

# 2021-2022 IMPACT REPORT

# The COTA Community: IMPACTING TRANSPLANT FAMILIES FOR A LIFETIME

by Rick Lofgren, COTA President and CEO

community is a group of people with a common interest or characteristic who live in a particular area, or a group of people with a professional interest who are scattered throughout a larger society. These words describe the Children's Organ Transplant Association (COTA). Another appropriate word, impact, is defined as having a strong effect on someone or something. COTA's impact was extensive and made a life-saving difference throughout the 2021–2022 fiscal year.

One of my favorite mini-series is *Band of Brothers*, which is based on the book by Stephen Ambrose. In addition to being a powerful portrayal of soldiers fighting to liberate Europe during World War II, the producers' extraordinary efforts to interview many of these heroic soldiers decades after they served to ask about their relationships with fellow veterans is enlightening. Their responses paint a picture of a common sense of purpose ... a common bond ... a common connection. All coming together, all unifying, while fighting for their lives.

I do not believe it is too much of a stretch to say that many COTA families are in the fight of their lives. And those friends and family members who lock arms and encircle them (literally and figuratively) during their children's transplant journeys represent another 'band of brothers' ... what we call **The COTA Community**. A community that was established more than 37 years ago in Central Indiana by one family -- a family who turned to their local community because their toddler son needed a life-saving liver transplant they could not afford.

Throughout this Impact Report, you will learn about **The COTA Community** through the eyes and experience of COTA Families ... COTA Volunteers ... COTA Miracle Makers (financial supporters) ... and COTA Partners.



**Rick Lofgren** 

#### **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.

#### The COTA Community: FAMILIES

recently was asked to record a podcast with a COTA Partner organization called BARE Inc., which stands for Biliary Atresia Research and Education. Biliary atresia is a disease of the liver that typically requires a liver transplant for long-term survival. Many COTA Kids have had, or are waiting for, a liver transplant because of a biliary atresia diagnosis. I joined three COTA parents on the podcast whose lives have been traumatized by this devastating disease. They all spoke from the heart and their words were powerful. COTA Mom Jen Lau (a BARE Co-Founder) said, "Once you hit transplant, you find yourself in survival mode." COTA Dad Robert Anselmo said, "COTA staff members shared their expertise and guidance when I could not even think."

'Survival mode' and 'When I could not even think' are strong representative statements of what a parent experiences when they are, most times without any warning, thrust into transplant territory. COTA Mom Carly Anderson said, "COTA parents are 'dumped' into the transplant world and any new parent who hears this news needs help navigating the process."

In each of these families' transplant journeys, COTA was (and continues to be) a lifeline. To learn more about our newest patients, you can access a list of those families who joined The COTA Community between July 1, 2021, and June 30, 2022, by scanning this QR code.





"Knowing that COTA was there simply made everything easier for my family. My mom did not lose our home and she was able to take care of my younger sister's needs as well throughout the ups and downs of my journey. COTA allowed us to have food at our house and food at the transplant center. COTA ensured we could put gas in the car for the many dialysis appointments I had to be driven to while we waited for my perfect kidney. All of the prescription medications. Even my living donor's hotel room near the transplant center when she traveled to donate her kidney ... all of it. I will continue to depend on COTA's amazing support and guidance for a lifetime."

#### Jazlyn McRavin

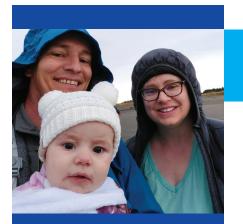
New Bern, North Carolina Date of Transplant: December 21, 2021 Kidney Transplant Recipient *(Best Friend, Eva, Living Donor)* University of North Carolina Hospital

#### The COTA Community: VOLUNTEERS

e at COTA have a unique understanding about the burden and fear that accompanies the shocking words our parents hear, "Your child needs a life-saving transplant to survive." COTA provides relief by shifting the responsibility of fundraising for transplantrelated expenses to a team of volunteers our staff members train and coach. This allows COTA families to let go of many financial fears. And as a 501(c)3 charity, all contributions to COTA are tax deductible to the fullest extent of the law and funds are available for a lifetime of transplant-related expenses.

The three COTA parents I previously quoted had incredible teams of COTA community volunteers in different areas of the country who, in total, raised in excess of \$200,000 for transplant-related expenses. These families felt financial relief at the time of transplant, and COTA continues to help each family today ... 5, 10 and 15 years later. These funds raised are a testament to the families' COTA volunteer teams who planned and implemented events and raised awareness of the need.

Key COTA volunteers receive written materials and trainings provided by COTA staff members. Each COTA community campaign also receives, at no charge, a fundraising website the volunteers personalize and share electronically within their communities of support. This quote from a COTA family illustrates why volunteers are a critical component of **The COTA Community**. "COTA provided tools to help our volunteers plan fundraising events and the COTA staff helped get our volunteers excited about supporting our family. COTA provided our community campaign credibility. With COTA's ongoing help, our volunteers met the fundraising goal."



"COTA was critical to us during a time of great need and great unknowns. COTA created a platform for our support network that was easy to use. COTA funds have been crucial to keeping our family financially whole when we were at our miracle baby's hospital bedside and were unable to work. With COTA, we did not lose everything. COTA gave us a platform where we could share Betty's transplant journey with our networks back home. And when our family and friends could respond and share their words of encouragement and support, we were given a gift we will always treasure."

Lester Stoltz and Andrya Dodson Parents of Betty Date of Transplant: January 19, 2021 Heart Transplant Recipient Seattle Children's Hospital

#### The COTA Community: PARTNERS

OVID-19 necessitated that we reassess our organizational training, fundraising and communications model and institute changes to ensure our families would continue to receive financial assistance and our volunteers could be successful during a time when face-to-face fundraising had to be halted. While our top priority during the first year of the pandemic was ensuring COTA families had our support and guidance, we soon determined this would be a good opportunity to expand our professional network of influence. Transplant professionals have always been COTA's main pathway to transplant patients. But the pandemic gave us the opportunity to expand that pathway in unique and constructive ways. COTA's Partners are those who enhance and expand the multitude of ways we make connections and build bridges on behalf of our families. COTA is proud to partner with organization across the country that help transplant families with various aspects of their journeys.

I have already introduced you to one of COTA's Partners – BARE Inc. COTA Mom Jen Lau is a BARE Co-Founder because several transplant parents saw a need and addressed it. In Jen's case, her son was born with biliary atresia. BARE's mission is to help fund research to find a cure of this disease, which is the most common cause of end-stage liver disease in children. Jen and other COTA parents who have begun working around the nation to help meet the needs of many of our families are a wonderful example of our newest community collaborators.

Another COTA Mom, Melissa McQueen, has been instrumental in starting and growing an organization called Transplant Families, which is another COTA Partner. Melissa co-founded Transplant Families in 2017 as a support network devoted solely to pediatric transplant. This group was an outgrowth of Melissa's desire to help other parents as she was helped during her son, Dylan's, transplant.

Several years ago, COTA Parents Richie and Reagan Reeder decided to create an organization that would help transplant families better manage certain elements of their journeys. The Reeders' organization, Pressing On, is also a COTA Partner. Richie and Reagan walk with families during their time of need to uplift and coach them through tough times. Based on their journey with daughter Myka Joy, they are now passionate about bringing hope to the hurting, providing care in crisis and helping others put plans in place to persevere -- especially those dealing with long-term hospitalizations.



"After being introduced to COTA by a financial coordinator at St. Louis Children's Hospital and calling the 800 number, I instantly knew we would be forging a lasting relationship with this team of caring individuals. I found peace in the fact they would be walking alongside us as we faced so much uncertainty and so many transplant-related expenses. From the very first conversation, I realized everyone at COTA was filled with hope and empathy ... not just for our daughter ... but for our family and they would be by our side for a lifetime."

Christen and Justin Williams Parents of Annabelle Date of Transplant: July 9, 2019 Double Lung Transplant Recipient St. Louis Children's Hospital

#### The COTA Community: MIRACLE MAKERS

he COTA Community is constantly expanding in number and impact thanks to our nationwide network of COTA Miracle Makers, volunteers and supporters who work tirelessly throughout the nation to make sure COTA Kids get a second chance at life. COTA Miracle Makers are individuals and organizations. Since 1986, COTA has grown from a regional organization assisting transplant families in Indiana to a national network of families, volunteers and Miracle Makers in all 50 states. Thanks to our Miracle Makers, more than \$150 million has been raised to assist thousands of families grappling with the many stressors of a life-saving organ or tissue transplant. And also, thanks to our Miracle Makers, COTA's services and guidance are provided at no charge to transplant families. 100% of each contribution made to COTA in honor of patients helps meet transplant-related expenses, and gifts to COTA are tax deductible to the fullest extent of the law.

COTA Miracle Makers' generosity and compassion are indeed a lifeline for our families. Recently an Arizona COTA Mom told me her child was 'ill' at the end of May and went from an emergency room visit to a heart transplant in under 10 days. A COTA Parent in Kansas told me that whenever life 'gets them down' they think back to when they were inpatient and went from "Zero to ECMO" (meaning no problems to being on a heart assist device) waiting for the call that a heart was on its way. That parent told me the memory of those frightening times now brings everything into perspective for their family.

Every COTA family story that is shared with our COTA team is made more challenging due to the unrelenting arrival of bills, frequent clinic and pharmacy trips and additional financial hurdles transplant families face.

Over the past year, the impact of **The COTA Community** was greatly increased thanks to new relationships that were established. Specifically, COTA patients and their families have benefited from new and incredibly generous support from the Scripps Family Impact Fund.



"The Children's Organ Transplant Association (COTA) has given us space to breathe knowing that the heavy financial burden associated with a life-saving transplant has been lifted off our shoulders. Having COTA on our team has been a gamechanger for us. During the time when neither of us could work, our household bills were covered, and we did not lose our home. There are no words to adequately describe the security we as parents feel knowing that thanks to COTA, our son, Daniel, will be able to receive the care he needs for a lifetime."

Mary Beth and Robert George Parents of Daniel New Castle, Pennsylvania Date of Transplant: December 7, 2021 Kidney Transplant Recipient *(University of Pittsburgh Colleague, Molly, Living Donor)* UPMC Children's Hospital of Pittsburgh This investment in our future helped establish new funds for patients with specific transplant needs, an emergent medical need, and those from various geographic areas around the country.

Additionally, this year, several forward-thinking Miracle Makers became part of the **COTA Hope Society** and established estate plans to ensure a strong future for **The COTA Community**. Some supporters have chosen to help fund direct patient assistance, others are funding medication funds, and others are supporting one of COTA's endowed funds.

As our number of transplant families keeps growing, continuing to identify new sources of support and assistance will be critical to COTA's commitment to help alleviate transplant families' financial hurdles and barriers to care. During countless conversations with COTA parents, grandparents and others connected to our families, I have heard repeatedly that if COTA had not been there to step into the gap, the family would have been financially devastated. Since 1986, COTA Miracle Makers, like you, have pledged their support and calmed many fears. COTA has been able to take that support and use it to ease the financial burden of thousands of transplant families throughout the nation.

COTA families in crisis ... COTA families in need ... COTA families in turmoil ... COTA families in need of a lifeline. These are the stories we encounter daily. Each part of The COTA Community shares a bedrock awareness that transplant-related expenses do not end once a transplant is received. We also all know that transplant families need the network of support and avenue of hope that COTA provides. That is why all of us 'band' together to ensure COTA is the Trusted Leader Supporting Families ... *For a Lifetime*.

One of my favorite *Band of Brothers'* quotes resonates with me when reflecting on what **The COTA Community** accomplished during the 2021-2022 fiscal year, "You had to be a little bit awed that you were part of a thing that was so much greater than you."

# **COTA NUMBERS** 2021–2022

# \$6.2 MILLION RAISED FY21-22

## <u>\$3,61</u>9,381

ALLOCATED TO ASSIST 899 FAMILIES WITH TRANSPLANT-RELATED EXPENSES

\$1,483,946 MEDICAL \$2,135,435 NON-MEDICAL

25,813 CONTRIBUTORS

**197** New cota patients

**150** Patients transplanted



#### **COTA FINANCIAL STATEMENTS**

#### Children's Organ Transplant Association, Inc.

#### **Statement of Financial Position**

June 30, 2022

ASSETS			
Cash & cash equivalents	\$ 126,131		
Interest receivable	303,000		
Prepaids & other assets	83,002		
Investments	39,223,144		
Property & equipment, net	<u>385,692</u> \$ 40,120,969		
LIABILITIES AND NET ASSETS			
Liabilities			
Accounts payable & accrued expenses	\$ 199,329		
Deferred revenue	72,117		
Line of credit payable	22,275		
Note payable	31,391		
	325,112		
Net Assets			
Without donor restrictions	(2,111,806)		
Without donor restrictions, board designated	2,513,052		
Total without donor restrictions	401,246		
With donor restrictions	39,394,611		
	39,795,857		
	\$ 40,120,969		

If you would like a copy of our 2021-2022 audited financial statements, please contact our office at 800.366.2682 or email us at COTA@COTA.org.

### **Statement of Activities**

Year ended June 30, 2022	Without Donor Restrictions		With Donor Restrictions		Total	
REVENUE				_		
Contributions	\$	430,408	\$ 5,601,569	)	\$	6,031,977
In-kind contributions		30,750	-	_		30,750
Other fundraising income		159,051	-	_		159,051
Interest and dividend income (net of investment expenses of \$187,379)		1,609,768	7,77	5		1,617,543
Realized and unrealized gain (loss) on investments		(9,146,136)	(93,48	5)		(9,239,621)
Lease and other income		126,693	-	_		126,693
Releases from restrictions		3,619,381	(3,619,38	1)		
Total revenues		(3,170,085)	1,896,478	8		(1,273,607)
EXPENSES						
Patient campaign program		4,939,778	-	_		4,939,778
Management and general		894,542	-	_		894,542
Fundraising		551,793		_		551,793
Total expenses		6,386,113		_		6,386,113
Change in net assets		(9,556,198)	1,896,478	8		(7,659,720)
Net assets, beginning of year		9,957,444	37,498,133	3		47,455,577
Net assets, end of year	\$	401,246	\$ 39,394,61	1	\$	39,795,857

## **Statement of Functional Expenses**

Year ended June 30, 2022	Patient Campaign	Management and General	Fundraising	Total	
Salaries and wages	\$ 831,027	\$ 432,512	\$ 287,991	\$ 1,551,530	
Payroll taxes	58,013	29,831	20,839	108,683	
Employee benefits	188,411	100,383	65,329	354,123	
Professional services and fees	37,986	169,524	42,276	249,786	
Transplant patient-related expenses	3,619,381	_	_	3,619,381	
Travel	30,980	33,800	23,362	88,142	
Certification fees	14,808	_	_	14,808	
Advertising	55,094	324	25,319	80,737	
Utilities	6,058	3,104	2,112	11,274	
Insurance	12,657	6,635	4,374	23,666	
Repairs and maintenance	7,016	9,658	2,429	19,103	
Depreciation	30,506	15,967	10,549	57,022	
Contracted services	_	3,333	_	3,333	
In-kind expenses	30,750	-	_	30,750	
Supplies and office equipment	1,798	24,484	609	26,891	
Postage	6,894	4,345	3,920	15,159	
Telephone	7,801	8,039	1,740	17,580	
Miscellaneous	598	52,603	60,944	114,145	
	\$ 4,939,778	\$ 894,542	\$ 551,793	\$ 6,386,113	

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## VOLUNTEER SPOTLIGHT

OTA community campaign volunteers are vital members of **The COTA Community**. COTA provides resources, tools and support to equip a nationwide network of volunteers to raise funds to assist with transplant-related experience. Their dedication and creativity give hope to COTA families.

Each year, COTA trains hundreds of volunteers who host benefit dinners, organize t-shirt campaigns, plan 5ks and fun runs, promote the COTA campaign on social media, and orchestrate many other creative fundraising activities and events.

Volunteers for the COTA campaign in honor of Evan McGuire raised more than \$100,000 through restaurant percentage events, a Homerun Derby, a golf

tournament and a dinner and silent auction. They also raised money with bracelets and coin canisters placed throughout the community. COTA campaign volunteer Bonnie shared,

"COTA is wonderful, and

everyone has been so encouraging every step of the way in our efforts to raise funds."





## PARTNER Spotlight

OTA partners with organizations across the country to provide support and resources to transplant families. Working together we can address questions families have and assist with the wide array of challenges these families face throughout their transplant journeys. From family support groups to pharmacies to transportation providers and more -- COTA Partners are committed to serving COTA families' needs.

One example of COTA partners in action is the distribution of backpacks to COTA families nationwide, as well as families facing medical crises at UPMC Children's Hospital of Pittsburgh. Thanks to a generous gift from Donna and Ed Stack, COTA and Pressing On (a nonprofit organization started by COTA parents Richie and Regan Reeder) have provided backpacks filled with items to assist families as they navigate their child's medical journey.

Another partner, Walgreens, provides direct billing for eligible transplant patients. Walgreens' transplant-specialized pharmacies provide expert, convenient services to COTA families.

These organizations provide services and support to COTA families that complement the fundraising guidance and family support COTA provides. COTA Partners are a vital part of **The COTA Community**.



#### 2021-2022 Honor Roll of Cota Contributors

#### THE HOPE SOCIETY

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

JoEllen Baldwin Jean Berger Estate Philip Joseph Canciglia + **Colleen Coyle** Tim and Cheri DeBruicker Patricia Dudas Roberta Edrington Estate **Michael Fletcher** T. Michael Ford Ron and Pat Formella Herman Gans Jerry and Anne Gleim Marquita Holzinger Louise Kaiser Estate Michael Kelly Laurent and Pamela Leferre Jim and Sereta Leiter **Douglas Lippert Rick and Lisa Lofgren** Kathleen and Doug McNeely Anne Monahan Estate Tony and Dawn Paganelli Connie and Henry Passaro, Jr. Estate of James Pyle Audrey M. Shanahan Janice Stafford Estate Dr. Mirian Taddei + **Deborah Sigrid Taylor** Don and Rebecca Wampler Estate of Bill Weary Mike and Kerri Welsh + Deceased

#### **MIRACLE MAKERS**

COTA is grateful for the generous support of more than 25,000 contributors this past year. These contributors, COTA Miracle Makers, assist the Children's Organ Transplant Association to ensure transplantneedy 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 Taliaferro 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, 2021, and June 30, 2022, 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, 2021, and June 30, 2022, please call COTA at 800.366.2682 or email a request to COTA@COTA.org.

# MIRACLE Maker Spotlight

ach year COTA works with thousands of Miracle Makers nationwide to raise funds that allow COTA to provide services, guidance and support to transplant families at no cost. From individual contributors to community service organizations to corporations to foundations, Miracle Makers are an essential part of **The COTA Community**.

Hunter CONTRACTING CO. Pay to the Order of Children's Organ Transplant Association \$446,403.42	
Forty-six thousand four hundred three and 42/100 Dollars	and the second
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Hunter Contracting, a long-time COTA Miracle Maker headquartered in Arizona, orchestrates an annual golf outing to raise funds for COTA. In 2022, the Hunter Contracting Golf Outing raised more than \$46,000 to ensure transplant families are never charged a fee for COTA's services and guidance. Hunter Contracting's support of COTA began nearly 30 years ago when an employee's family learned their son would need a life-saving liver transplant. He became a COTA Kid and their ongoing support has provided nearly \$300,000 to assist with transplant-related expenses.

This year COTA welcomed the Jeunesse Kids Foundation as a COTA Miracle Maker when Jeunesse North America selected COTA as a charity partner of their annual corporate gathering. Contributing more than \$104,000, the Jeunesse community made a significant difference for COTA families.



Long-time COTA Miracle Makers, and those new to **The COTA Community**, give hope to transplant families throughout the country. To see a full list of COTA's Miracle Makers, scan this QR code .



#### **BOARD OF DIRECTORS AND STAFF MEMBERS**

June 30, 2022

#### **COTA Board Members**

Cassie Franks Amadio Rob Aukerman, Chair JoEllen Baldwin Zina Berry, DPharm Marc Collins Tim DeBruicker \* Matthew M. Drowne, M.Ed, M.A. Jolene Ellis, MD Patrick F. X. Fitzpatrick, JD, Secretary T. Michael Ford Lisa Fulkerson, CPA, CFO + Scott Ganton James C. Gilroy, III \* Mark Hannah, CPA Nelson Hellwig, MBA Craig Huffman, CPA \* Lauren Isaacs Bob Kayne \* Rick Lofgren, President & CEO + Nick Lynum \* Arlene Macdonald, PhD \* Rebecca Martinez Reid, PhD \* Chella McClead Tedrow, MSW \* Kathleen T. McNeely, Vice Chair Julie Morgan David Ormstedt, JD F. Anthony Paganelli, JD \* Sarah Parks ' Scott Price, CPA, Treasurer Suzanne Seiders, BSN Brent Starks \* Susy Timmons MG Clif Tooley \* Yolanda Trevino, PhD Nancy Vazquez-Soto Dr. William Winslade \*

- \* Denotes President's Advisory Council Member
  + Denotes Non-Voting Ex Officio
- Denotes Non-Voting Ex Officio Board Member

#### **COTA Staff Members**

Administrative Staff Randi Bradley, Contributions Specialist Teresa Cracraft, Accounts Payable Specialist Lisa Fulkerson, Vice President and Chief Financial Officer Susan Gray, Contributions Specialist Rick Lofgren, President and Chief Executive Officer

Development, Marketing and Communications Staff Kristy Brown, Chief Development Officer Terry Egan, Director of Development Jordan Lewis, Director of Technology and Digital Media Kristin Martindale, Strategic Development Manager Joelene Nielsen, Grant Writer Kim Carter Parker, Director of Communications Danielle Rabideau, Campaigns and Communication Manager Lauren Scott, Marketing Manager Sherry Stevens, Family Outreach Specialist Lauren Wilmer, Campaigns and Outreach Manager

#### Family Services Staff

Emma Bentson, Family Services Specialist Christy Boles, Family Services Specialist Abbey Chambers, Family Services Specialist Shauna Hockett, Family Services Specialist Rebecca McCall Martin, Family Services Manager

If your family, or a family you know, is on a transplant journey and is not currently working with COTA, we would love to help. Please use this QR Code to learn more about how transplant families can "Get Started" with COTA today.





2501 West COTA Drive, Bloomington, IN 47403 800.366.2682 • COTA@COTA.org COTA.org



