMAGINE DRAGONS



BRAND NEW HEART
LAURA MARANO

SCAN THE CODE BELOW ON SPOTIFY TO ACCESS THE PLAYLIST



Finding Comfort in Dialysis

WORDS BY MELANIE WICKERSHEIM
PHOTO BY ALISON CONKLIN

The word “dialysis” was thrown around countless times by my transplant teams over the years. Yet, until I was sitting in that vinyl chair actually being dialyzed, I realized I only had a vague understanding of how it works and what my treatment options were. We are all better advocates for ourselves when we’re well-informed. So here is a very quick and dirty primer to help kick-start a thorough conversation with your nephrologist.

When kidneys can no longer function, dangerous waste builds up in the bloodstream. Dialysis helps remove this waste and excess fluid through a filtering process using a special solution called dialysate. There is tragic irony in the fact that our transplant medications can create the need for more transplants. There is a steep learning curve when it comes to dialysis. You’ll want to know about all the various types of delivery models (and all the annoyingly endless acronyms): hemodialysis (HD), home hemodialysis (HHD), and peritoneal dialysis (PD). Will your treatment be during the daytime or nocturnal? How many days a week and for how many hours? What type of

access will you need—fistula, graft, or catheter? What will your dietary restrictions be? What new medications will you need? You’ll want to talk to your doctor about what’s best for your body and lifestyle. Hot Tip: Bring a pen and paper—your tired brain will thank you later.

But listen, I’m not here to overwhelm you with medical jargon—that’s your nephrologist’s job! I’m here for the fun stuff. Because once you get through the learning curve and settle into your new dialysis routine, it’s really not so bad. Honest. And unless you’re doing nocturnal dialysis (usually PD), you’re going to have some significant time to kill sitting your days away in a big ol’ vinyl chair. So let’s explore some ways to stay cozy, entertained, and—dare I say—joyful?

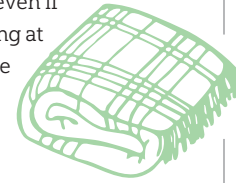
Here are my essentials for bringing comfort to your dialysis routine.

Our bonus days are precious. Let’s make the most of them, even when we’re tethered to a big, clunky machine.



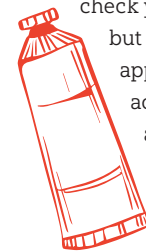
Washable Blanket

Dialysis centers are notoriously cold. If you’re going to hang out in a freezer for 3-4 hours at a time, you’re going to need a blanket. Make sure it’s washable in case you get blood on it... because you will spring a leak. You’ll want one within reach even if you’re dialyzing at home. Snuggle up and get cozy!



Numbing Cream

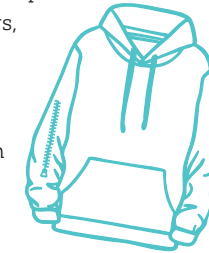
If you have a fistula or graft access, the needles are the worst part. Give yourself a bit of relief and ask your nephrologist for a prescription numbing cream. There are also numbing sprays and lidocaine injections, but I find the creams are best. Rushed in-center techs may not always use the sprays as directed, which can lead to skin irritation, discoloration, and thinning. Injections are powerful, but usually more than what’s needed for most people. Lidocaine cream offers a pain-free stick with minimal fuss. Just make sure you don’t forget to put it on beforehand! Always check your prescription label, but you’ll typically want to apply it generously to your access about an hour in advance and add some stylish plastic wrap around your arm to avoid a mess.



Talk to your nephrologist about your concerns. If you’re worried about side effects of numbing products, consider limiting use to days when your access is a little extra bruised and bothered. Or days when you just need a mental break from the pain. If you’re on dialysis, you’ve already got thick skin—figuratively, at least. Do whatever you need to get through it.

Sweater with Two-Way Zip Sleeves

Listen, y’all. Did I mention you’re going to be cold? Blankets are your first defense, but with a blood pressure cuff on one arm and lines coming out of the other, it’s going to be awkward—not to mention risky—to maneuver your arms and keep your blanket up over your shoulders at the same time. Enter the two-way zip sleeve. I’m a big fan of the IV Zip Hoodie by the adaptive clothing makers, Be Well. These sweaters have dual-direction zippers on both sleeves so you can stay warm while your lines are out. No more frozen shoulders. No more techs yelling at you to keep your arm straight. Yeah, it’s brilliant.



Snacks

Keep a little water and a high-protein snack handy. Whether you’re at home or in-center, you’re not going to be getting up to eat or drink during your hours-long run. It’s usually not recommended to eat a full meal during dialysis and the goal is to remove fluids, not add them. But having a little snack nearby can be helpful. See what your center allows and what your nephrologist recommends.

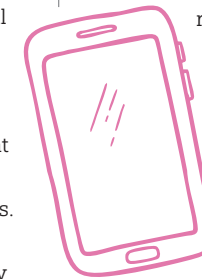


Aside from hunger and thirst, there’s safety to consider. If you’re diabetic, keeping your blood sugar steady is important. And if your blood pressure starts to dip, a light snack and a bit of water can help raise it. Just don’t confuse a mild dip in blood pressure with a low BP emergency. If you feel unwell or start cramping—even a little—get help right away.



Entertainment

It’s 2025—you don’t need an old dialysis center TV flashing in your face. Bring your own entertainment! I use my iPhone, but a tablet would be the better choice to prevent eye strain (you don’t need another ailment). A smart device is a one-stop shop for all your movie-watching, series-bingeing, and Instagram-scrolling needs! And, if you’re not too clouded with kidney failure brain fog, you could even do some work, read an e-book, or journal your experience. Just remember to bring your charger or external power bank!



I like having everything in one place so that I don’t have to rummage through a bag of stuff and risk tugging my needles out. Everyone is different though! If a real book with paper pages, a knitting project, or an adult coloring book suits your fancy best, by all means bring whatever makes you happy. And obviously, we are all going to want a copy of *Bonus Days* to read. Maybe you’re reading this article in dialysis right now! You’re so meta.

You can do all of these fun things... or you can simply sleep for 4 hours. You’re sick—it’s ok to nap. I’ve certainly done it! Make this time your own. Make it enjoyable and restorative. Your body and mind deserve it.

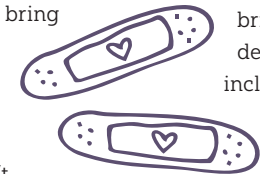
Noise-Canceling Headphones

Dialysis centers are loud. If that’s where you’ll be and you don’t want to hear 20 machines incessantly blaring alarms, you will want to bring a pair. And if you’re planning to use a smart device, make sure your headphones can connect. It’s polite, and often required, to keep your music and other device noise to yourself when you’re in-center.



Cute Bandages

Because if you’re going to need them, why not make it fun! Sometimes, it’s the little things in life, am I right? I like Welly bandages for their bright and beautiful designs. Themes include dinosaurs, dogs, planets, camping, ice cream—some of them even glow in the dark and change color in the sunlight! Come on now! I started out stealing from my daughter’s collection, but now I have my own special Mama stash. Whatever you use, go gentle on your skin by removing them with soap and warm water in the sink or shower.



However you approach your time in dialysis, remember to always give yourself compassion. The things we go through in transplant life are hard and dialysis can feel daunting. I hope knowing more about it and how you can prepare and care for yourself during treatments helps you find comfort in this unexpected place.

@openheartmel

Night Shift

WORDS BY NICKOLAS MASSAR
PHOTO BY ALISON CONKLIN

Looking back on it, I had no idea what I was getting into when I started as a nurse on the cardiac care unit.

I could not have guessed back then what it would be like to take care of patients pre- and post-transplant, what the process of transplant looks like, and what life for these individuals can be like before, during, and after they get their second start. More than anything though, I did not realize how much I would also change in tandem with my patients, and how much I would learn from them as we worked to optimize them for transplant.

When I chose to be a nurse, I did so because I wanted to be there for people in their times of strife, I wanted to be that rock that they could rely on. But I couldn't fully comprehend how my patients felt when I was new; I sympathized and I empathized and I cared a lot about how they felt, but taking care of a person and being the person in that bed are two very different experiences.

I should probably note here that I was not a natural when I started as a nurse. I was anxious and awkward, and I struggled with the critical care environment, which can be chaotic and challenging for so many reasons. That changed through practice and patience, but nothing was more elucidating to me than when I went from being the person providing care to the person needing care.

The day after I took (and passed!) my critical care registered nurse (CCRN) certificate, I was called by my doctor and told to go to the emergency room immediately. For the year prior, I had been experiencing intermittent visual changes while running, and was repeatedly told that I had a simple astigmatism. After cycling through a few providers, I finally reached out to a neuro-ophthalmologist and got an MRI of my brain and spine, which revealed areas of damage (termed lesions) throughout my spine and sparsely along visual regions of my brain. I was diagnosed with multiple sclerosis, an incurable neurodegenerative illness, and was instructed to immediately begin treatment, which involves taking medications that significantly suppress my immune system in the hope of slowing down the progression of my condition.

My first round of treatments failed; we had to change course. Throughout all of this, I continued to work with patient after patient who was going through what felt like a very analogous lived experience, and it changed my life. It changed and colored how I worked as well. I came to realize that the smallest things could have an outsized impact. These days, I try to offer every single ICU patient a hair wash, because

having clean hair can be just as important to someone as getting their medication on time. I really do get how that feels. Finding every opportunity to ensure that my patients retain their personhood while also supporting them through their journey is at the heart of my practice.

Optimizing a patient for a heart transplant is a project. You could probably write a textbook on just this process, but it is a project that we as part of the care team are exceptionally proud to be a part of. The goal is to give someone the best possible shot of having a successful transplant by supporting them hemodynamically while practicing strong infection prevention protocols, and by making sure that the patient is involved in the process every step of the way.


The thing about transplantation is, the journey doesn't just end on the day of the transplant. There is the recovery period, the new medications, the new diet, the problems that could occur and what to watch out for, as well as the follow up schedule. It is a lot for anyone to manage, and we do everything we can to support our patients (and even caretakers) in this process. We really do try to take the time to meet someone where they are, explain clearly

but concisely what life with a transplant will entail, and listen carefully to the patient's concerns.

More than once, I have been told by patients that they felt the most cared for while on our floor, and I take a lot of pride in that – we all do. Our care is particularly mission driven: we get the patient ready for their next step and do everything in our power to prevent barriers to transplant. This lends itself to an environment that has particularly high standards in quality control, and it is so important to us that our patients have the resources and access that they need to get their care addressed. I rest easy knowing that we do everything that we can to advance the care of our patients, and I have learned so much from them as we've worked together.

There is no nursing course on "life before and after getting a heart transplant." Tacrolimus was not a drug that many of us knew about prior to working in our specialty, and most of us have never had to think about whether we can or cannot eat raw vegetables, salad, or sushi. The inverse is also true— I have had patients tell me that their nurses and care teams are some of the only people who "get" what they're going through, and we really do— we really do care and understand.

What has surprised me more than anything in this field though, is just how many moments of joy there are in between the moments of worry and waiting. The pathway to transplant is a winding one, and the first year of a transplant is a roller coaster, yet during these periods I have shared so many moments of laughter with my patients. I have taken selfies

and clinked diet ginger ale cans to celebrate little wins. I have shared stories during bed baths and hugs on the way to the OR. I have held hands during times of tragedy and held hands during times of elation. It is a connection that I feel truly lucky to be a part of. It is the best job I have ever had in my entire life, and I am grateful every day to be a part of this project. 



WORDS BY KRISTIN KING
PHOTOS BY ALISON CONKLIN

I couldn't think of one specific day that really stood out or made a lasting impression...but that could be the anesthesia still in my system, or the trauma and PTSD.

It may sound cliché, but leaving the hospital after several months was my first favorite memory after my heart transplant.

My nurse helped me into the back seat where I was surprised to see a gift basket from my husband's new work family. A few heart warrior shirts, cash, my favorite

candy, and photos of larger items that were waiting at home, which included a hospital side table, an air filter, and a backyard patio set. The latter, so I can safely visit with friends and family. The fear of isolation was washed away with each thoughtful item.

I become a little emotionally overwhelmed, so I couldn't go through everything, and crying hurt my chest terribly. I was ready to go.

Leaving the hospital grounds was all I had wanted and thought about for months. I felt like I had just been rescued from my worst nightmare, by my new husband nonetheless. He went to roll up the windows, because I normally cannot stand the aura of rush hour, but this time I told him to leave them down. The foliage seemed greener. The clouds seemed whiter and fluffier. The colors seemed more vivid and vibrant, almost like they weren't real, but rather an artist's impression of reality.

Everything felt faster. I can still feel the wind on my dried face and thinning hair. I can still smell the city, its exhaust, its cooking, its people.

I can still hear the Hispanic music blaring from the red truck next to us at the first stop light. I remember dancing to the music and feeling so alive. I remember smiling and waving at every stranger that looked at me. I remember holding my hands to my heart, closing my eyes because the stimuli was too much and saying, "Oh my God, thank you, donor. Thank you. Oh my God, I'm alive."

Despite the pain, I cried almost the whole ride home.

I've had several moments like this post-transplant, feelings of tremendous gratitude, unbelievable joy, peace and quiet, and serene calm. They're magical, beautiful and make me feel connected to my donor and grateful for the bonus time with which I was blessed.

I started calling them my "little moments," but I've recently found someone else has named them glimmers. I fell in love with the term, being glitter obsessed since I can remember, the name seemed more than serendipitous. So glimmers they are.

When in recovery, the nurses called me a "light" for myself, other patients, and the CVICU staff that took care of me. I couldn't imagine a better term than "glimmers."


Glimmers that give me particular joy could be as broad as watching my loved ones grow and flourish or as simple as holding my youngest son, Gage. I remember holding him for the first time without having any cords, tubes, or machines that screamed beeps. I remember being able to hold him by myself, without having any sternal precautions. He didn't have to be strategically propped onto me with pillows and towels, for safety. I could wrap my arms around him. I could embrace him fully.

I remember hugging my teenage daughter, Taylor, after surprising her at school. I remember the pride and love I felt seeing my stepson, Grady, thrive and shine while leading his marching band on the field. I remember all of my first holidays and the new complicated, but peaceful feelings associated with them.

A very favorite glimmer of mine is walking down the Survivor Lane at the American Red Cross Heart Walk with one of my transplant friends after recovery. That was a feeling like no other, and one I won't soon forget.

When I have a glimmering moment, the tears will well up like glitter on either side of my eyes. I often have to excuse myself or find a quiet place to sit with my emotions and take the time to appreciate my donor and their loved ones. To hold their sacrifice, and yet my survival, in a single clutch, always drowns me in a sea of emotions.

I know without my donor I would never have these moments so I like to dedicate my glimmers to their memory. I had bracelets made that read, "for my donor" with my transplant date labeled underneath, to remind me of everything, good and bad. I take a photo of them when I have glimmers. All things seem possible and positive when the glimmers come.

I dream, sometimes, of sharing the glimmers with the family of my donor. I want to make them feel their very life, their love, that now courses through me... Let them know that the love they lost, found its way to me, and I plan to share it with the world! 

@mamawithasecondbeat

My whole being **GLIMMERED.**



One day, my heart stopped working.

A few days later, I received the gift of life in the form of a heart transplant from someone I had never met. And a few days after that, I was discharged from the hospital with a new heart and a new shot at life.

It was surreal. Exhilarating, terrifying, and overwhelming all at once. I remember being wheeled out of the hospital with my mom and thinking, "OK. Now what?"

I felt this pressure— mostly from myself and my "Type A" personality that probably helped get me into medical school— to make it count. I wanted to volunteer. I wanted to advocate. I wanted to go back to being a doctor. I wanted to win all the awards. I wanted to do something big with this second chance. I wanted to show the world that I was worth saving.

And don't get me wrong— I'm still grateful. I still wake up every day and think about my organ donor, Lucy. I still try to live with purpose and contribute to something greater than myself.

But I also want to say something that isn't talked about enough: Just existing is enough.

There's a strange pressure in survivorship, especially after something like a transplant,

to prove your worth through productivity. You survived, so now what are you going to do? Are you going to write a book? Start a non-profit organization? Run 10 marathons?

And sometimes... you're just trying to make it through the day.

I think we forget that waking up with a transplanted organ and brushing your teeth is a miracle in itself. Taking your meds on time and maybe watching an episode of your favorite show... that's enough.

That's living.

Your value isn't measured in milestones. You don't have to be the most inspiring transplant recipient or the busiest. You're allowed to have days when you don't feel brave or grateful or strong. You're allowed to just be.

I spent so much time after my transplant trying to live "big." But some of the most healing moments have come in the quiet: sitting on the couch, beading a new bracelet, talking to my partner, folding laundry, sipping my fun little drink and thinking- I am alive.

This message is for anyone who feels like they have to justify their existence, especially those

of us with chronic illness or those who've been through trauma.

You don't have to earn your second chance.

You're already doing enough.

Existing is a radical act on its own. And being alive doesn't always look like it does on

social media. Sometimes it looks like naps, and tears, and doing absolutely nothing "productive."

And that's more than OK.

That's beautiful. [h.](#)

@a_change_of_heart_blog



Just Existing is Enough

WORDS BY DR. ALIN GRAGOSSIAN
PHOTOS BY ALISON CONKLIN

I'm so grateful for this second chance at life and I'm honored to share my story.



My Favorites

TV show: *Gravity Falls*

Sport: *wrestling*

Video game: *Spider-Man 2*

Bonus Day: *Make-A-Wish Disney Cruise*

Food: *Steak and Crab*

Sports team: *ASU Wrestling*

Dream job: *Video Game Designer*

Band: *My Chemical Romance*

If you could have dinner with someone famous who would that be? *The Rock*

Dylan McQueen



“Once you’ve wrestled, everything else in life is easy.”

— Dan Gable, Wrestling Legend

For 11th grader Dylan McQueen, life was never easy - even before he ever set foot on a wrestling mat.

Born with idiopathic dilated cardiomyopathy, a rare condition that weakens and enlarges the heart’s main pumping chamber, Dylan faced a battle from the very beginning. His heart had grown so large it filled 83% of his chest cavity, crushing his lungs and other organs, leading to labored breathing and multi-organ failure.

At the time, Phoenix didn’t have a pediatric transplant program. So, the McQueen family traveled to Children’s Medical Center in Dallas, where they had relatives nearby. Dylan was just six months old when he was placed on the transplant list. Six weeks later — on the very day doctors had scheduled him to receive a temporary Berlin heart (a pump device used for pediatric patients that can support one or both ventricles) the call came: a donor heart was available. At only eight months old, Dylan received the gift of life from a child tragically injured in a farming accident.

When Dylan turned 12, he had the opportunity to meet his donor’s family. They’ve kept in touch since then, exchanging texts and emails. It’s no surprise the donor came from a family of

athletes. Dylan, with the heart of a hero and a relentless spirit of his own, has gone on to live an extraordinary, active life.

Just one year earlier, Dylan announced he wanted to join the local wrestling team. His mother, Melissa McQueen, was understandably hesitant - her son had fought so hard to survive. But after talking with his doctors, she gave her blessing.

“You’re honoring your donor and their family by living the life you want to live,” she told him. “That’s what they gave you this chance for.”

Watching her son thrive inspired Melissa to start Transplant Families (transplantfamilies.org), a nonprofit that connects pediatric transplant recipients and their families to vital support and resources.

Now a high school junior in Peoria, Arizona, Dylan is thriving both in the classroom and on the mat. He lives with his parents and his sister Maddie, a senior. His older brother Alex is in his second year of college. After school, Dylan works at Dairy Queen - where he tries to balance maintaining his wrestling weight with his love of Oreo Blizzards. He also



proudly participated in Dairy Queen’s Miracle Treat Day, which supports children’s hospitals with every Blizzard sold. Mark your calendars: the next Miracle Treat Day is July 31, 2026!

Today, Dylan is a multi-sport athlete. In addition to wrestling, he competes in track and field, running distance events, and the long jump. He shined at the 2022 Transplant Games in San Diego, earning 11 medals across distance running, long jump, and shot put.

Dylan’s plans after graduation include attending a local community college before transferring to his dream school, Arizona State University, where he hopes to major in journalism or marketing.

This year, his wrestling and track seasons were cut short after suffering a concussion during the state wrestling tournament. He’s now in rehabilitation and looking forward to rejoining his teammates at summer wrestling camp.

Tough as nails before he could walk, stronger still every day since, Dylan McQueen doesn’t just live with a new heart - he lives with purpose, passion, and the will to keep moving forward. [ht](#)

@transplanttz

SEEKING

THE GAME AGAIN

WORDS BY NICOLE CLEMENT CROOK
PHOTOS BY ALISON CONKLIN

ONE DAY, YOU'RE A COLLEGE ATHLETE, INTERNING AT ONE OF THE COUNTRY'S MOST BEAUTIFUL AND ICONIC GOLF COURSES, THINKING YOUR FUTURE IS PLANNED OUT.

NEXT, YOU'RE STRUGGLING, CALLING YOUR CLOSEST FRIEND WHILE ON YOUR DORM ROOM FLOOR BECAUSE YOU CAN'T FIND YOUR CONTACT LENSES.

YOU REALIZE SOMETHING IS DEFINITELY WRONG.



ANTHONY GIANNETTI

Anthony Giannetti had previously never had eye problems. At 18, he had contracted an eye infection and sought out care from the eye doctor. Unfortunately, the eye doctor told him he also had Keratoconus, a progressive eye disease that causes the cornea to bulge from being thin into a cone-like shape, distorting vision.

His reaction was, "Alright, all the same to me." The eye doctor provided him with glasses. The following nine months, Anthony had gone through seven pairs of glasses. And then there were no more prescriptions that would suit him.

He stated, "As quick as I could get them, they'd become obsolete." By sophomore year in college, he was legally blind. It continued into junior year when he was the blindest he had ever been.

Anthony, determined not to quit, stayed through his internship during summer. His supervisors suggested that he go home, but he was adamant about finishing the job. He struggled silently on that Virginia golf course.

"There were mistakes happening at work because I just couldn't see. I'd look down and see seven golf balls, even though there was only one."

This was his new reality.

"I couldn't even see the hair on my own arm. I couldn't read my cell phone."

With that constant struggle, he ended up taking a leave of absence from school and work. He endured depression and isolation which was a new feeling for him. Usually outgoing and charismatic, he struggled with these dark feelings hovering overhead.

In April of 2010, a new chapter began for Anthony: cornea transplants. The first was performed that month, followed by a second a few months later. Doctors don't perform both cornea transplants at once on the same patient, he explained, to reduce the risk of infection and to ensure each eye has time to heal and adjust individually.

The recovery was not a straight drive down the fairway. He had sutures in his eyes for a year. When they'd rupture, it felt like paper cuts. Following that, he had severe glaucoma. With the pressure buildup in his eyes backing into his optic nerves, he required yet another surgery so he didn't become completely blinded.

"I remember the first day post-op even with sutures in and crusty eyes, I could see better than pre-op," he says. "You realize it doesn't get much worse. There's no downside from here."

Through all of this, Anthony had a change in his perspective. His go-getter approach has shifted and he understands that health is of the utmost importance. He values rest and stepping back to take care of himself. He no longer



BY THE END OF MY LIFETIME, **AT LEAST FIVE PEOPLE WILL HAVE MADE UP MY BODY.** IF I LIVE LONGER, IT COULD BE SIX OR SEVEN PEOPLE.

believes in holding onto paid time off. He chooses to not take anything for granted and only worry about what he can control.

"I used to aim at trees when golfing because I couldn't see the hole. I feel safe again."

One day at a time. One stroke. One shot. Life is a fairway. While we all get in the bunkers, we have to enjoy the course, too.




CORNEA DONATION

The process of cornea donation is quite unique. While most potential organ recipients get listed and wait for a living or deceased donor, Anthony and other cornea recipients go into surgery to receive corneas that are kept in an eye bank. It could be similar to a dental procedure in the sense that you schedule it for whenever it is needed. There is no waiting necessary.

The upkeep of Anthony's transplanted corneas requires daily steroids and he wears glasses and sunglasses to protect his eyes. He says that most people will need contacts or glasses at some point after their transplant, which eventually will lead to another transplant. Transplanted corneas last roughly fifteen years.

Believe it or not - cornea transplants are the most common tissue transplants in the country. Anthony is extremely thankful for science and its evolution because with bad corneas, he'd just be a blind guy wandering around in pain.

He credits much of his success to the Wells Eye Hospital in Philadelphia. "A lot of my good fortune, I credit to them." 



A Better Way to Monitor

When Daniel's parents, JoDee and Moise, walked into their 20-week ultrasound appointment, they were expecting to find out if they were having a boy or a girl. Instead, they were told their baby had less than a 2% chance of survival due to a rare condition that trapped all his amniotic fluid inside his body. The doctor recommended they terminate the pregnancy.

But JoDee and Moise chose to fight.

That hope carried them through two groundbreaking in-utero surgeries, one of which had only been successfully performed three times in the world at the time and into the uncertain future of raising a child who would need a kidney transplant to survive.

Years later, after a miracle birth and a successful kidney transplant at age five, Daniel is now a thriving teenager. He is about to juggle AP classes, he plays sports, and dreams about becoming a pilot or anesthesiologist. His kidney came from his father, Moise, a deeply personal gift of life.

"He beat me by one antibody," JoDee says with a smile. "I was convinced it would be me, but in the end, Moise was the better match."

Now a big brother to Benjamin, Daniel embraces his role with the same heart and determination that has carried him through his medical journey.

However, even with a successful transplant, managing Daniel's health remains a full-time job, one made more manageable by innovations like Natera's Prospera™ transplant assessment test, a routine

noninvasive blood test that helps monitor for signs of organ rejection.

"Every time I get back three days of my life because Prospera ruled out the need for a biopsy," JoDee says, "those are bonus days. Those are days we get to be more."

LIFE BEFORE—AND AFTER—TRANSPLANT

Before his transplant, Daniel remembers constantly feeling exhausted. "I couldn't even hold my water bottle at school," he recalls. "By the time I got in my family's car at dismissal, I was already asleep."

The transplant marked a turning point. "After that, I took a huge leap in my health," he says. "I haven't been that sick since."

Still, managing a transplant means constant care. Daniel takes daily immunosuppressants and follows a strict schedule - including overnight routines. His mom describes their life as a "game of threes" with something needing attention every three hours.

THE DISRUPTION OF BIOPSIES

In the early years after Daniel's transplant, biopsies were the only option for monitoring his kidney. But unlike adults who often undergo outpatient procedures, Daniel's biopsies required hospital stays.

"We've missed birthday parties. We've had to cancel vacations. Every biopsy means we press pause on everything," JoDee says.

"He misses school, falls behind, and can't be with his friends. It's not just a procedure, it's a disruption to his whole childhood."

A BETTER WAY TO MONITOR: PROSPERA

Everything changed with Prospera. The test works by detecting donor-derived, cell-free DNA in the bloodstream providing early insight into the risk of rejection of the transplanted organ.

"This is just one more little tube of blood," JoDee explains, "and life goes on."

Just as importantly, Prospera can help doctors rule out rejection, allowing them to explore other causes for symptoms - like a virus, a UTI, or hydration issues - without rushing into a biopsy.

"With Prospera, we can say with confidence: this is not rejection," she says. "That kind of clarity brings so much peace of mind."

For JoDee, the ability to provide her son's care team with actionable data is invaluable. "I want to give his doctors every piece of information I can. Prospera gives us one more tool in the toolbox. And when you're managing a gift as precious as a kidney transplant, that data is everything."

A FUTURE THAT'S FULL OF LIFE

Daniel now manages more of his care himself, tracking his medications, adjusting his schedule, and speaking up for his health needs. And thanks to tools like Prospera, his family is able to focus more on living.

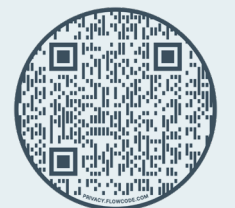
"Prospera keeps our family's life moving, and that's the whole point. We want him to live."



Learn more about Prospera.

natera.com/info/be-proactive-with-prospera

@nateragenetics



THE VIEW FROM

HERO



Words & Photos by
Alison Conklin

My son Jonas and I sat in Ken Sutha's car as he navigated the steep hills of San Francisco. I had heard Ken speak many times on the podcast *Both Sides of the Stethoscope* and had spoken to him briefly a few months earlier—now here I was, in his city, sitting in the passenger seat of his car.

When we had chatted about photo locations, my email went something like this: "What about the Golden Gate Bridge? Did you just scream TOURIST at the top of your lungs while you read this?"

I have a long history with what I consider one of the prettiest bridges I've ever seen. My uncle once wrote a song about it after my mom asked, "Why is the Golden Gate Bridge not actually gold?" He sang it at her funeral and it's one of those core memories that brings me to tears every time I think about it. For years, I carried a small keychain of the bridge until the red paint chipped away entirely. In 2017, I walked across



it with my family. My boys were much younger then and even though I was in heart failure and struggling, it remains one of my favorite memories.

We planned to drive across the bridge to Sausalito first, Ken had mentioned getting ahead of the traffic, and I trusted him. I may drive frequently in New York City and Philadelphia, but I still find California roads intimidating.

The view from the bridge was just as beautiful as I remembered. I found myself gazing up at the cables and rods, those towering lines of red stretching skyward, steady and surreal, as we crossed.

Ken parked, and the three of us walked toward a little cafe. I ordered my usual - a decaf latte and a grilled cheese. Ken chose a chocolate chip cookie, and Jonas went with

Ken was 10 years old when he was diagnosed with Focal Segmental Glomerulosclerosis (FSGS).

a pesto mozzarella sandwich. We tucked into a corner booth, the kind that makes you want to stay a while and began our conversation.

I knew he was ten when he was diagnosed with Focal segmental glomerulosclerosis (FSGS). A kidney disease characterized by scarring (sclerosis) in the filtering units of the kidneys, called glomeruli.

"Did you see that coming? Were there any symptoms you can look back on that felt like foreshadowing?" I asked.



But there hadn't been anything that stuck out in his memory. It was a routine urine test that first revealed unusually high protein levels and led to the diagnosis.

Ken talked about the medications he had to start and the lifestyle changes that followed. Like me, he was an only child, so I asked: "What was that like for you, being back with kids your age back to school after a diagnosis like this?" He didn't hesitate.

"Anything that makes you feel different from other kids

is always difficult. I didn't feel sick yet, just different."

"The hardest part wasn't the disease, it was the side effects of medications, the isolation, and not knowing anyone else like me."

I so very deeply understood this statement.

Ken was 20 and still in college when conversations about a kidney transplant first began. By the time he entered medical school at 22, he had started the evaluation process. At the end

of his second year, at age 24, he received his transplant. His father had stepped up early on and turned out to be a match.

As Ken shared that part of the story, I found myself picturing the in-between: the quiet weight of waiting, of carrying a disease inside your body while studying to one day treat others.

There's a particular vulnerability in being both the patient and the future doctor. Ken talked about trying to keep his focus on

ANYTHING THAT MAKES YOU FEEL DIFFERENT FROM OTHER KIDS IS ALWAYS DIFFICULT.

THE HARDEST PART WASN'T THE DISEASE, IT WAS THE SIDE EFFECTS OF MEDICATION, THE ISOLATION, AND NOT KNOWING ANYONE ELSE LIKE ME.

-Ken Sutha, MD, PhD

school, planning to finish his classes and take his exams before scheduling the transplant over summer break.

"I told my advisor I'd wait until after finals," he said, almost smiling. "She looked at me and said, 'Why?' And that stopped me. I realized this is my life we're talking about."

It was a familiar kind of reasoning. The kind where you push through because you can, because you're used to it, because asking for help still feels like failure,



even when you're literally studying medicine.

His professors gave him full support. No exams. No red tape. Just permission to take care of himself.

The transplant was successful. His father's kidney gave him time and Ken returned to medical school with a renewed sense of focus. It wasn't long before he found himself drawn to pediatric nephrology.

"I just found that I really gravitated to pediatrics, not just the patients and families, but also the other people that were taking care of them. These are my people. Not only are these my people, but I also have a lifelong passion for the subject and I can bring my own personal experience to it as well."

I smiled at him, "What a gift you must be to your patients and families. Understanding them exactly where they are."

Ten years later, Ken found himself facing the thing he had once imagined was far off in the distance—he needed a second transplant.

It wasn't sudden. A few years after his first transplant, complications had started to surface: persistent infections, low-level viral activity in his bloodwork, and a gradual decline in kidney function.

The very medications that had protected his first transplant were becoming unsustainable, a constant balancing act between preventing rejection and avoiding infection.

"There was this back-and-forth," he explained. "They kept adjusting things, but eventually the door to rejection opened,

BEING A PATIENT MYSELF GAVE ME A DIFFERENT KIND OF EMPATHY.

I KNOW WHAT IT FEELS LIKE TO LIVE WITH UNCERTAINTY.

and by then, the damage was already happening."

The kidney that had once saved his life could no longer keep up. He began dialysis while continuing to work and navigate life transitions. Eventually, he joined the transplant list again, this time as a more seasoned patient, but still carrying the emotional weight of starting over.

The toll was heavier. Ken knew exactly what was ahead, what it meant to wait, to hope, to be tethered to machines while trying to live a full life.

He began peritoneal dialysis, a type he could do from home overnight. It involved connecting to a machine each evening and letting it run for hours while he slept, using the lining of his abdomen to filter his blood.

"It gave me flexibility," he said. "But it was still exhausting, both physically and mentally. Dialysis is hard, no matter how you do it."

At the time, Ken was finishing his residency and about to begin a nephrology fellowship. Balancing dialysis with the relentless demands of medical training required a level of discipline and grit most people can't begin to imagine.

He also began the search for a living donor. His inner circle, friends, acquaintances, even

some people on social media had stepped forward to get tested. He said, "There was a woman from near Portland. She didn't know me personally, but she saw the post and signed up to be tested."

That kind of response, he told me, meant everything. Even though the living donor path didn't ultimately work out, the gestures reminded him he wasn't alone.

Eventually, a match came through from the deceased donor list. After nearly three years of waiting, Ken got the call.

That surreal moment, waking up with someone else's organ inside you never really leaves, and for Ken it reshaped the way he approaches medicine.

"Being a patient myself gave me a different kind of empathy," he said. "I know what it feels like to live with uncertainty, to sit in those waiting rooms, to carry the weight of questions with no easy answers. I try to bring that into every conversation I have with patients."

Having personally lived that perspective became the foundation for more than just his bedside manner. It fueled his advocacy and inspired his research.

Ken now works at the intersection of clinical care

and innovation, studying ways to make transplant medications safer and more targeted. He hopes to help move the field away from the "one-size-fits-all" approach of broadly suppressing the immune system and toward something more personalized.

"We're trying to find new ways to study the immune response in the lab," he explained. "We can eventually develop better therapies, with fewer side effects, more precision, and more possibility for people like me."

I let myself imagine for a minute what that would even look like.

"At some point, you stop seeing yourself as just a patient. You realize you can be part of the solution."

I looked at Ken at that moment. In awe of his strength and tenacity. I looked at my son Jonas who had been listening to us chat and he looked as impressed as I did.

Ken also sees value in giving back to the medical world that's given him so much. "I've taken part in clinical trials as a subject," he said. "It's one way patients can help advance the very research that helps keep us alive."

Ken's advocacy doesn't end in the lab or at the hospital. This summer, he joined over 2,000

riders for the AIDS/LifeCycle, a 7-day, nearly 600-mile bike ride from San Francisco to Los Angeles that raises funds for the San Francisco AIDS Foundation and the Los Angeles LGBT Center.

The event, which began during the height of the HIV/AIDS crisis in the 1990s, carries decades of history and healing. For Ken, it also represents something deeply personal: proof that he's still here. Still riding. Still contributing. Still living.

"Even if I don't ride every single mile, it still matters. The stories I hear along the way, the people I meet—that's the heart of it."

It's a powerful parallel: the physician who once felt so alone as a ten-year-old only child with a rare disease, now cycling in a sea of people who understand what it means to fight for your health and to show up anyway.

"It's not a race, it's a ride," he said. "It's about resilience. About showing up. About honoring the people we've lost, and celebrating the people who are still here."

AT SOME POINT,
YOU STOP SEEING
YOURSELF AS
JUST A PATIENT.

YOU REALIZE
YOU CAN BE
PART OF THE
SOLUTION.



Ken, Jonas, and I headed outside for photos. It was one of those classic Bay Area days: sunny, beautiful, and impossibly windy.

We started at the overlook that gives you the feeling of standing above the Golden Gate Bridge. I climbed hills I never could have managed the last time I was here (pre-transplant) and then we just stood there, the three of us, taking in the view alongside a handful of other tourists.


I captured the image that's now on the cover and I knew it the second I took it. The sunlight catching Ken just right, the blue of the sky behind him. Behind the scenes, it was so windy we could barely hear one another. The bridge hummed with sound, the wind rushing past us. Jonas and I kept trying to

yell over it and we all just kept laughing. It was one of those perfectly imperfect moments. One that I'll remember just as clearly as the photo itself.

We also headed down below the bridge for a few other backgrounds. Each of us stood there for a few quiet moments, taking it in from a different angle.

Eventually, I found myself saying, "It really is so beautiful from any perspective, isn't it?"

Ken nodded, eyes on the horizon.

"Funny how the view keeps changing," he said, "and somehow, only gets better." 

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WORDS & PHOTOS BY ALISON CONKLIN

UNPACKING THE

Gift of Life

EVEN ON THE HARD DAYS

VALEN KEEFER OPENED THE DOOR TO HER HOME AND SHE WAS RADIANT. HER BIG, BEAMING SMILE AND INCREDIBLE JUMPSUIT IMMEDIATELY STOLE THE SHOW.



"Wait," I said, before even saying hello, "where is this jumpsuit from?"

We both laughed, then finally got around to formally saying hi. We'd chatted plenty before today, so honestly, it didn't feel like I was meeting her for the first time.

Our last few texts however had mostly been versions of "should we reschedule?" or "let's wait before we call it and see how you feel in the morning."

Today almost didn't happen. A flare-up of pain, stemming from a herniated disc and the spinal rods placed during childhood for severe scoliosis, had left Valen barely able to stand.

"I had alarms set to ice my back every two hours," she told me. "I literally did it around the clock all weekend. But even that wasn't

enough on its own. My husband Noah helped immensely, cleaning the house, running errands, and picking up groceries, while I did what I could, pushing through to handle the smaller tasks. Thanks to his support, I was able to show up today."

It wasn't luck that got her to the door that morning. It was an effort. Partnership. And a deep, steady belief that some things are still worth pushing for.

Valen doesn't sugarcoat the hard days. "Sometimes our days can change in a split second - like bending down to load the dishwasher and suddenly I can't walk normally or stand up straight," she told me. "The pain shoots through and I think how am I supposed to do a photo shoot like this?"

On those days, she gives herself permission to cancel plans if she has to, though it's never easy. She admits to feeling guilt and frustration but she gets strategic.

"Maybe that means I am on the couch tackling my inbox, prepping podcast content, or simply giving myself grace to rest without apology. It's not about pushing through at all costs, it's about redefining what strength looks like."

I always know and understand that plans change. It happens in my life too. That sometimes our bodies have other ideas for us. Schedules get rearranged, trips we were excited about become impossible, and even the simplest daily tasks can suddenly feel out of reach. That's why I was so grateful to be in Auburn, California, for a few hours,

EVEN ON THE HARD DAYS ←

life is still worth showing up for.



spending them taking photos and getting to know Valen, not just for her story, but for the way she carries it.

A quick online search will show you a list of accolades and advocacy work spanning over the past two decades. She's spoken at national conferences, launched a podcast *Unpacking the Gift of Life*, created a docuseries, and helped change the way people talk about kidney disease and transplantation.

However, today I knew it was hard. She was battling the pain and a looming surgery. Valen will soon undergo a type of cranial base surgery to repair a vascular diverticulum and reconstruct eroded skull bone near the brain, a rare complication of PKD (Polycystic Kidney Disease), an unexpected turn in a journey that's already asked so much of her, and one she's meeting with her usual mix of grace, honesty, and quiet strength.

"What's your trick when it comes to living through the fear of the unknown?" I asked.

She paused for a moment, then offered quietly, "Joy is an act of resistance" a quote from poet Toi Derricotte that she adopted as one of her mantras.

There was no toxic positivity in her tone, just raw resolve.

"I've learned that when something new comes up, I need to let myself feel it first. The fear, the anger, the disappointment. But then I try to shift. I remind myself of what's gotten me through before. That mindset of taking things day-by-day, not getting swallowed by the big picture. That's what helps me move forward."

In that moment, I could see how she'd handled decades of uncertainty and survival.

It's been 23 years since Valen received her kidney transplant due to PKD. Twenty three years of medication, labs, advocacy, and resilience. Seven years ago, she also received a liver also due to the same disease. I thought about what it takes to carry that much for that long and still show up with joy. Still laugh. Still radiate light.

"I've lived more years because of my transplants than I did before it," she said. "My life has been more than doubled. And honestly, that still blows my mind."

Valen never thought she'd see 42 (I often had thought the same about myself). Never imagined years and milestones would stack up like that.

"We didn't even know if there would be a next day," she quietly said. "When I was 18 and 19, I spent nearly a year in the hospital. We were living hour-by-hour. My family had already lost so much, we couldn't even picture this kind of future."

But now, nearly a quarter of a century later, she can see it, and it's shaped how she sees the world.

We talked about what it means to live this long with a transplant. To hit year after year of anniversaries. There's a strange shift that happens, Valen said, when you go from being the youngest person in the waiting room to realizing that you're not anymore.

"I grew up in that waiting room," she said. "I was always the youngest. The one in dialysis surrounded by elderly patients. The one the nurses would crouch down to talk to." She smiled, "Now, my nurses are younger than me."

It's a surreal experience, aging in a place that often expects you not to. Still sitting in the same chairs, still filling out the same forms, still managing the same disease. But everything else - your body, your mind, your community - has shifted.

There is an awareness in her voice. An understanding that she's living through what many never get the chance to. "I remind myself all the time," she said. "It's a privilege to age."

I understood that feeling intimately. The strange tension of growing up alongside your illness. I knew what it was to be the youngest in the room since I was diagnosed at 13. The one that people whispered about. The one who didn't quite belong, but couldn't leave.

When Valen spoke about it, I felt an ache of recognition.

We talked about what it's like to hold both truths at once. To feel the weight of all of the years with gratitude and grief. I say all of the time that those two feelings can exist simultaneously and Valen and I both agreed we still are learning to carry that.

Recently, Valen and her husband took an RV trip up the Oregon coast, a vacation they had both been so excited for. However, on day one, they pulled over on the side of the road for a telehealth appointment, one that delivered hard news about a new health issue and upcoming surgery.

JUNIPER



"I stood on the Oregon coast and thought - yes, things are coming," she said. "But I'm not sitting at home letting my health hold me back or waiting for the next hard thing."

That sentence stayed with me. Because it's easy to talk about hope when things feel good. But what I witnessed in Valen was something deeper. A decision. A defiance. A quiet refusal to let fear steal the moments that still belong to her.

"We had the most incredible week," she told me. "Nature has a way of resetting me. And I felt proud of us. Proud that we didn't let the worry stop us from living."

Even on the hard days, life is still worth showing up for.

There's a quote from the beautifully written book *The Fault in Our Stars* by John Green that I've never been able to forget:

"There's no way of knowing that your last good day is your last good day. At the time, it is just another good day."

I thought back to when I read that book and how much that quote hit me. We talked a lot about how hard it can be to conquer the mental part of transplant and even just illness in general. Embracing life with the knowledge of how fragile it all is.

It echoed in my mind as Valen spoke. Because that's what we were talking about, not the pretending, not the bypassing, but the act of holding fear in one hand and wonder in the other. Of choosing to be present, even when the future is uncertain.

In many ways, Valen's life has become a living archive of survival, of perspective, of hard-won wisdom. And she's found countless ways to share it.

IT'S EASY TO TALK ABOUT HOPE WHEN THINGS FEEL GOOD. BUT WHAT I WITNESSED IN VALEN WAS SOMETHING DEEPER. A DECISION.

A defiance.

A QUIET REFUSAL TO LET FEAR STEAL THE MOMENTS THAT STILL BELONG TO HER.

Most recently, through her podcast *Unpacking the Gift of Life*.

"I've done a lot of advocacy work over the years," she told me. "But the podcast is a place where I get to sit down and have real, emotional, empowering conversations. The relaxed kind that feels like two people having coffee."

Season one focused on emotional well-being during the kidney disease and transplant journey, topics she said were rarely discussed in her own care. She co-hosted with a friend and fellow PKD and transplant recipient, a counselor and professor, and together they unpacked everything from diagnosis to family planning - strengthening listeners with valuable insights and emotional support along the way.

The second season launching in September 2025, Valen is hosting solo and unpacking the realities of rare disease, transplantation, and the evolving world of healthcare through heartfelt conversations. Each episode shares real-life experiences, expert insights, and practical guidance to help you navigate challenges,

celebrate progress, and live well alongside chronic illness.

"It's really about connection," she told me. "About showing people they're not alone. That their experience is valid. That there's space for honesty."

The two of us found ourselves settled beneath the shade of a large umbrella at a coffee shop in downtown Auburn. At first, I wiped the tears that slipped down my cheeks discreetly, then eventually stopped trying to hide them. It was the beauty of the moment. The warmth of the sun (with sunscreen carefully reapplied), the comfort of two coffees resting between us, and the quiet power of an honest conversation.

There's no sign on someone's face that tells you the battles they've fought to be here, but that's the thing about resilience - it doesn't always announce itself. Sometimes, it just sits quietly at a table, sipping coffee, telling the truth, and daring to hope.

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Defining



IN LATE OCTOBER 2020, MADDIE FLICKINGER SAT IN HER ROOM IN THE PEDIATRIC TRANSPLANT UNIT AT MEDSTAR GEORGETOWN UNIVERSITY HOSPITAL, DRAFTING HER COLLEGE APPLICATION ESSAYS.

A SUPPLEMENTAL ESSAY REQUIRED FOR THE HONORS COLLEGE AT GEORGE MASON UNIVERSITY ASKED, "OUTSIDE OF ACADEMIC ACHIEVEMENTS, WHAT ARE TWO GOALS YOU'D LIKE TO ACCOMPLISH DURING YOUR TIME AT GMU?"

WORDS BY MADELINE MARRIOTT // PHOTOS BY ALISON CONKLIN

Never ^{but} Defined



eing just 4 months out from a life-saving liver transplant and riddled with complications, just completing the application on time seemed like a far-fetched dream, let alone finishing a degree and additional accomplishments.

As improbable as it seemed, she knew exactly what she'd do if her body gave her the chance; she wanted to do medical research, and she wanted to increase awareness around organ donation and transplantation. Both goals, she hoped, would act as a foundation, leading her closer to a career focused on helping patients like herself. She didn't realize the small, 200-word essay would become such a defining moment of her post-transplant life.

When Maddie was 12, she began to get sick. The once avid swimmer started to struggle at practices and sit out. School, something Maddie has always

loved, became a chore. Each day seemed to grow longer, leaving her exhausted and foggy. Over several weeks, more symptoms developed, prompting multiple doctor visits and eventually bloodwork. May 16th, 2015, an early Saturday morning phone call rang that her mom answered. A panicked pediatrician on the other line told her to take Maddie to the nearest ER because her liver functions were extremely elevated.

The days and weeks following were a whirlwind. Maddie was in acute liver failure due to Budd-Chiari syndrome meaning all three of the hepatic veins in her liver were clotted. The medical team acted. To delay the need for a transplant, Maddie underwent a transjugular intrahepatic portosystemic shunt procedure (TIPS). She was the youngest patient to undergo the procedure at her center.

It was later found that the reason Maddie had clotted was due to a rare chronic blood cancer called MPN. In 2015, at the time of her diagnosis there were less than 30 other children on the pediatric MPN registry. After 5 years with the TIPS, Maddie received a liver transplant at the age of 17. Heading off to college, she wanted to help people going through the same process.

"You go through something that's completely life-changing, and then go back to being surrounded by those who haven't gone through it, and can't fully understand just how life-changing it really was. That's so isolating," Maddie says.

"That's the angle I was looking to take with it: I wanted to connect people, both inside

and outside the transplant community, and give them more opportunities to advocate, but also to find support."

That's when Maddie came across the Student Organ Donation Advocates (SODA) on Instagram. Sara Royf founded the organization five years after her sister, Laura, died unexpectedly of a brain tumor. Her family found comfort and meaning in Laura's legacy living on through Trish, a special education teacher who received Laura's liver.

"I can remember when we got off the phone with Trish after talking with her for the first time, our two girls basically ran down the stairs and started dancing in the kitchen," says Susan Angel Miller, Laura and Sara's mother and a member of SODA's Board of Directors. "We got this feeling that a split-second decision we had made on the worst day of our lives had infused some meaning into what was a senseless death."

Sara took the cause to heart and founded the first chapter of SODA five years later at Washington University in St. Louis. Her goal was to encourage people on her campus to become organ donors through education and registration drives, both increasing the number of organs that would be available for people who needed them and providing that same sense of purpose to other families in the wake of tragedy.

"We have gained an immense amount of pride, meaning, and purpose from the fact that Laura lives on through Trish," Susan says.

Soon, the cause spread to nearby campuses, and by 2019,



NICOLE (SODA NATIONAL), DAVID, MADDIE, MAYA

SODA was incorporated as a 501(c)(3) non-profit. In 2021, the organization hired its first full-time employee, Nicole Nidea, now the executive director.

Nicole had joined the original chapter of SODA at WashU in 2015, and now works on fundraising and collaborations with national organizations to fund and manage the over 100 campus chapters operating this year. The non-profit has grown to partner with organ procurement organizations (OPOs) and is on track to educate nearly 90,000 people this year.

"After passing our big 100 chapter goal, we're really trying to figure out how to grow and sustain our chapter network to bring us closer to our overall vision of every student being an organ donation advocate," Nicole says.

SODA chapters host a variety of events from registration drives to making cards for transplant patients.

The organization's website features a map of the upwards of 100 chapters around the country alongside forms for hosting one's own events or beginning the process of starting a chapter on a new campus.

In 2022, Maddie teamed up with two friends to create a SODA chapter at GMU. Through its first few years, they focused on registration drives and education events about organ donation. Now, almost everyone that stops at their tables is already a donor, but is looking to spread the message themselves.

"We see a lot of people who are coming back to our events and telling us they've registered and are now helping other people get registered," Maddie says.

"That's the impact we've always wanted to see on our campus and in our community. Being able to start that conversation and create a safe place for it has been inspiring."

Maddie continues, "I've also been lucky enough to meet with the Millers. Their story as to why SODA was started and Laura's legacy is something we try hard to incorporate into our campus advocacy. They've also been great to talk to as a recipient. It was Ron who looked at me during a meeting and said 'define what has happened to you but don't be defined by it'. I think that's become my motto for my advocacy efforts both on and off campus."

Maddie has served as SODA's college student liaison on the Board of Directors in addition to the role as president of GMU's chapter. Her involvement with SODA opened the door for additional activism in the transplant community. In 2023, she joined the Transplant Community Advisory Council with the American Society for Transplantation.

"I went in knowing I would be the youngest one there, and





WE'VE LEARNED THAT ORGAN RECIPIENTS CAN FEEL A SENSE OF GUILT AFTER RECEIVING AN ORGAN FROM SOMEONE WHO HAS DIED, **AND THAT SHOCKED US.**

AS A DONOR FAMILY, WE CAN TRY TO RELIEVE THAT GUILT, BECAUSE **TRISH IS LIVING PROOF OF LAURA'S EXISTENCE,** AND SHE HONORS LAURA BY BEING A

Survivor.



- SUSAN ANGEL MILLER

SODA BOARD MEMBER & AUTHOR OF *PERMISSION TO THRIVE: MY JOURNEY FROM GRIEF TO GROWTH*



that has turned out to be kind of status quo for me," Maddie says. "I specifically focus on patient education and perspective, particularly with adolescents, to introduce and emphasize the young adult voice within the transplant community."

"I've gotten to see different angles of transplantation, which I'm really glad to have," she pointed out. "I think it has made me a better advocate for SODA, but it has also given me more perspective on what needs to change in the transplant world as well."

Maddie also participates in a research initiative called Partner Ad3vance with multiple pediatric transplant learning health networks and hospitals. She serves as a young adult voice for

Transplant Advocacy Partners (TAP) and has recently begun telling her story as a speaker at conferences across the country.

"Attending these conferences taught me how many transplant specialists are interested in hearing the patient's perspective," Maddie notes. "You go to your appointments and you know that it's their job to listen to you as a patient, but this has shown me how much doctors, nurses, researchers, and other professionals really do value what patients have to say and want to work alongside us to make a difference."

As for her goal of completing medical research, Maddie is working toward it, involved in childhood cancer research at Georgetown University's Lombardi Cancer Institute.



THIS FIRST CHAPTER OF SODA WAS FOUNDED IN 2014 AT WASHINGTON UNIVERSITY IN ST. LOUIS. TODAY, OVER 100 CAMPUS CHAPTERS EDUCATE THEIR SCHOOL COMMUNITIES ON THE IMPORTANCE OF

organ donations.

The lab she works with focuses on understanding sarcomas, a group of soft tissue and bone cancers most often found in children and young adults, working to find new and targeted therapies for the disease.

"It's been a sink or swim situation, because I got into it without really knowing anything, but it's been a really incredible experience," she shares. "I've learned so much and have had the opportunity to work with a lot of really passionate researchers. It's even helped me become involved in pediatric cancer advocacy."


Maddie hopes to attend medical school after graduation and have the same impact on patient's lives that her doctors had on her during her darkest

moments. She hopes her time as a patient will give her a unique point of view as a provider but she also wants to stay involved with research.

"I wouldn't be here without medical research and the providers who took risks, spent countless hours researching and discussing the best course of action to save my life. They showed humility, passion, and empathy that I'll always be so grateful for," Maddie says. "I'm 100% alive because of it, and that's a powerful perspective to have."

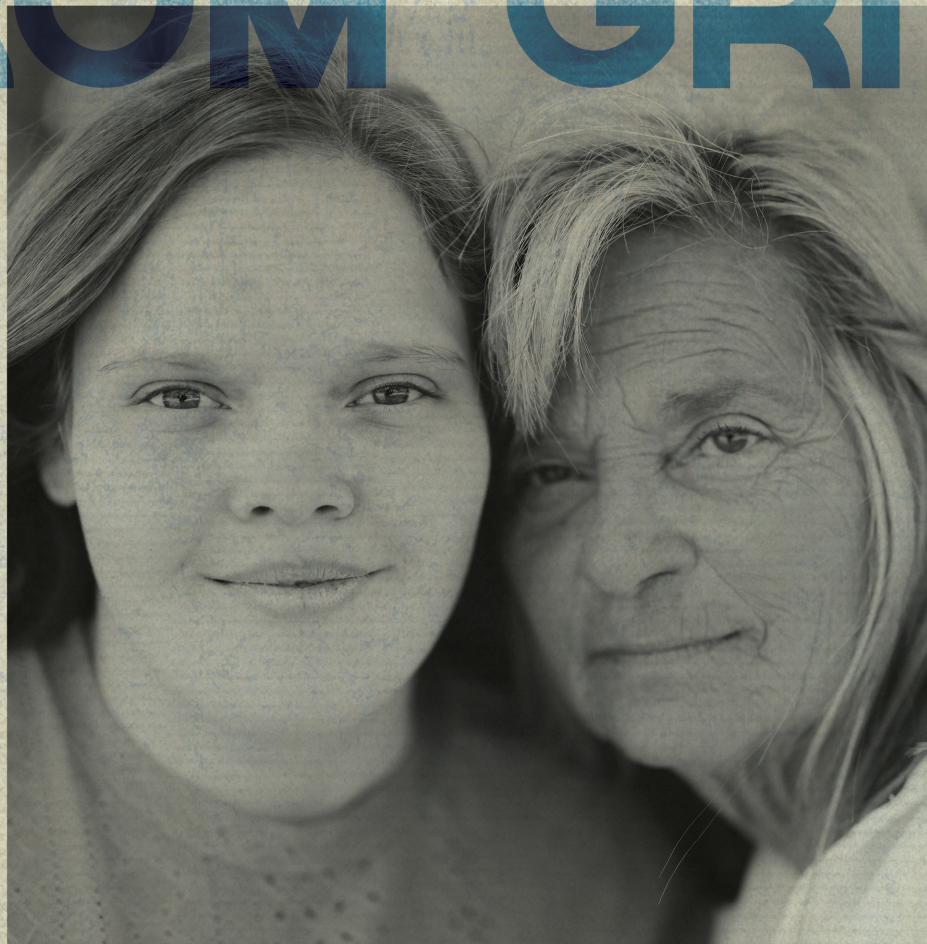
She also plans to remain deeply involved with advocacy and the transplant community noting how it's a community you don't even know exists until you are thrown into it.

"It also shows you how much perspective and connection can change, and even save the lives of others. I think that's the part that has really drawn me to this journey and hopefully a future career in medicine: that you can not

only save a life in the moment, but change it forever." 

[sodanational.org](https://www.sodanational.org)
 @madflick02
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FROM GRIEF



TO GIVING

WORDS BY Susan Gottshall

PHOTOS BY Alison Conklin





In that moment — the nightmare moment that changed the course of Kelly Duren's life — it's his eyes she remembers. Not his name. Not his face. Just his blue eyes. Connecting with hers.



It was 2006, 19 years ago now, when the emergency room trauma physician sat across from Kelly, so close their knees touched. Yet she still sees those blue eyes through the curtain of memory.

So after the doctor with the blue eyes delivered the soul-shattering news, "I was still struggling," Kelly says. "It wasn't hitting home for me. I got up and I walked out. I took a walk for a minute, and I came back."

And the doctor's words still echo in her ears, "I'm sorry. But your son has suffered a brain stem injury. We're not going to be able to save him. We'll need to make some decisions, because his body won't last long either."

Then everything "just became chaos." She had to make "those terrible phone calls." And gather her family.

It was getting close to midnight, just a little more than two hours since Kelly got the call, "Listen, Rocky's been in an accident," she heard when she picked up her phone. "You need to get here."

When she finally saw Rocky, he "looked normal," Kelly says. There was no road rash. It didn't appear there was anything wrong with him. But her son was on life-support, and as the doctor had pointed out, very soon decisions needed to be made.

It didn't "trigger" at first. Kelly knew her 22-year-old son, Rocky, had gone out to ride his motorcycle that night. He was an experienced cyclist; he always wore a helmet. She got to the hospital expecting to find nasty road rash or broken bones.

That's when friends of the family, Rocky's widow's parents, who both worked in the medical field, asked if Kelly had thought about organ donation. She looked at them: "Organ donation? What is that?"

After a quick explanation by them and the regional Organ Procurement Organization

(OPO), then the Pacific Northwest Transplant Bank, Kelly considered the possibility. The family gathered to talk about it.

They remembered Rocky and the person that he was. Kelly says her son was "very much the kid growing up that always helped out the underdog. If he saw somebody being picked on, he was there facing the bully, saying 'I'm here now. What are you gonna do about it?'"

When he was older, he reached out to young adults involved in drugs or alcohol, helping them quit, finding them jobs.

The family agreed Rocky would have wanted to share the life he had lost to give others the opportunity to live, so donating

his organs felt right. Also, Rocky left behind an eight-month-old daughter, Monique, and the family thought donating his organs would give her pride in her father's legacy.

Until the surgery two days later that removed Rocky's major organs— heart, lungs, liver, pancreas, and kidneys— the family stayed with him in the ICU around the clock. Also a tissue and eye donor, Rocky gave the gift of sight to two people.

"When we finally got to that night that they did the surgery, when ... they took him back, I couldn't help but sit and think about those seven people that were going to be receiving the best news of their life," Kelly says.

Rocky's donation was also the family's salvation. "We couldn't change the outcome for him that day. He was going to pass away," says Kelly. "What he was able to do was give life to other people. And through that, it gave us the ability to also move forward knowing that his gift changed the course for so many."

Still, losing her son made Kelly take a right turn asking herself, "How can I take this deep grief I'm dealing with daily and turn it into something good?"

As her children grew up, Kelly had spent years coaching sports in the community because she believed sports helped children grow in many ways. That no longer worked after the accident. It was time to find something new to focus on but that still helped people.

Kelly wanted to better understand organ donation, so she started working with the local OPO, sharing her story to learn from other donor families, encouraging them to share their stories, and finding outlets for utilizing grief in positive ways. As she learned more about organ donation, she felt that donor family stories and their struggles were not being heard.

"The donor family and what they deal with post-transplant is a road of both grieving and healing," says Kelly. "You don't ever get over it. You just learn how to live with it."

Donor families live in limbo for a time. Because you don't really know if the transplant process was completed. Were the organs received? Is the recipient doing well? These answers are part of a

family's closure process as they grieve the loss of their loved one. It became important to Kelly to be a voice for donor families, to share their perspective so medical staffs could better support them, and recipients could better understand the transplant process from the other side.

She got involved with local police departments, sharing insights on dealing with families in traumatic situations like hers. Close to a decade ago, she joined the Fallen Riders Fund Idaho, where she is now chairman of the board, helping families of motorcycle riders who have been in tragic accidents, walking the walk with them that she walked with her son.



ROCKY'S SIBLINGS (LEFT TO RIGHT): Randy, Nick, Rachael, Sydney



ROCKY'S DAUGHTER
Monique



A conversation with Rocky when he was 16 years old sticks in Kelly's memory.

“There are two things in life we have no control over,” THE TEENAGER TOLD HIS MOTHER, “that’s the day we’re born and the day we die. It’s what we do in between—in the dash—that’s what’s important.”

Kelly and her family ensured that every second in that dash of Rocky's life mattered, even to the very end. [tb](#)

She also participates with the American Society of Transplantation as the first donor family represented on its advisory committee, where she brings the donor perspective to the recipient world, and contributes a patient perspective to the medical staff. All of the learning, speaking, and sharing Kelly has done took what happened in her “darkest hour,” she says, and turned it into something “so positive” it helped in her healing process.

When she looks back to the night of Rocky's accident, she says, “I wish I would have known what I didn't know.” She would have liked to have understood how the donation process works, the steps

that lead there, the decisions that need to be made, how donors and recipients are matched so quickly, how organs are recovered in surgery, and how organs are transferred.

Three years after Rocky's death, Kelly felt ready to contact the recipients of Rocky's organs. Monique was a toddler, talking and comfortably sharing that her daddy was in heaven riding his motorcycle. Kelly and her family wanted to underscore Rocky's legacy for his daughter.

In reply to the family's contact came a letter from Rocky's kidney recipient— a young man and former drug addict working with at-risk youth. Thanks to Rocky's

donation, he was continuing his work, saving teenagers otherwise headed down a destructive path. The family also heard from a grade school teacher who got Rocky's pancreas, and a relationship with her and her family grew. She lived for ten years with Rocky's organ before she died from other causes.

Hearing from recipients— just even a thank you— helps a donor's family in their grieving and closure, says Kelly. Those two simple words tell the family the recipient thinks of their loved one and his or her gift. It honors the precious person that left behind a grieving family. For the family, knowing that the recipient is a

good steward of the organ, that he or she is making good choices and living life, it transforms the tragedy.

The teacher's sons shared that after their mother received Rocky's pancreas, she was able to go out and do things and play with her grandchildren, when previously she had been sick as long as they could remember.

Kelly says her story is not about Rocky's accident. Rather it's about what she heard from the teacher's sons, knowing what Rocky's organ did for their mother—and them— and so many others. Knowing that something good came out of the tragedy brings her solace.

YOU CAN MAKE A DIFFERENCE

The U.S. federal agency Health Resources & Services Administration reports more than 100,000 men, women, and children are waiting for organs on the National Transplant List and another name is added every eight minutes.

Kelly Duren encourages people to consider organ donation when she speaks to groups, because “you can't take it with you, but what you can do is change the course for so many people going forward.” Even if just a few people decide to become donors as a result of her experience, Kelly feels her family's story will have made a difference.

First, educate yourself about the issue. Then have a conversation with your family, Kelly advises. Make sure your family knows your wishes, and make sure you understand the wishes of other members in your family.

Is it great dinner conversation? Probably not, she says, but it's an important conversation to have. Should you ever find yourself in a position like Kelly's on the night of her son's accident, you'll be able to easily answer the questions that, inevitably, will come at you, fast and furious.

Organ and tissue donation offers the opportunity to give the greatest gift of all—the gift of life, says Kelly, “And that's a pretty great gift.” Whenever she speaks, she reminds groups, “Without donors, we have no recipients.”

LEARN ABOUT ORGAN AND TISSUE DONATION AT [REGISTERME.ORG](https://www.registerme.org)



My Earrings & MY UNEXPECTED SURGERY

WORDS BY SYDNEY KURLAND
ILLUSTRATIONS BY OLIVIA MALONE

In the days immediately following my transplant, I was very fixated on one thing. Technically, three things. My little hoop earrings with the bead closure. These hoop earrings I'd worn for years in a dainty cascade down the top of my left ear. In all the time that I've had these piercings, the surgery was the first time I'd removed the earrings in them.

Somehow, I'd been allowed to keep them in for the MRIs, for the biopsy. Somehow, I'd convinced myself that this wasn't all that serious. I'd be better soon. The ultrasounds, the echocardiograms, the visits from the psychiatrist, the surgeon—they were a failsafe. In case my liver didn't recover, all the data needed to list me for a transplant would be ready, but it would never really get that bad. It could never.

The nurse manager of the floor I was initially admitted to urged me to allow her to call my mother, call somebody to come to the hospital and be there for me. I insisted I didn't want to bother anyone. Unless things were truly dire, it would only be a disturbance. I repeated this several times.

Ignorance is bliss, they say. I don't know what they say about denial. Or fear. Or maybe it was hope? Wishful thinking? I don't remember what exactly got me to cave.

Early in the morning, while I had wanted to be taken down for my transplant surgery, my mother had taken out my earrings in preparation for the operation. Out came the two little hoops in each of my earlobes. With a bit more effort, out came the top most hoop in the upper part of my ear, then the second, but before my mother could remove the final hoop, the ICU nurse came into the room and announced that it was time for me to be brought down to the operating room.

I don't remember if the operating room nurse said much to me as he wheeled me into the elevator. We passed TV screens lit up with OR assignments and mostly empty nurses stations en route to our final destination. I don't remember if I said anything to him either. What I do remember is that once we were right outside the operating

room, he noticed my remaining earring. It needed to come out.

As he carefully unscrewed the bead closure, he assured me that he'd find a place to keep the earring safe. It would be returned to me once the surgery was over. He'd make sure of it.

I heard something small and metal hit the floor. Maybe the bead? Probably the bead. That stupid bead. The nurse thought he may have broken the earring. He apologized and took a minute to scan the floor for the broken piece. He apologized again. I didn't have the energy to be upset. Even if I had, there wasn't time. The nurse brought me into the operating room.

The first thing I remember asking for after the transplant surgery was some water. The second thing I asked for was something to eat. The third thing I asked for was my earrings to be put back in.

Many hours after my initial requests, I was permitted water to drink. Then juice. Then eventually, an artificially-apple-cider-flavored meal replacement drink. The next evening, I was finally given my first real meal since the surgery. My mother,

who had traveled across the country to be with me during and after the surgery, didn't understand my insistence on having my earrings put back in.

Once I was transferred from the ICU to the regular transplant floor, I repeated my requests for my earrings. My mother was too tired. I would have to remind her again the following day. When she did take the time to look at the earrings, she deemed them too difficult to put back in on her own. The beads were so small, too small for an amateur to manipulate.

We'd go have a piercer or someone at a jewelry store put them back in once I was discharged, she said. I begged her to at least try. The hoop went in fine, but the bead closures were just too difficult to manage.

A night nurse with a carefully curated earring stack of her own overheard me begging my mother to try just one more time to put the earring back in, and offered to help once she was done with her evening med passes. I was thrilled. I thanked her and anxiously waited for her to return.

That night, it turned out, would not be the night I had my earrings put back in. My nurse was busy tending to a more emergent matter. She had asked another nurse to come in and give me my evening medications. I understood.

The nurse with the many earrings was back the following night. She even brought pliers to aid in manipulating the tiny beads.

The night nurse on the transplant floor tinkered with my earrings for a good few minutes then announced that she was unable to properly

secure them back in. I tried my best to hide how deeply disappointed I was. The nurse suggested I look into a favorite jewelry brand of hers, noting that their earrings were very easy to exchange at home all by yourself. The style I liked was simple enough that she was sure they'd have a perfect substitute.

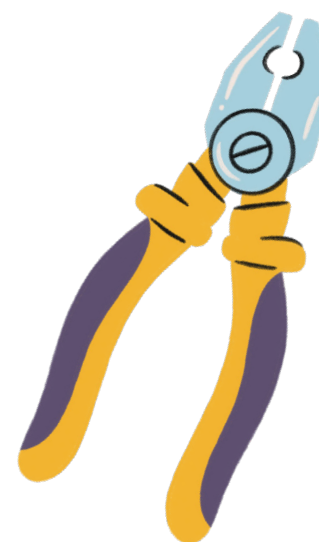


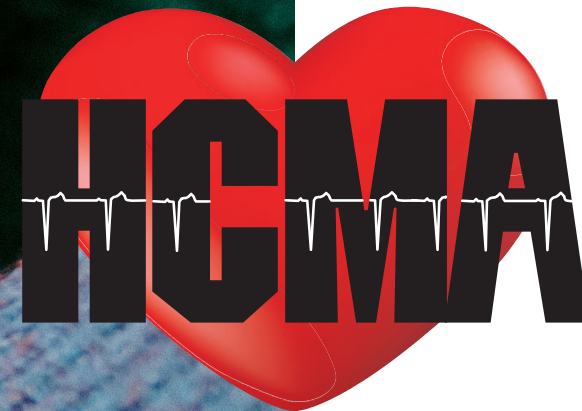
My mother and I browsed the jewelry brand's website. There were no exact matches for my earrings. The earrings I liked to flick up and down when I felt fidgety. The earrings I liked to admire in the mirror after putting my hair in a half-up style. The earrings I had worn continuously for years. The earrings that had become a part of my identity.

I settled on simple silver hoops. No beads. The new earrings were in a package waiting for me when I finally arrived home. I eagerly opened the package. Even though my hands were shaky from my new anti-rejection medications, I was able to put the new earrings in all on my own. I went into the bathroom to get a good look at them in the mirror.

The hoops I'd selected for the two uppermost piercing holes in my ear were smaller and had a much tighter fit than I'd hoped. The hoop in the piercing hole below was larger and hung looser than the one I'd previously worn there. I was pleased to have earrings in, back where they belonged.

I didn't find the new earrings ugly. Still, they looked different. They felt different. They were different. And now so was I.





**Hypertrophic
Cardiomyopathy
Association[®]**
Home for the Bighearted Since 1996

You Are Not Alone. **And You Don't Have to Navigate HCM Alone Either.**

Living with Hypertrophic Cardiomyopathy (HCM) can feel overwhelming, but there's a community here for you. At the Hypertrophic Cardiomyopathy Association (HCMA), we've spent over 29 years advocating for patients, empowering families, and providing the latest information on treatment and care.

Whether you're newly diagnosed or years into your journey, our free Zoom support groups connect you with others who understand what you're going through—because they've been there too. Led by trained patient advocates, these virtual sessions offer a safe space to ask questions, share experiences, and find strength in community.

While every HCM journey is unique, approximately 3–6% of patients will ultimately require a heart transplant as part of their treatment. That's why HCMA offers dedicated support and discussion groups specifically for patients facing advanced stages of HCM, including transplant preparation and recovery.

Support. Advocacy. Education. Empowerment.
That's the heart of what we do.

Join a free support group at: **4hcm.org**

Firecracker Salmon Bowls with Peanut Sauce

A flavorful, heart-healthy meal that's packed with protein, fiber, and color. Easy to prep ahead and sure to impress.

PHOTOS BY ALISON CONKLIN



Ingredients for the Bowls:

1 cup dry jasmine rice
Pepper to taste
2 heaping cups finely shredded cabbage (red, green, napa, or savoy)
3 Tbsp thinly sliced green onion (plus more for garnish)
1 Tbsp seasoned rice vinegar
1 tsp toasted sesame seeds
2 Tbsp extra-virgin olive oil
4 (6oz portions) skin-on salmon fillets
1/3 cup roasted peanuts, roughly chopped (dry roasted or honey roasted)

Ingredients for the Peanut Sauce:

1/4 cup creamy natural unsweetened peanut butter
2 Tbsp lower-sodium soy sauce
2 Tbsp Thai sweet red chili sauce
1 1/2 Tbsp rice vinegar
1 Tbsp sesame oil
1 garlic clove, minced
1 tsp freshly grated ginger (or 1/2 tsp ground ginger)
Optional: 1/2 tsp sriracha or chili oil for heat

Directions:

1. Cook the Rice

In a saucepan, combine rice with 2 cups of water. Bring to a boil, cover, and reduce heat to low.

Simmer for 13-15 minutes, until water is mostly absorbed. Fluff with a fork, cover again, and let sit off heat until ready to serve.

2. Make the Sauce

In a mixing bowl, whisk together all sauce ingredients until smooth. Add 1 Tbsp water to thin, if needed, to reach desired consistency.

3. Toss the Slaw

In another bowl, combine shredded cabbage, green onion, rice vinegar, sesame seeds, and a pinch of salt. Toss well and set aside.

4. Cook the Salmon

Season salmon fillets with salt and pepper. Heat olive oil in a large skillet over medium-high heat. Place salmon skin-side down and press gently with a spatula. Cook for about 5-7 minutes, until the sides look 75% cooked. Flip and cook for an additional 3-5 minutes, depending on thickness. Remove from heat.

5. Assemble the Bowls

Divide rice among four bowls. Top with salmon and slaw. Drizzle generously with peanut sauce and finish with chopped peanuts and extra green onion.

University of Colorado Hospital

Nutrition plays a powerful role in every stage of transplant care, from recovery to truly thriving in your new normal. The clinical dietitians at the University of Colorado Hospital understand that, and they're here to support you before, during, and after your transplant.

At UCHHealth, dietitians are involved in key aspects of your care - from assessing frailty to ensure you're strong enough for surgery, to using indirect calorimetry after transplant to determine your exact calorie needs during recovery. If you're struggling to eat enough after surgery, a dietitian may help place a feeding tube to support your nutrition until you're able to meet your needs on your own.

It's well proven that adequate nutrition before and after transplant can significantly

impact your recovery and long-term outcomes. The goal is always to help you thrive—fueling your body with wholesome, healing foods so you can return to the life you love.

The recipes shared here reflect that goal. They're more than just meals—they're practical, approachable ideas from professionals who work every day to help transplant patients feel strong, supported, and nourished.

Whether you're weeks post-op or years into your bonus days, food can be a powerful source of comfort, energy, and healing. [Read more](#)

UCH Transplant Dietitian Team (left to right): Rachel Smith, Analeise Kett, Emily Burch, Cami Tynan, Victoria Newman-Green, Natalia Szawiel, and Angela Willson. Not pictured- Jackie Cheek



Natalia, Cami, and Rachel are dietitians on the team with additional skills to place feeding tubes using IRIS technology (left) and determine exact calorie needs using indirect calorimetry (right).



Make It Yours!
Swap oats for other rolled grains or mix a few together. Adjust seeds and sweeteners to your liking. If you are watching your potassium swap out the seeds for more oats. Try dried apples, pecans, and pumpkin seeds in Fall—or cherries, sunflower seeds, and coconut flakes in Summer. If you increase your dry mix, adjust the oil and honey as needed. This recipe can easily be doubled for a crowd.

Seasonal Seed & Grain Granola

A customizable, nutrient-rich granola perfect for breakfast, snacks, or sprinkling over yogurt.

Ingredients:

- ¼ cup canola oil or olive oil
- ½ cup honey
- ½ tsp vanilla or almond extract
- 4 cups rolled grains (like oats, spelt, rye, or barley)
- 1 cup shredded coconut (raw or unsweetened preferred)
- ¼ cup sunflower seeds
- ¼ cup pumpkin seeds
- ⅛ cup sesame seeds
- ⅛ cup ground flax
- ⅛ cup chia seeds

Optional Add-Ins:

- Raisins
- Dried cherries, apples, or other fruit
- Wheat germ, brewer's yeast, or additional seeds and nuts

Directions:

1. Preheat oven to 350°F. Line a baking sheet with parchment paper.
2. In a small saucepan, gently heat the oil and honey until combined.

Remove from heat and stir in the vanilla or almond extract.

3. In a large bowl, combine the rolled grains, coconut, and all seeds. Pour the warm liquid over the dry mixture and stir well to coat.

4. Spread the mixture evenly onto the prepared baking sheet in 2-3 batches. Bake each batch for about 10 minutes. If the edges begin to brown too

quickly, rotate the mixture with a spatula and bake for a few more minutes.

5. Let cool completely before stirring in any dried fruit or optional add-ins. Store in an airtight container for up to two weeks.

YOU GET TO *Live!*

Karen Lunt



Katie



Karen's daughters (left to right): Casey, Anna, and Caroline.

Waiting for my lung transplant back in 2022 was a time when my life was on hold. I was very sick and I knew that if I didn't receive a transplant, I would only have maybe six months to live, at most. My focus was on surviving the next minute, breath by breath, until those moments grew into hours, and then days. Each day that passed was harder than the last. The world passed by, relatively unnoticed by me. Every effort and thought I had was consumed by breathing and staying alive.

After my transplant and recovery, I was suddenly aware of the world around me in ways unlike before. I noticed the clouds contrasting against a bright blue sky. The colorful fall leaves being carried in the wind. The beautiful colors of the sunset. The stars in the night sky. It was then that I realized how much my life had changed.

It was not just because I could breathe easily on my own again, but because I was no longer hyper-focused about my breathing. My focus was on living life again. I could simply just live. I am blessed to be able to fully live my life again because of this generous gift from my donor. [ht](#)

- Walk, bike, hike, and live without lugging around heavy oxygen tanks.
- Ride my e-bike on the beautiful trails in my area with my husband.
- Attend the high school graduation of my youngest daughter and the college graduation of my oldest daughter (more college graduations to come!).
- Watch my "kids" become young adults.
- Teach students in virtual school.
- Find new recipes to cook and bake for my family.
- Take several vacations up and down the East Coast, from South Carolina to Maine.
- Walk with my donor's mom and his family in the Sharing Hope SC Race for Life.
- Tell everyone I meet about the amazing miracle of life that I have received.
- Encourage others to Donate Life.
- Travel out west to see some amazing National Parks.
- Visit Niagara Falls.
- Bike the entire C & O National Historic trail 185 miles from Maryland to Washington DC.
- Travel overseas again someday.
- Sharpen my photography skills.
- Write about my transplant experience.



Bella

QUILT



what this
side feels like.

WORDS & PHOTOS BY ALISON CONKLIN



Lisa Salberg was just twelve years old when everything changed. One moment, she was a typical kid in New Jersey who loved roller skating, Queen, and playing softball. The next, she was standing shirtless in a school hallway for a health screening, listening to a nurse urgently whisper, "It's like her. It's like her."

She didn't know who her was at the time, but she knew what it meant.

"I got what my uncle and sister had, and what my grandfather died of," Lisa remembers. "I went from being just a kid to being a scary kid. The adults were looking at me weird. It was very unsettling."



“In the darkest day of my life, there was this tiny little pinpoint of light,” Lisa says. “We couldn’t stop what was happening, but she could still do something good for someone else. That made an almost unbearable situation bearable.”

That day, she learned she had hypertrophic cardiomyopathy (HCM), a genetic heart condition. What followed wasn’t medical clarity or emotional support—it was silence. Her parents, overwhelmed in their own ways, shut down. Doctors offered no compassion, just cold facts.

“I was advised that I could die suddenly and unexpectedly,” she recalls. “And that CPR wouldn’t bring me back. I have no idea why an adult cardiologist thought that was appropriate to say to a 12-year-old.”

So she did what many kids do—she tried to carry it on her own. Lisa didn’t talk about it with her friends; it scared them. She didn’t talk about it with her parents; it upset them. “There were only two people I could talk to: my best friend, Julie, and my sister, Lori.”

That sisterly bond would become a thread that pulled through every chapter of Lisa’s life. Lori also had HCM. They leaned on each other for support, even when the system failed them. And years later, in one devastating moment, it was Lori who collapsed—sudden cardiac arrest, while her young children were in the house.

Lisa’s father, a volunteer EMT, was the one who ran into the house and began CPR. They got her back, but the damage had already been done. Lori would never regain consciousness.

“She was on a ventilator,” Lisa says. “But she wasn’t coming back. I remember saying to my family, to my husband, ‘I’m going to be on the other side of this someday. Remember what this side feels like—to give.’”

Lisa’s voice catches when she talks about that week. About her niece and nephew, who watched their mother die. About her father, who had already performed CPR on his own dad, only to lose him in 1953—and now his daughter. About signing the paperwork that would make Lori an organ donor.

Lori donated her kidneys and liver. Lisa, already signed up as a donor herself, found a new mission rising out of grief.

“We were raised in a volunteer family. This is just an extension of community service. An extension of being human.”

That moment, that loss, shaped everything that came after.

In the years that followed, Lisa would go on to establish the Hypertrophic Cardiomyopathy Association (HCMA), a global organization built from her kitchen table. It began with a simple conversation with her sister in 1995, a dream of starting a support group for families like theirs. But after Lori’s death, Lisa became the one to carry it forward.

And she did. Fiercely.

She took on the United States government, fighting for better protections for research subjects after her sister’s treatment was mishandled in a clinical trial. She advocated for thousands of patients across the country, helping them access care, find their voices, and navigate the impossible decisions that come with HCM. She helped rewrite transplant listing guidelines to make space for patients like her—people who were often overlooked or misunderstood.

“I don’t think I save lives,” she says. “I think I put people on a safer path. I help them do it with less stress, more focus, and more hope.”

Eventually, Lisa would need that path herself.

For years, she ignored her own worsening symptoms while helping others. She convinced herself she was fine—until she wasn’t. One day she nearly passed out in the White House after speaking on behalf of HCM patients. Shortly after, she was admitted for transplant evaluation.

“I knew. I knew transplant would be part of my story,” Lisa says. “I just didn’t know when.”

In 2017, Lisa received a new heart from a female donor whom she thinks about constantly.

“I don’t know them. I don’t know if I ever will. But I love them. A lot. A lot.”

She began sharing her journey publicly—raw, unfiltered, and with her trademark sarcasm.

“I went on Facebook Live the day I got home and held up my old ICD to the camera. I wrapped the lead around my hand and shocked myself. On camera. My husband ran in like, ‘What are you doing?’”

Humor is her survival skill. Advocacy is her purpose. And legacy is what drives her.

“I still hold on to that moment with Lori. That we got to give. That spark of light in the darkest dark,” she says. “That’s why I fight so hard for patients. Why I push for change. Because nobody should have to go through what our families have gone through. We’re smarter now. We have tools. And I want to use them to make the next person’s journey easier.”

Lisa ends many of her talks with a quote by Mary Oliver that shaped her post-transplant life:

“Tell me, what is it you plan to do with your one wild and precious life?”

She answers it every day. With action. And she hopes you will, too. ^{tr}

[@lisahcma](#)



WANT TO SEE MORE OF MY INTERVIEW WITH LISA? VISIT THE *BONUS DAYS* YOUTUBE CHANNEL.

Inspiration Card Art Project

WORDS BY HEATHER RODALE
FOUNDER, HEALING THROUGH THE ARTS

As an inspirational quote collector, these inspiration cards were another way to share the love of hope and inspiration. I started making the cards when my daughter across the country was going through a difficult time. My gift of 30 Days of Inspiration was able to be there to comfort her when I could not physically. It was welcomed and shared with others she knew struggling as well and needed that little boost of joy.

INSPIRATION CARDS

Inspiration Cards (about 4" x 2 1/2") are little handmade cards with a positive message that can uplift your spirit, spark creativity, and provide encouragement. Each card combines a quote with visual embellishments. You can use stickers, drawings, washi tape, art from greeting cards, old postage stamps, any picture or design.

When giving them as a gift, you can place each card in a small envelope and put them in a decorative box. Open one envelope each day for 30 days. Thirty days of repetition can change a habit and encourage a more positive mindset. This activity is impactful for the creator as well since it inspires creativity to make each one. Collect your favorite quotes to use. Cut out designs from magazines. Take beautiful photos to print. The limit is endless. But handing away one card, that little gesture, can mean the world to someone who needs a boost.

LUNCHBOX LOVE NOTES

Adapt this activity for kids! When my grandkids started school, I noticed that some of their peers were not as kind as I had raised my kids to be. A Lunchbox Love Note was to encourage them to focus on helping others or teach them fun facts about animals. They could give the card to a friend or bring it home. They could not throw it away. [👉](#)

DECORATE THE COLORING PAGE THEN CUT OUT THE INDIVIDUAL CARDS. KEEP THEM HANDY FOR YOURSELF OR PASS ALONG TO OTHERS WHO NEED A PICK-ME-UP. →

TAG @BONUSDAYSMAG AND @HEALING.THROUGH.THE.ARTS WHEN YOU MAKE AND SHARE YOUR ART!



Some Quotes to get you started...

- In life, when a door closes, open it. Doors are meant to be open.
- Not all classrooms have 4 walls.
- Sometimes people show you how NOT to behave.
- The average hand can hold 10,000 grains of sand. My hand can hold yours.
- Opportunities are like sunrises. If you wait too long, you miss them.
- If you don't pick a day to relax, your body will do it for you.
- When your heart is broken, make art.
- Quiet the mind and the soul will speak.
- You can't give your life more time, so give it more life.
- Do the right thing even when no one is looking.
- Bumble bees warm up before they take-off.
- Friends come in all shapes and sizes.



Heather's handmade Inspiration Cards she loves to share with others.



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!



While in Paris on my daughter's 23rd birthday (she's the one who called 911 during my stroke) I climbed 360 steps up the Eiffel Tower, my strongest moment since three years of physical therapy began. I paused at the first level with my mom, proud of how far I've come while my daughter and partner continued to the second level.

Tania Saiz

My favorite bonus day was at my one year celebration where I hosted a fundraiser for my transplant hospital. It was spent with my Transplant and dialysis medical teams, along with Fellow Transplant warriors, family and friends.

LaVise McCray



My best bonus day was being present at my older sister's wedding. It was such a big life moment that I did not think I would survive to share with my sisters. The gift of a new heart, and my family's support as I continue to recover from my strokes, gave me the opportunity to laugh, cry, and dance at Michaela's wedding. It was an incredible day!

Hana Hooper

I am a metalhead and one of my bucket list items has always been attending Wacken Open Air in Germany. I received my heart and kidney transplants in 2020, and in the summer of 2022 I heard back from my donor's family. A month before I went to meet them, I went to Wacken and saw Slipknot, a group that turns out is not just one of my favorite groups, but was one of my donor's favorites as well.

Tony Young



My favorite Bonus Day so far was on April 29th, 2023. It was a little more than a year after my life saving small bowel transplant, and I was meeting the family of my donor Rohen on what should have been his 12th birthday. Meeting them allowed me to understand my new organ so much better, my cravings for new

things so much more clear, and it increased my family size by (at least) three. Having them in my life is the greatest gift that this new transplant has brought into my life and I'm so grateful for all of it.

The photo here is of me on Blue & Green Day this year in my bonus days hat (which I have been

your favorite bonus days ❤️

saying since my transplant in 2022) and my donor's Michigan hoodie. GO BLUE.

Wendy Ryan

I had my heart/double lung transplant in June of 2020 from one donor. I've been listed for over 9 months for a second double lung transplant. My favorite bonus day was when my second granddaughter, Emily, was born and I got to hold her.

Sheila Connors



My favorite bonus day was taking a trip to Seattle in 2023 and meeting a fellow heart transplant recipient on the other side of the country! I met Bella online in 2020 and we exchanged instagram DMs back and forth for years following up to our trip, so meeting her was incredibly bittersweet.

Madeline Mitchell



One of my favorite bonus days came in 2021, 9 months post-transplant, when my wife and I were able to enjoy a weekend in Monaco. We had always wanted to visit Monaco and thanks to my donor we were able to make it happen. I am forever grateful to my donor for the wonderful gift of life.

Willie McLaughlin



One of my favorite bonus days was being able to go to Disney for my birthday a few months after my liver transplant!

Susan Adepoju



After years of sharing my dialysis reality on social media, I was invited to be a paid patient advocate with Baxter Renal Care (now named Vantive). I had been doing a lot of virtual events with them but one of the most life changing experiences was when I got invited to attend my first in-person public speaking event where I got to share my personal story and advocate for all the things I feel passionate about; emotional support, mental health, green nephrology, bettering the patient experience, social determinants of health, and so much more. They even created a short film documentary about my story and I've been given so many wonderful opportunities to travel and advocate for kidney patients!

Taylor Kriss

While I was in the hospital in the few days awaiting my heart transplant on ECMO (heart lung bypass), my husband asked me what I was most excited to do when this was all behind us. I wanted to walk on a white sand beach and spend the days snorkeling with turtles. One year and 2 weeks after my transplant I got to feel the sand under my feet and snorkeled everyday. You go from one day not knowing if you would ever feel the warmth of the sand again, to living a dream.

Tyler Chavez



I got my second transplant on March 14th 2022 (a kidney) and three weeks later on April 4th we officially tied the knot after 7 years together!

Jamie J.

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

This page exists because of people like you and so does this magazine.

Bonus Days was born from a heart transplant and built on the belief that storytelling can heal, unite, and empower. It exists because someone said yes to organ donation. Because a stranger shared their story. Because a hospital believed in the power of connection. Because people like you have supported it—by reading it, sharing it, and helping it grow.

As we continue to tell stories that matter. We're looking for partners to help us keep going. If you or your organization is interested in supporting *Bonus Days* through advertising, sponsorship, or distribution, we'd love to connect.

Your support helps us get this magazine into the hands of patients, caregivers, and medical professionals around the world. Through the very hospitals and transplant centers where journeys begin.

Let's do something meaningful together.
Email me: alison@bonusdaysmag.com

@bonusdaysmag | BonusDaysMag.com



Become an Organ Donor

Were you inspired by our readers' bonus days?

You can provide lifesaving organs to as many as eight people by registering to be an organ donor.

RegisterMe.org

Once you register, be sure to let your family know your wishes.



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...**ANESTHESIOLOGIST!**
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