

COTA FAMILY

Zach Jones and Elizabeth Puglisi
with COTA Kid Teagan



Children's Organ
Transplant Association®

*The Trusted Leader Supporting Families
... For a Lifetime*

2019-2020

IMPACT REPORT

CELEBRATING  35 YEARS

2019-2020 IMPACT REPORT

Obstacles do not have to stop you. If you run into a wall, do not turn around and give up. Figure out how to climb it, go through it or work around it.

Michael Jordan

Perseverance in the Face of Adversity by Rick Lofgren, COTA President

Without a doubt, 2020 has been filled with obstacles none of us likely ever imagined or anticipated. But I am pleased to report that while we have had to adjust to new working environments, online meetings and greatly reduced travel, we have continued to fully support our transplant families nationwide. Even with unexpected obstacles, the mission of the Children's Organ Transplant Association (COTA) to serve transplant-needy children, teens and young adults has not wavered. While many of us may have been, or continue to be, more physically disconnected than we are accustomed to, I am grateful and proud that Team COTA remains a united community that has figured out how to keep our eye on the ball.

I was recently on a call with a COTA parent who was experiencing significant challenges and obstacles. I was able to reassure this mom we could indeed help. The sense of relief -- even over the phone -- was palpable. This call was a good reminder that what we do at COTA is much more than financially helping and supporting our families. What COTA really does (*and has done for nearly 35 years*) is to give hope to families at various stages of a transplant journey. That 'dose of hope' is more critical now than ever before due to these turbulent times.

Another COTA parent shared this message with me, "Thank you for taking the time to call me. I am grateful for all that COTA continues to do for us. It means a lot that you and your team are on top of things and with everything else going on, it makes me even more thankful for COTA. I appreciate you being calm; it is very reassuring to me and makes me think our family can get through this."



Lawson Riley

Washington, Indiana
Multivisceral Transplant Recipient
Date of Transplant: June 8, 2017
Riley Hospital for Children
Indianapolis, Indiana

COTA's staff members work with our families on an individualized basis, endeavoring to analyze each challenge, obstacle or stressor and then determine how to get them to the other side. Our nationwide network of Miracle Makers . . . community campaign volunteers . . . transplant professionals . . . all provide a safety net of hope for COTA families. COTA's model of support and guidance is truly a team effort that is guided by a motto of never giving up, no matter what. That motto has resonated with thousands of COTA families for more than three decades and will lead us into our next year of service where there will likely be new obstacles and challenges.

COTA was founded nearly 35 years ago. Throughout that period of time we have connected more than 3,700 patients, and their families with medical professionals, volunteers and contributors to assist with transplant-related expenses and to ease the stress of their transplant journeys. While 2020 has provided new obstacles for our transplant families, it is important to remember how resilient COTA families are -- no matter what the challenge or uncertainty.

During turbulent times, COTA offers a sense of stability and a dose of hope. Being recognized as the **Trusted Leader Supporting Transplant Families . . . For a Lifetime** is a responsibility we embrace. It is our ethos and our guiding vision. We also know we are only able to publicize this tagline because of our nationwide network of Miracle Makers. Working together as a team, we ensure our families can focus on caring for their kids, teens and young adults while we focus on fundraising for transplant-related expenses and finding new avenues of support.

"Through this incredible journey, COTA has been like an experienced friend to us. From day one, COTA has been there for us providing comfort, understanding and hope . . . when we needed it the most. The COTA staff is always trying to find new and better ways to help transplant families -- not only financially, but also emotionally. Our son is now three and half years post-transplant and COTA continues to offer support and guidance . . . *for a lifetime.*"

— Megan and Brian Riley, Parents of Lawson

Since 1986, COTA has assisted thousands of transplant-needy children, teens and young adults. This past year which this Impact Report surveys, we helped a record 255 new transplant patients and their families -- and in the past four years, COTA's staff and Miracle Makers (volunteers and supporters) have served a record 917 new transplant families by allocating nearly \$16 million to meet transplant-related expenses. If you would like to know who these kids, teens and young adults are, visit [COTA.org](https://cota.org) for a complete listing of transplant patients who became part of the COTA Family this past year.

Over the years COTA's team of committed staff members have had thousands of conversations with parents who have heard the devastating news that their child has been diagnosed with a life-threatening disease. We often hear the intense fear in their voices and are very aware they are crying on the other end of the line. This past year, with the extra stress associated with a pandemic, an economic crisis and social unrest, COTA parents' fears have been magnified. It is not a stretch to say that 2020 with its many obstacles has been the most challenging year to date for many COTA families in a multitude of ways.

However in the midst of the myriad of challenges facing our families, we also hear many parents clinging to the possibility that tomorrow will be a better day . . . a day where our families can focus on hope.

I want to share one such hope-filled story about a COTA teenager and his family. I first met Sharon and Kelvin Brown, Sr. at Duke University Hospital while their son Kelvin, Jr. was recovering from his bone marrow transplant in the spring of 2018. I immediately sensed this family's intense faith and strength even in the midst of what had been Kelvin's nearly 18-year battle with Sickle Cell Disease. Please take a moment to learn more about Kelvin and his family's transplant journey, and the role COTA has played in it: <https://cota.org/kelvinb>.

In talking with these stressed and anxious parents, I learned more of the crippling details of Kelvin's transplant journey and the incredible work that Sharon's twin sister, Karen McPherson, was doing leading the COTA in honor of Kelvin B volunteer team and fundraising effort. Kelvin's story has touched the lives of thousands of Americans who have been introduced to it in COTA communications, watched news clips, followed it on a number of social media platforms as well as read a feature story that was published in *Transplant Nation Magazine*.



As he now waits for a life-saving kidney transplant, Kelvin continues to study as a college student, while dreaming and hoping for a healthier future. Miracle Makers, like you, have given Kelvin the chance to dream about a future instead of dwelling on obstacles.

It is always my pleasure to share COTA's stories of hope with supporters, community volunteers,

campaign contributors, transplant professionals and the many COTA family members who regularly introduce new transplant families to us. Even as I write this message, I am confident there are COTA families on the telephone right now with COTA team members who are learning how to deal with current obstacles and are sharing messages of hope and perseverance. It is important to realize that while COTA exists to help children and young adults who need a life-saving transplant, we are not singularly focused on the short-term goal of getting them home following a transplant. We are committed to navigating their financial and emotional challenges for a lifetime.

One major obstacle we face as an organization is the rising cost of health care for our families -- the pandemic has only added to this escalation. Adding even more stress is the fact that many COTA families lose a significant portion of their income when either parent becomes a full-time caregiver at a time when out-of-pocket medical expenses are rising dramatically. This is a specific example of how thousands of COTA Miracle Makers around the country make a tremendous impact on the lives of our families and give them hope. Our Miracle Makers volunteer and host 'face-to-face' and now a growing number of virtual fundraising events. Our Miracle Makers are contributors who give sacrificially to ensure lifetime expenses are met for COTA kids. Miracle Makers are folks who share COTA with new transplant families who desperately need help navigating challenges. No obstacle will deter Miracle Makers from doing everything in their power to support COTA families in need, and to raise the necessary funds to meet out-of-pocket, transplant-related expenses.

COTA'S MISSION

The Children's Organ Transplant Association helps children and young adults who need a life-saving transplant by providing fundraising assistance and family support.

Autumn Jackson

Phoenix, Arizona
Bone Marrow Transplant Recipient
(Brother, Austin, Donor)
Date of Transplant: July 10, 2019
Phoenix Children's Hospital
Phoenix, Arizona



"COTA is a big reason why hope has been restored to our family. Literally overnight we became a single income household suffering under the weight of very big medical bills. The costs associated with Autumn's transplant were astronomical. And they did not stop once the transplant was over. Autumn will need to be medically monitored for life. COTA has been right beside us on this journey through the most challenging and critical part, and we are forever grateful COTA will continue to be with Autumn ... *for a lifetime.*"

— Lavonna Buckhanan, Mother of Autumn

Thank you for being a COTA Miracle Maker!

COTA families across the country are extremely grateful for all who step up to help them avoid financial ruin and allow them to focus their energy squarely on their transplant-needy child, teen or young adult. Because of the pandemic, we cancelled the Miracle Maker Celebration that was scheduled for June 2020. But incredibly, many Miracle Makers (event sponsors and individual supporters) fulfilled their financial pledges, raising nearly \$100,000 without a physical event taking place. What we thought was going to be a tremendous obstacle for COTA's budget was instead an expression of generosity, human compassion and support of COTA's mission. COTA Miracle Makers show us time and again they have really big hearts.

Your actions, your words of encouragement and support, your sacrifices and your gifts allow COTA to continue to work each and every day with transplant

families who are in different stages along their journeys. Each of their situations is full of unique challenges and obstacles; our team of professionals offers advice, counsel and a large dose of hope with each phone call, email or text message. COTA Miracle Makers are an inspiration to all of us who are working with these families each and every day.

As you review our 2019-2020 Impact Report, I think you will likely understand why most COTA families are 'raving fans.' Our families' collective gratitude is not just focused on their own post-transplant kids, teens, young adults and their life-saving organ/tissue donors -- it is much more universal. It is gratitude that is rooted in hope and grows exponentially for a lifetime. Thank you for making it possible for us to offer a lifetime of support to each COTA family 'figuring out how to work through obstacles' and looking for hope.

2020 MIRACLE MAKER CELEBRATION SPONSORS

Presenting Sponsor
Comprehensive Financial Consultants

Miracle Maker Sponsor
Scott & Nikki Ganton
Hern Family Limited Partnership

Awareness Sponsor
Cook Inc.
Tim & Cheri DeBruicker
Flower Mama
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Support Sponsor
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David and Sharon Ormstedt
Tony Paganelli & Dawn Shea
Potts, Hannah & Fischer
Suzanne and Jim Seiders
Larry & Janie Smith
Yolanda Treviño



COTA again receives Charity Navigator's Four-Star Rating

COTA has once again received Charity Navigator's 4-star rating, its highest, in June 2020. Receiving Charity Navigator's coveted 4-star designation this year marks a decade of COTA being recognized as a nonprofit organization that demonstrates strong financial health and a commitment to accountability and transparency.

"Only 2% of the charities we rate have received at least 10 consecutive 4-star evaluations," wrote Michael Thatcher, Charity Navigator's President and CEO. "This is our highest possible rating and signifies the Children's Organ Transplant Association outperforms most other charities in America."

According to Charity Navigator, receiving four out of a possible four stars shows that COTA adheres to best practices and executes its mission in a financially efficient way.



Addilyn Hawks

Severance, Colorado

Liver Transplant Recipient

(Local Nurse, Pam, Addilyn's Living Donor)

Date of Transplant: January 16, 2018

Vivienne Hawks

Severance, Colorado

Transplant Candidate

Children's Hospital Colorado

Aurora, Colorado

"COTA has been part of our family fiber for almost a decade. We are so thankful for this organization and how it helps financially, but also for its great big heart. One of the greatest gifts COTA gives is hope. Our family of six could not today be travelling two transplant journeys, with our home intact and bills paid, without this amazing organization. What a huge relief for us to know that when the girls are grown and begin lives of their own, COTA will still be there for them. COTA funds help with transplant-related expenses now ... *for a lifetime.*"

— Krystin and Aaron Hawks
Parents of Addilyn and Vivienne

MIRACLE MAKERS IN ACTION:

Organizations Offered Assistance to COTA Despite Obstacles

For nearly 35 years, the Children's Organ Transplant Association (COTA) has been able to provide guidance and support to transplant families nationwide due to an extensive network of volunteers who 'step up' to coordinate fundraising and solicit contributions in communities of all sizes. Even during a year that was filled with obstacles and challenges, COTA volunteers connected with community-based businesses to organize virtual fundraisers in honor of COTA kids including 'no bake' bake sales, virtual fun walks/runs, online auctions, online product parties, t-shirt and mask sales, and social media challenges.

According to COTA's President Rick Lofgren, "The spirit of our volunteers across the country continues to amaze and inspire me. I have learned this year that human ingenuity can triumph most obstacles -- no matter how daunting they are. COTA's volunteers and campaign contributors creatively continued to raise funds for transplant-related expenses in spite of the fact many of us were sheltered in."

Using the power of social media, COTA featured several organizations and companies that provided financial support during this complicated year. Recognized with 'Miracle Maker Shout Outs' on COTA's social media platforms, some of these amazingly generous entities included:

The American Legion Family with a nationwide network of Posts, Units, Squadrons and Riders, the Legion continues to help COTA kids in small towns and large cities alike.



Pictured left to right from The American Legion, Department of Florida: Bruce Comer, Department Assistant Adjutant, Rick Johnson, Department Commander and Mike McDaniel, Department Adjutant.

Bee a Blessing that raises funds for COTA in honor of New Jersey kids to help with transplant-related expenses.



Custom Ink and **Bonfire** who have both streamlined the process for COTA team personalized t-shirt, hat and mask fundraisers so COTA Community Campaigns can benefit from merchandise sales. As supporters wear these items, there is the added bonus of raising a community's awareness of transplant families in need.



Hayden's Hope, which has made a life-saving difference for many COTA heart transplant patients by raising more than \$300,000 for transplant-related expenses.



Kohl's Volunteer Program that has provided many 'helping hands' with COTA community fundraisers.



Nora's Home in Houston, Texas, that partners with COTA to make our families' lives in that area more comfortable by providing a 'home away from home.'



Smiles With Love for their LemonAid and Love Boxes fundraisers that have been held in honor of COTA kids.



As Mr. Rogers' mother told him when he was a boy, *"Look for the helpers. You will always find people who are helping."* No truer words have been spoken about COTA's nationwide network of volunteers and supporters.

2019-2020 BY THE NUMBERS

MIRACLE MAKER SPOTLIGHT

255 New Families Served

Transplants 168

\$1.5 million

Medical Expenses Paid

\$2.3 million

Non-Medical Expenses Paid

3,700+ Families Served
Since 1986

More Than \$130 million
raised

Carroll Shelby Foundation

In June 2020, the Carroll Shelby Foundation announced it would donate a total of \$150,000 to the COTAs Hope Fund over a three-year period. The donation will help provide a safety net for families facing the financial and emotional challenges of raising a child who needs a life-saving transplant.

"The Carroll Shelby Foundation and COTA have worked together to support families in need for many years, but this is the first time that we have made such a substantial and long term commitment to the organization," said Aaron Shelby, co-President of the Carroll Shelby Foundation (CSF). "Our shared passion for helping families facing the crisis of an organ transplant is why we doubled our annual donation for 2020 and will do that again each of the next two years."

"Both charities were established to help kids in 'the race for life,' as Carroll Shelby used to say," said Rick Lofgren, President of COTA. "The funds contributed by the Carroll Shelby Foundation to COTA will ensure that no child is denied a second chance at life due to financial issues."

CSF made its first donation to COTA in 2009. Over the past decade, the two organizations have continued to collaborate on programs that benefit the families of transplant patients across the nation.



COTA President, Rick Lofgren
with Carroll Shelby Foundation
co-President, Aaron Shelby

William "Bill" Van Hart Laggren



William "Bill" Van Hart Laggren was born in Philadelphia when horse carriages still parked at the curb. Within days of his second birthday, he succumbed to pneumonia prompting the attending physician to write his death certificate. Bill's father and an uncle removed the blue-tinged toddler from his stuffy room and took him outside into the December sleet where he started breathing again. To keep their little boy healthy, his family relocated to Beachwood, New Jersey, where the pine trees and nearby bay and ocean breezes kept the air clean.

During his high school years, Bill excelled in high school track and field sports. In World War II, 19-year-old Bill got as close as he could to the airplanes he loved by enlisting in the U.S. Navy. He was assigned to the USS Wake Island, which was part of the Pacific fleet and had operations in the Philippines campaign, the invasion of Iwo Jima and the Battle of Okinawa. After the war, Bill returned home to work for the family business, Laggren Awning Company.

In 1949, Bill met Dorothy Jeanne Stone and they were married in 1950. They had one child, Elizabeth Janine. Their life in Toms River included many family yachting excursions. Bill worked long days at Lakehurst Naval Air Station, and still sold and installed awnings. Later he added real estate and yacht sales to his resume. In 1965 he moved his family to Fort Lauderdale, Florida, to sell yachts for Pacemaker, Hatteras and Chris Craft. In a short amount of time, Bill became the company's top salesman nationwide.

After his wife died in September 1991 Bill reconnected with a high school friend, and he and Elizabeth married and traveled the world. Bill updated his estate plan during his final years of life. This included a generous donation to further the mission of COTA while honoring his military service and the three decade partnership between COTA and The American Legion Family. If you would like information about how to make an estate gift to further COTA's mission, please contact Rick Lofgren, COTA's President at rick@cota.org or call him at 800.366.2682.

Statement of Financial Position

June 30, 2020

ASSETS

Cash and cash equivalents	\$ 202,739
Interest receivable	306,000
Pledges and grants receivable, net	477,811
Prepays and other assets	64,031
Investments	39,289,022
Property and equipment, net	443,203
	<u>\$ 40,782,806</u>

LIABILITIES AND NET ASSETS

Liabilities	
Accounts payable and accrued expenses	\$ 156,662
Refundable advance	311,200
Deferred Revenue	18,935
	<u>486,797</u>

Net Assets

Without donor restrictions	2,518,129
Without donor restrictions, board designated	<u>2,513,052</u>
Total without donor restrictions	5,031,181
With donor restrictions	<u>35,264,828</u>
	<u>40,296,009</u>
	<u>\$ 40,782,806</u>

If you would like a copy of our 2019-2020 audited financial statements,
please contact our office at 800.366.2682.

Statement of Activities Year ended June 30, 2020

	Without Donor Restrictions	With Donor Restrictions	Total
REVENUE			
Contributions	\$ 331,908	\$ 5,368,753	\$ 5,700,661
Other fundraising income	98,613	—	98,613
Interest and dividend income (net of investment expenses of \$148,326)	1,571,388	4,299	1,575,687
Realized and unrealized gain on investments	1,578,199	11,132	1,589,331
Lease and other income	126,993	—	126,993
Net assets released from restrictions	<u>3,803,648</u>	<u>(3,803,648)</u>	<u>—</u>
Total revenues	7,510,749	1,580,536	9,091,285
EXPENSES			
Patient campaign program	5,009,736	—	5,009,736
Management and general	734,535	—	734,535
Fundraising	<u>462,080</u>	<u>—</u>	<u>462,080</u>
Total expenses	6,206,351	—	6,206,351
Change in net assets	1,304,398	1,580,536	2,884,934
Net assets, beginning of year	<u>3,726,783</u>	<u>33,684,292</u>	<u>37,411,075</u>
Net assets, end of year	\$ 5,031,181	\$ 35,264,828	\$ 40,296,009

Statement of Functional Expenses Year ended June 30, 2020

	Patient Campaign	Management and General	Fundraising	Total
Salaries and wages	\$ 766,210	\$ 456,779	\$ 250,492	\$ 1,473,481
Payroll taxes	53,363	31,312	17,445	102,120
Employee benefits	185,438	113,861	60,624	359,923
Professional services and fees	33,377	25,364	48,707	107,448
Transplant patient-related expenses	3,803,648	—	—	3,803,648
Travel	42,883	26,126	21,408	90,417
Certification fees	14,166	—	—	14,166
Advertising	35,203	1,924	33,795	70,922
Utilities	4,635	2,764	1,516	8,915
Insurance	10,571	6,302	3,456	20,329
Repairs and maintenance	10,123	10,210	3,309	23,642
Depreciation	26,246	15,647	8,580	50,473
Supplies and office equipment	2,022	18,341	290	20,653
Postage	9,576	5,094	3,678	18,348
Telephone	6,674	9,620	1,857	18,151
Miscellaneous	<u>5,601</u>	<u>11,191</u>	<u>6,923</u>	<u>23,715</u>
	<u>\$ 5,009,736</u>	<u>\$ 734,535</u>	<u>\$ 462,080</u>	<u>\$ 6,206,351</u>

2019-2020 HONOR ROLL OF COTA CONTRIBUTORS

Miracle Makers

COTA is grateful for the generous support of more than 28,000 contributors this past year. These contributors, COTA Miracle Makers, assist the Children's Organ Transplant Association to ensure transplant-needy patients receive support for a lifetime. All contributors are listed at COTA.org.

COTA is also thankful for the ongoing and significant support of contributors to the organization's endowment funds. These funds include the George Talaferro Patient Emergency Endowment (for medical emergencies) and the Operating Endowment (for patient benefit, donor education and registration efforts, and ongoing support of COTA's mission).

To receive a list of those who made gifts between July 1, 2019, and June 30, 2020, please call COTA at 800.366.2682 or email a request to cota@cota.org.

Memorial and Honor Gifts

Numerous individuals were memorialized or honored by family, friends and others who wished to recognize them through a contribution to COTA. All contributors are listed at COTA.org. To receive a list of contributors who made these gifts between July 1, 2019, and June 30, 2020, please call COTA at 800.366.2682 or email a request to cota@cota.org.

If you would like a copy of COTA's audited 2019-2020 financial statements, please call 800.366.2682 or email a request to cota@cota.org.

The Hope Society

The Hope Society was established to recognize forward-thinking individuals who have remembered the Children's Organ Transplant Association in their estate plans.

Jean Berger Estate
Colleen Coyle
Patricia Dudas
Roberta Edrington Estate
Michael Fletcher
T. Michael Ford
Ron and Pat Formella
Herman Gans
Marquita Holzinger
Louise Kaiser Estate
Michael Kelly
Laurent and Pamela Leferre
Jim and Sereta Leiter
Douglas Lippert
Rick and Lisa Lofgren
Anne Monahan Estate
Tony and Dawn Paganelli
David and Judy Rubin[†]
Audrey M. Shanahan
Janice Stafford Estate
Dr. Mirian Taddei[†]
Deborah Sigrid Taylor
Don Wampler, Sr.[†]
Don and Rebecca Wampler
Mike and Kerri Welsh

[†] Deceased

BOARD OF DIRECTORS AND STAFF MEMBERS

June 30, 2020

COTA Board Members

Cassie Franks Amadio *
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Tim DeBruicker *
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Jolene Ellis, MD
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* Denotes President's Advisory Council Member
+ Denotes Non-Voting Ex Officio Board Member

COTA Staff Members

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Susan Gray, Contributions Specialist
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Heather Steele, Administrative Assistant

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Kristy Brown, Chief Development Officer
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Jillian Lawrence, Campaign Specialist
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Christy Boles, Family Services Specialist
Abbey Chambers, Family Services Specialist
Shauna Hockett, Family Services Specialist
Rebecca McCall Martin, Family Services Manager
Sherry Stevens, Family Outreach Specialist



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