



Children's Organ
Transplant Association®

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



2022-2023
IMPACT REPORT

Impacting Transplant Families Today ... and for a Lifetime

by Rick Lofgren, COTA President and CEO



Rick Lofgren

COTA 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.

Impact. Looking back over our past fiscal year, the word 'impact' succinctly describes the positive difference we have made for hundreds of transplant families. 'Impact' also aptly illustrates what we have achieved because of the thousands of contributors who have financially supported our mission. As COTA continues to grow in scope and outreach, because of generous gifts of treasure and of time, we are able to focus on families who are taking the first steps of their children's transplant journeys ... as well as those families whose transplant journeys started five, 10 or in some cases, more than two decades ago.

When used as a noun, 'impact' is defined as forceful contact or a significant effect. Every COTA contributor's gift makes an impact on an individual COTA family or on the COTA Community as a whole. Every COTA volunteer's commitment of time makes an impact on the transplant family they have agreed to help until a goal is reached. Every transplant professional who talks to a new transplant family about how COTA could possibly ease some stressors makes an impact. And every COTA family who encounters a transplant family in crisis and suggests they reach out and talk to us makes an impact.

Recently, I was talking to a new COTA parent about her infant daughter who was awaiting a life-saving heart

transplant. This child was just a few weeks old, and she had not left the hospital nor did the mother know when that might be possible. I could hear the fear and anguish in this mom's voice as we spoke. After she detailed the challenges she had faced with her daughter thus far, I told her about a family I had met in Texas the week before. That young man had recently celebrated his 22nd transplant anniversary (and 23rd birthday), and was doing incredibly well. As we continued talking, I could hear a sense of hope return with each word this new transplant mom spoke. Hearing the Texas COTA family's hope-filled story made an impact; she seemed to have a glimmer of hope that was not there before. A desperately ill baby who underwent a life-saving transplant more than two decades ago and today is a thriving young adult was a COTA story I could share thanks to our volunteers, our contributors, our transplant professional partners, and our COTA families who are thriving and are thankful.

Hope is a powerful message, and it's something that can positively impact and sustain us in our most challenging times. As I think about the 25 years I have been with COTA, I immediately recall numerous family stories I regularly share with parents who I know desperately need a glimpse of hope. Families waiting for their child's transplant to occur. Families in the

hospital following their teen's transplant praying for a smooth transition home. Families many months and even years after their child's transplant who have had a smooth transition, or others who have experienced 'bumps' in their journeys.

We stand firm in our commitment to provide a lifetime of support to transplant families. A parent who is sitting at her baby's hospital bedside waiting to hear the perfect heart has been found needs to hear about COTA patients like Weylin (see pages 6-7) who is 22 years post-transplant. Or Kevin, whose kidney transplant (from his dad) occurred more than two decades ago. Or COTA patients like Ben, who is more than 30 years post-transplant and recently welcomed his first child with his wife. These COTA stories are filled with hope and make a positive impact when shared with a new COTA transplant parent, sitting at a child's hospital bedside, intensely focused on today but finding comfort in contemplating a lifetime.

Today, looking back over the recent year completed, I am incredibly grateful for a number of our largest gifts of support in our history which will definitely impact COTA families nationwide. First, as long-time COTA supporters, the trustees of the Texas-based JLH Foundation approved a three-year grant of \$768,000 to help our kids and families from the Longhorn State. COTA families will

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"Everything with Cayce's heart transplant happened very quickly. There was so much to worry about when we first heard the devastating diagnosis. We simply could not focus on the financial piece of a life-saving transplant, in terms of the immediate impact on our family, and on him later in life. Being introduced to COTA removed a huge burden during one of the most stressful times in our lives. COTA's expertise and guidance helped our family and friends to orchestrate and promote fundraising for transplant-related expenses. COTA gave us, and continues to give us, peace of mind."

— Melissa and Brian Cobb
Parents of Cayce



"We do not know what we would have done without COTA travelling this journey with us. COTA gave us hope we would be able to continue on after Savanna's transplant and not be trapped in years of medical debt. Dedicating 100% of your time and energy to a sick child is extremely hard, and figuring out how to pay for it adds so much weight and stress. COTA absolutely helped us find relief and breathe easier so we could focus on what was most important -- our daughter."

— Nicole and Wade Wrobel
Parents of Savanna

Continued from page 3

also benefit tremendously thanks to a \$500,000 grant from an anonymous foundation to help patients who require a pancreas, TPIAT (islet cell), or another pancreas-related transplant. And long-time COTA supporters at Hunter Contracting (see page 11), hosted the company's 33rd Annual Golf Outing in April that raised a record \$61,000 for our Arizona kids. Additionally, generous grants from Healthcare Initiatives, Inc., the FORVIS Foundation, the Carol Stuhr Family Foundation, The John W. Anderson Foundation and Walgreens totaled nearly \$200,000 to directly benefit COTA Kids and their families in a variety of ways. Each one of these gifts has made, or will make, a significant impact on COTA families' transplant journeys.

I am also thrilled to report that planned or estate gifts will make a tremendous impact ensuring that COTA's lifetime of support commitment will continue to give our families peace of mind for many years to come. In fact, over the past five years more than \$2 million has been generously provided to ensure we remain mission-focused and mission-driven.

As you review our Impact Report, know that the stories you read are not simply stories — they are patients and families who are impacted by COTA Miracle Makers every day. Thank you for joining us in providing these families with hope, and a brighter tomorrow!



“Before Bianca’s journey began, we had no idea who COTA was, or what they did ... nor did we know anything about the financial hardship associated with a life-saving transplant. Even though we had just received devastating news, we felt a sense of comfort speaking with COTA’s President. He specifically talked about COTA’s commitment to us and to Bianca. The idea of working with a team of experienced professionals who had travelled the path we were about to walk with so many families gave us much-needed peace of mind while facing a future of unknowns. Ultimately, COTA allowed us to breathe easier, and we are forever grateful.”

— Nick and Laura Gozola
Parents of Bianca

NEARLY \$7 MILLION RAISED FY22-23

229 NEW COTA PATIENTS	NEARLY 30,000 CONTRIBUTORS	170 PATIENTS TRANSPLANTED
\$3,619,381 ALLOCATED TO ASSIST 899 FAMILIES WITH TRANSPLANT-RELATED EXPENSES		
\$1,483,946 MEDICAL / \$2,135,435 NON-MEDICAL		



2023 Miracle Maker Legacy Gift

LEONARD PAUL KLEINMAN, PhD



Dr. Leonard Paul Kleinman



Dr. Leonard Paul Kleinman was born on July 25, 1933, in the middle of America's Great Depression. His childhood was spent in New York City and then Los Angeles as his family navigated the challenges of those difficult years. His parents instilled in him the necessity of pursuing higher education to ensure a financially strong pathway through times of future economic recessions. Len graduated from the University of California, Los Angeles in 1955. He completed the Hughes Masters Program at UCLA in 1956, which required working 26 hours each week for Hughes Aircraft; this was the catalyst for his interest in solid state physics. In September 1956, he continued his studies at the University of California, Berkley.

Following graduation from Berkley, Len and his wife, Faye, relocated to Chicago but only stayed 16 months, when the University of Texas at Austin made him an offer he could not refuse. The Kleinmans raised their children, Julie and Paul, in Austin and Dr. Kleinman made an indelible mark on UT's Department of Physics through his teaching and research. Paul remembers those early years, "Dad was definitely a kid of the Great Depression. We were raised in a middle-class neighborhood and always had what we needed, but not more than that. I remember when the dishwasher broke, he told us to wash the dishes in the sink."

It was not until Paul faced a life-or-death situation with his newborn

son when he realized firsthand how his frugal upbringing had allowed Dr. Kleinman to save and invest a significant amount of his earnings.

Paul's son and Dr. Kleinman's grandson, Weylin, was born in July 2000. Prenatal testing had shown possible signs of trouble, but it was not until his birth when he was diagnosed with a rare condition. At three days old a surgery was performed, which unexpectedly caused Weylin to lose function in his small bowel. Due to a side effect of having no small bowel, the baby's lipid production was interrupted causing his liver to fail. Throughout those chaotic first months, Weylin was listed at several transplant centers for a rare transplant that would hopefully save his life.

When Weylin was three months old, a transplant social worker told the family about COTA. "We were young and there were only four medical centers in the country that performed this transplant on infants. We had no idea what our insurance would cover or where the transplant would happen. Fundraising seemed necessary; however, we had no idea how to do it ... but COTA did." In 2000, Weylin became a COTA Kid. Austin-area neighbors and friends utilized COTA's guidance to plan fundraisers for transplant-related expenses.

The family's first transplant-related financial hurdle came when they received 'the call' in early June 2001 that organs were available for Weylin. The call came from UPMC Children's

Hospital of Pittsburgh, nearly 1,500 miles from the family's home in Austin ... and the family was given very little time to get there. Their only choice was a \$10,000 private jet. Paul knew this would be a transplant-related expense for which COTA funds could be used, but they had to pay the money immediately. It was Dr. Kleinman's first experience with COTA. Paul explained that if he paid the \$10,000 bill, COTA would reimburse this transplant-related expense. Dr. Kleinman readily agreed. The family boarded the jet after midnight and by 8:00 am, Weylin was rolled into the transplant center. On June 8, 2001, Weylin received his liver and small bowel transplant ... and a second chance at life.

Today, Weylin is in his early 20s and Paul says the transplant has been a success. For the most part, Weylin has been able to lead a normal life and is stepping into adulthood. For the two decades since his transplant, Paul and Weylin made numerous trips to Pittsburgh for checkups and tests, but eventually found a specialist in Austin who took over his care.

Dr. Kleinman retired from the University of Texas' Physics Department in 2014. He enjoyed many years with his grandchildren. Paul describes a deep love his dad had for Weylin. "Once we moved Dad to a nursing home, Weylin visited him more frequently. It was apparent my dad cared deeply for his family, was driven to do what was right and was determined to help organizations that cared for others."

Dr. Kleinman passed away at the age of 89 on October 25, 2022.

Dr. Kleinman and Paul had conversations about his estate and how he hoped the investments of his lifetime would be used to make life better for others. Paul learned his dad had 10 charities he chose to include in his giving plan. When Paul saw COTA on that list, he smiled. "Dad never forgot how COTA stood by its commitment to help families during challenging times. And he never forgot the \$10,000 jet payment that was necessary to save Weylin's life. COTA's mission held a special place in Dad's heart."

So much so that when Dr. Kleinman finalized his estate plan, he provided 20% of his estate portfolio to COTA.

Dr. Leonard Paul Kleinman, who built his successful career as a physicist focused on solid state theory, bequeathed COTA the organization's largest gift to date. In honor of his forethought and generosity, COTA has named its planned giving program in Dr. Kleinman's memory, and it is now the **Leonard Kleinman Legacy Society**.

If you would like information about how to make an impact like Dr. Kleinman through a bequest or other estate planning option, please contact Rick Lofgren, COTA President, at 800.366.2682.

2022-2023

Honor Roll of COTA Contributors

The Leonard Kleinman Legacy Society

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

JoEllen and Tim† 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
Dr. Leonard Kleinman†
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
David and Judy Rubin Estate
Audrey M. Shanahan†
Janice Stafford Estate
Dr. Mirian Taddei†
Deborah Sigrid Taylor
Don Wampler, Sr.†
Don and Rebecca Wampler
Estate of Bill Weary†
Mike and Kerri Welsh

† Deceased

Children's Organ Transplant Association, Inc.

Statement of Financial Position

June 30, 2023

ASSETS

Cash & cash equivalents	\$ 342,010
Interest receivable	326,000
Pledges and grants received	525,890
Prepays and other assets	60,294
Investments	40,467,479
Property and equipment, net	496,428
	<u>\$ 42,218,101</u>

LIABILITIES AND NET ASSETS

Liabilities

Accounts payable and accrued expenses	\$ 151,593
Deferred revenue	71,317
Note payable	24,775
	<u>247,685</u>

Net Assets

Without donor restrictions	(1,573,469)
Without donor restrictions, board designated	2,513,052
Total without donor restrictions	939,583
With donor restrictions	41,030,833
	<u>41,970,416</u>
	<u>\$ 42,218,101</u>

If you would like a copy of our audited 2022-2023 financial statements, please call 800.366.2682 or email a request to cota@cota.org.

Statement of Activities

Year ended June 30, 2023

	Without Donor Restrictions	With Donor Restrictions	Total
REVENUE			
Contributions	\$ 1,367,735	\$ 5,391,515	\$ 6,759,250
Other fundraising income	198,592	–	198,592
Interest and dividend income (net of investment expenses of \$187,379)	1,741,318	9,216	1,750,534
Realized and unrealized gain (loss) on investments	(120,088)	97,809	(22,279)
Lease and other income	126,821	–	126,821
Releases from restrictions	3,862,318	(3,862,318)	–
Total revenues	<u>7,176,696</u>	<u>1,636,222</u>	<u>8,812,918</u>
EXPENSES			
Patient campaign program	5,252,322	–	5,252,322
Management and general	807,467	–	807,467
Fundraising	578,570	–	578,570
Total expenses	<u>6,638,359</u>	<u>–</u>	<u>6,638,359</u>
<i>Change in net assets</i>	538,337	1,636,222	2,174,559
<i>Net assets, beginning of year</i>	<u>401,246</u>	<u>39,394,611</u>	<u>39,795,857</u>
<i>Net assets, end of year</i>	<u>\$ 939,583</u>	<u>\$ 41,030,833</u>	<u>\$ 41,970,416</u>

Statement of Functional Expenses

Year ended June 30, 2023

	Patient Campaign	Management and General	Fundraising	Total
Salaries and wages	\$ 861,196	\$ 391,453	\$ 313,162	\$ 1,565,811
Payroll taxes	59,739	27,474	21,723	108,936
Employee benefits	197,722	91,974	71,899	361,595
Professional services and fees	39,813	149,489	37,683	226,985
Transplant patient-related expenses	3,862,318	–	–	3,862,318
Travel	69,340	23,363	22,724	115,427
Certification fees	20,372	–	–	20,372
Advertising	60,948	2,363	20,829	84,140
Utilities	4,441	2,019	1,615	8,075
Insurance	13,987	6,358	5,086	25,431
Repairs and maintenance	10,085	9,136	3,667	22,888
Depreciation	26,366	11,984	9,588	47,938
Contracted services	–	48,092	–	48,092
Supplies and office equipment	5,090	22,294	562	27,946
Postage	12,249	4,143	5,962	22,354
Telephone	8,512	6,094	2,077	16,683
Miscellaneous	144	11,231	61,993	73,368
	<u>\$ 5,252,322</u>	<u>\$ 807,467</u>	<u>\$ 578,570</u>	<u>\$ 6,638,359</u>

If you would like a copy of our audited 2022-2023 financial statements, please call 800.366.2682 or email a request to cota@cota.org.

THE AMERICAN LEGION

For more than 30 years, The American Legion Family which includes the members of The American Legion, The American Legion Auxiliary, The Sons of the American Legion and The American Legion Riders have raised more than \$1.7 million to help COTA kids across the nation. Exemplifying their commitment to their communities, The American Legion Family helps ensure that no child, teen or young adult is denied a life-saving transplant due to a financial barrier.

At local, state and national meetings, we share information with members of The American Legion Family about COTA's assistance to families facing transplant journeys in their



communities. We are honored that the Commander of the SAL Detachment of Indiana and the Commander of The American Legion Department of Florida have selected COTA as their projects for this year. In addition, COTA looks forward to being the Commander's Project for The American Legion Department of New Jersey and The American Legion Department of Florida next year. The advocacy and support of these generous Miracle Makers will have a direct impact on COTA families in their states.

PATIENT EXPENSE PORTAL

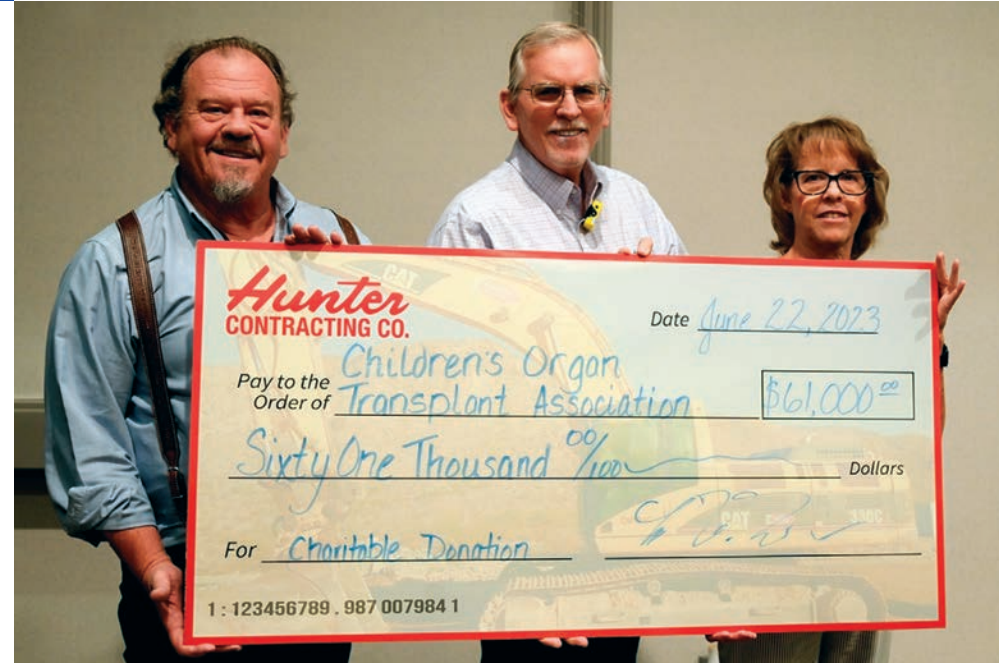
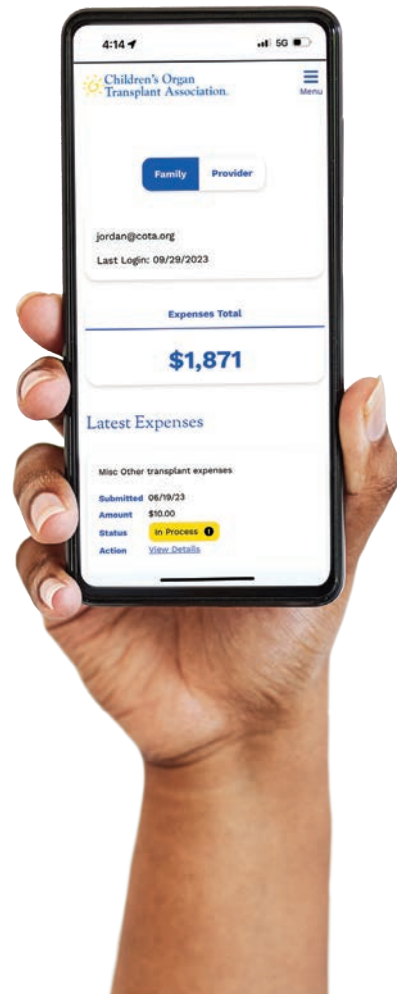
COTA strives to provide outstanding assistance to transplant families in many ways. As technology changes and new opportunities arise, we aim to ensure we are offering the highest level of service. We were pleased to launch a redesigned website that includes a new patient portal for the submission of transplant-related expenses. While COTA has accepted online submissions for several years, this new portal provides an enhanced experience for our nationwide network of families.

The new portal makes the submission process faster and more efficient, allowing families to submit using their mobile devices if they choose. A new dashboard lets families

see recent submissions as well as view and update patient and physician information. We anticipate this new feature will make working with COTA even easier for our families.

Technology upgrades come at quite a cost. We are grateful to Miracle Makers who helped us launch the new portal, including Healthcare Initiatives, Inc. Their support of our mission to assist transplant families helps ensure some of the stress of the transplant journey is lightened.

To learn about new COTA families, scan this QR code or visit cota.org/impact-report/patient-list.



HUNTER CONTRACTING CO.

COTA Miracle Makers help us provide assistance to transplant families through their generous gifts and selfless volunteer hours. Each year, new individuals, companies and foundations become Miracle Makers for the first time. But there are many who have supported COTA's efforts for decades.

For more than 30 years Hunter Contracting Co. has given hope to COTA families in Arizona. This year's 33rd Annual Charity Golf Tournament, which benefited COTA's Arizona Kids Fund, was a record-breaking event.

Proceeds of \$61,000 help ensure transplant families are never charged a fee for COTA's services and guidance.

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 or visit cota.org/impact-report/contributor-list.



MIRACLE MAKERS

COTA is grateful for the generous support of nearly 30,000 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 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, 2022, and June 30, 2023, please call COTA at 800.366.2682 or email a request to cota@cota.org or scan the QR code on this page.

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, 2022, and June 30, 2023, please call COTA at 800.366.2682 or email a request to cota@cota.org.

BOARD OF DIRECTORS AND STAFF MEMBERS

June 30, 2023

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+ Denotes Non-Voting Ex Officio Board Member

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Abbey Holbrook, 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

