



# THRIVE

## 2021 Impact Report



American Cleft Palate-  
Craniofacial Association





“ Together, we have accomplished so much in 2021. Thank YOU for being a part of ACPA, for the work you choose to do, and your generosity and support in helping us lead interdisciplinary cleft and craniofacial care so patients and families thrive.”

**Adam M. Levy, CAE**  
*ACPA Executive Director*

# About ACPA

The American Cleft Palate-Craniofacial Association (ACPA) is a 501(c)(3) nonprofit medical association representing patients and families with cleft and craniofacial conditions, and the professionals who provide their care. ACPA is dedicated to raising awareness of cleft lip and palate and the challenges of all individuals with facial differences.

Since 1943, ACPA has provided education, support, research and interdisciplinary team care to ensure the best possible outcomes for patients—enabling individuals to live complete and fulfilling lives.

ACPA members represent 34 medical disciplines, including plastic surgery, oral and maxillofacial surgery, orthodontics, otolaryngology (ENT), nursing, speech language pathology and more.

**MORE THAN 2,100 ACPA MEMBERS**  
work with patients and conduct research in all  
**50 states and 56 countries around the world.**

Argentina	Egypt	Kuwait	Slovakia
Australia	El Salvador	Mexico	Slovenia
Austria	Estonia	Nepal	South Africa
Bangladesh	Ethiopia	Netherlands	Spain
Belgium	France	New Zealand	Sri Lanka
Brazil	Germany	Nigeria	Sweden
Canada	Ghana	Norway	Switzerland
Chile	Greece	Oman	Taiwan
China	Hong Kong	Peru	Thailand
Colombia	India	Poland	Turkey
Costa Rica	Ireland	Russia	United Arab Emirates
Cyprus	Israel	Saudi Arabia	United Kingdom
Czechia	Italy	Serbia	United States
Denmark	Japan	Singapore	Uzbekistan



ACPA Members

# Numbers To Celebrate



## PATIENTS SERVED

The 198 ACPA Approved Teams in the U.S. and Canada provide care to patients affected by cleft and craniofacial conditions. Each year an estimated 6,800 babies are born with a cleft lip and/or palate in the U.S., making it the second most common birth defect.



## COLLEGE SCHOLARSHIPS GRANTED

ACPA Family Services awards college scholarships to outstanding students born with cleft or craniofacial conditions. In 2021, ACPA was honored to provide scholarships to four well-deserving students.



## ONLINE LEARNING PARTICIPANTS

ACPA provides access to online learning for cleft and craniofacial care providers worldwide. ACPA's webinars received more than 3,104 views in 2021, with select webinars offering professional continuing education credits.

# Top 3 Most Read Articles

## FROM THE CLEFT PALATE-CRANIOFACIAL JOURNAL

- 10,091** pageviews **ACPA's 77th Annual Meeting Abstracts**  
Volume 57 Issue 4\_suppl; 10.1177/1055665620901804  
<https://journals.sagepub.com/doi/full/10.1177/1055665620901804>
- 4,476** pageviews **Parameters for Evaluation and Treatment of Patients With Cleft Lip/Palate or Other Craniofacial Differences**  
Volume 55 Issue 1; 10.1177/1055665617739564, <https://journals.sagepub.com/doi/full/10.1177/1055665617739564>
- 2,235** pageviews **"All Eyes on Me": A Qualitative Study of Parent and Patient Experiences of Multidisciplinary Care in Craniofacial Conditions**  
Volume 56 Issue 9; 10.1177/1055665619842730, Mehri Agai, Kristin Billaud Feragen, Anita Myhre, Ingrid Dundas  
<https://journals.sagepub.com/doi/full/10.1177/1055665619842730>

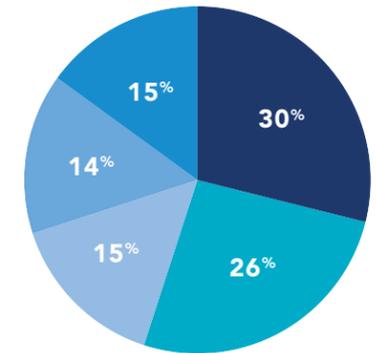
# Top 5 Most Read Blog Posts

- 521** pageviews **2022 Professional Scholarships**  
<https://acpa-cpf.org/2021/09/01/2022-association-awards-and-professional-scholarships/>
- 455** pageviews **Laura Livingood, Care Club Member Testimonial**  
<https://acpa-cpf.org/2021/04/29/laura-livingood-care-club-member-testimonial/>
- 443** pageviews **Study Examines How Sociodemographic Factors May Affect Success of NAM Treatment**  
<https://acpa-cpf.org/2021/03/10/study-examines-how-sociodemographic-factors-may-affect-success-of-nam-treatment/>
- 318** pageviews **Study Explores Facilitators, Barriers to Standardized Outcome Measurement for Cleft Care**  
<https://acpa-cpf.org/2021/01/22/study-explores-facilitators-barriers-to-standardized-outcome-measurement-for-cleft-care/>
- 246** pageviews **ACPA's 78th Annual Meeting Attended by More Than 1000 Globally**  
<https://acpa-cpf.org/2021/05/04/acpas-78th-annual-meeting-attended-by-more-than-1000-globally/>

# Financials

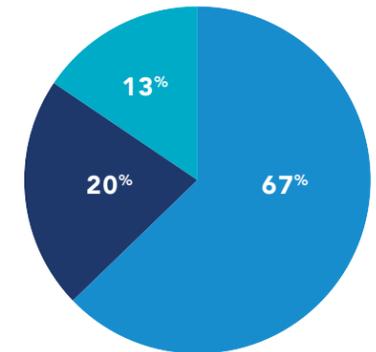
## Revenue

■ Professional Dues.....	\$388,614
■ Annual Meeting Income*.....	\$314,373
■ Donations** .....	\$192,656
■ TEAMS, Journal, and Other Sales. . .	\$182,024
■ Other Income*** .....	\$197,794
<b>TOTAL REVENUE . . . . .</b>	<b>\$1,275,461</b>



## Expenses

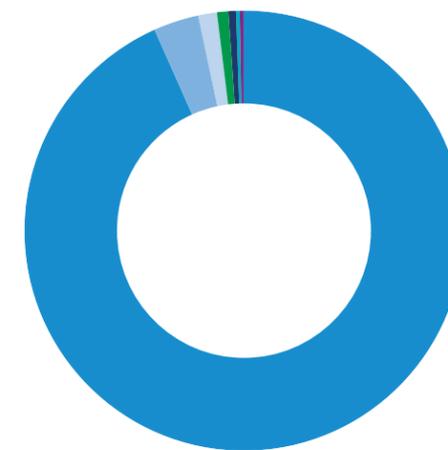
■ Program Services .....	\$735,839
■ Management and General .....	\$215,788
■ Development .....	\$141,588
<b>TOTAL EXPENSES . . . . .</b>	<b>\$1,093,215</b>



\* Includes Sponsors and Exhibits

\*\* Excludes bequests

\*\*\*Excludes grant received for restricted purposes in 2022, and government stimulus.



## Donations Received by Fund

- Unrestricted . . . . . \$184,236
- Randall/LaRossa College Scholarship Fund \$4,250
- Subtelny Junior Investigator Award . . . . . \$1,700
- Mazaheri Young Professional Scholarship. . . \$1,000
- Family Services Endowment Fund . . . . . \$720
- David P. Kuehn Speech Scholarship . . . . . \$500
- Samuel Berkowitz Long Term Study Award . \$250

Excludes bequests and grant received for restricted purposes in 2022.

# ACPA at a Glance

A SNAPSHOT OF MEMBERSHIP ENGAGEMENT IN 2021

**2,118 Members**  
(AS OF 12/31/2021)

## About Our Members

- **1,483** Active Members
- **304** Lifetime Members
- **218** International Members
- **91** Student Members
- **12** Retired Members
- **9** Associate Members
- **1** Transitional Members



**187**  
members contributed  
to the online community

**260 articles**  
published in *The Cleft Palate-  
Craniofacial Journal*

**1,002**  
**ATTENDEES**

at ACPA's 2021  
virtual Annual  
Meeting from  
40 countries

### TOP FIVE BENEFITS ACCORDING TO OUR MEMBERS

- 1) Subscription to *The Cleft Palate-Craniofacial Journal*
- 2) Reduced Registration Rate for ACPA's Annual Meeting
- 3) Reduced Registration Rate for ACPA Online Learning (webinars)
- 4) Access to the ACPA Online Community
- 5) Interest Group Membership

**194 volunteers** SUPPORTED ACPA'S MISSION

by serving on the board and committees, reviewing journal articles, evaluating junior investigators, chairing sessions at ACPA's Annual Meeting and more.



# New Strategic Plan

The ACPA Board of Directors and National Office Team collaborated in November to create a new strategic plan, and to craft updated vision and mission statements to define, inspire, and empower us to grow and evolve.

## OUR VISION

Leading interdisciplinary cleft and craniofacial care so patients and families thrive.

## OUR MISSION

We empower and support cleft and craniofacial healthcare professionals and the patients they serve through research, education, and advocacy. We promote team care and professional collaboration to ensure the highest quality resources are available to all with craniofacial differences throughout their healthcare journey.

## Communication and advocacy

- Set the standard and be the source to promote team care as the best model for cleft-craniofacial care.
- Communicate the importance of access to and value of team care to legislators, the public, providers and affected individuals.

## Drive excellence and innovation in education

- We will be leaders in the dissemination of evidence-based education for patients, families, and professionals.
- We will cultivate innovative multimodal educational offerings.

## Research advancement, engagement, and communication

- Foster development and promote involvement in innovative research from all stakeholders.
- Promote the advancement of science via the dissemination and discussion of basic science, clinical, and outcomes research through a variety of platforms.

## Collaboration, networking, and connections

- Encourage collaborations that enhance our ability to reach families and providers, locally, nationally and internationally to enable an environment that brings together families and providers across specialties and experiences.

## Embrace and advance diversity, equity, and inclusion

- Promote diversity and respect; identify and dismantle barriers to involvement; and create a welcoming and inclusive environment so that all ACPA members, employees, and families can thrive.

## ADVOCACY: ENSURING LASTING SMILES ACT

In 2021, ACPA worked to spread awareness and encourage support of the Ensuring Lasting Smiles Act (ELSA). This bill would ensure that any procedure related to restoring function or appearance due to a birth defect would be covered by insurance from birth until function is restored. ELSA would alleviate the financial hardship for people with cleft and craniofacial anomalies and ensure they have continued support for medical and dental needs beyond childhood. As ACPA enters 2022 and embarks on the new three-year strategic plan, additional advocacy efforts will be supported.

# Professional Award Recipients

ACPA is proud to present awards that recognize dedication to research, care, and the community. ACPA supports patients and families by equipping care providers with essential professional resources.

- **THE CPCJ PEER REVIEWER OF THE YEAR AWARD** is given each year to the peer reviewer recommended and selected by the Editorial Board who best exemplifies the core values and missions of *The Cleft Palate-Craniofacial Journal*.
- **SAMUEL BERKOWITZ, DDS, MS LONG-TERM OUTCOMES STUDY AWARD** is made annually to the primary author of the article judged to be the best long-term outcomes study published in *The Cleft Palate-Craniofacial Journal*. The author may be from any discipline represented in the American Cleft Palate-Craniofacial Association, and the article may cover any cleft/craniofacial subject area.
- **STEWART ROOD CPCJ SECTION EDITOR OF THE YEAR AWARD** is given each year to a section editor of *The Cleft Palate-Craniofacial Journal* in recognition of their significant and substantive contributions to the journal.



**Kristin Billaud Feragen, PhD**  
CPCJ Peer Reviewer of the Year Award



**Hilary McCrary, MD, MPH**  
Samuel Berkowitz, DDS, MS Long-Term Outcomes Study Award



**Alexis L. Johns, PhD, ABPP**  
Stewart Rood CPCJ Section Editor of the Year Award



**Dennis M. Ruscello, PhD**  
CPCJ Peer Reviewer of the Year Award

# College Scholarship Recipients

ACPA awards college scholarships annually to outstanding students born with cleft or cranio-facial conditions. Award recipients are selected by the ACPA Family Services Committee based on past academic performance, evidence of leadership and/or community and school involvement, indications of future academic success and the applicant essay. ACPA is pleased to announce the winners of the 2021 Randall/LaRossa College Scholarships.



## **GRACE DAVENPORT Honors Award, Randall/LaRossa College Scholarship**

With aid from the Randall/LaRossa College Scholarship, I intend on completing my BS in biology at James Madison University. After earning a graduate degree, I plan to work abroad as a prenatal genetic counselor in underprivileged cleft communities. Who better to conduct cleft genetic screening than a patient with cleft? Growing up, I experienced the social, physical and mental challenges associated with a cleft. When a mom's unborn baby is diagnosed with a similar difference, I can share my unique perspective. Awarding me this Scholarship is not only an investment in my education, but an investment in the future of cleft patient care.



## **ADDISON POOL General Award, Randall/LaRossa College Scholarship**

My early years were filled with struggles and unknowns as I overcame many surgeries, learned to hear with a unique hearing device, and spent many days in the hospital. As a toddler, I created my own sign language to communicate with my family before I was physically able to speak. Despite early health complications, I began to excel in school, keeping up with or surpassing my peers, and I have not looked back. Though I could have let these surgeries and medical complications hinder my ability to live a normal life, my medical struggles have shaped me into the strong person I am today. I'm attending Texas A&M University to study allied health.

I hope to get accepted into Texas A&M's nursing school and pursue neonatal nursing. I am thankful for the scholarship that I have received from ACPA and it will certainly go to good use as I continue on my path to becoming a healthcare provider.



## **AMANDA DAVID General Award, Randall/LaRossa College Scholarship**

I'll be starting my first term at the University of Texas at Dallas this fall. I plan on majoring in speech-language pathology and hope to work in the health center on campus. I'm excited to pursue a career that promotes confidence in people with communication disorders and spreads the message that all voices and opinions should be equally respected. I'm very grateful to the American Cleft Palate-Craniofacial Association for granting me this scholarship. Knowing that there are organizations dedicated to supporting and spreading awareness about people like me makes me feel empowered rather than alone.



## **ARIELLE PEREZ Vocational Award, Randall/LaRossa College Scholarship**

Being born with a cleft palate and as well as a genetic condition isn't an ideal look for a child, but later on I discovered that was my true beauty. It was a difficult journey to go through 22 surgeries. But many doctors' visits later, I pulled through and I'm stronger than ever. My new destiny is now attending college and this scholarship has made it even more possible to go. I will be attending is the University of Texas at Dallas and I will major in visual and performing art. I am proud to be a child born with a cleft palate because now I can show others nothing is impossible to achieve your goals and this award is truly a blessing.

# 2021 President's Circle Members

ACPA celebrates annual leadership contributions from members, families and friends. We are beyond grateful to our President's Circle Donors for their gifts of \$1,000 or more this year. President's Circle gifts make a tremendous impact at ACPA.

## PRESIDENT'S CIRCLE KEystone SOCIETY (\$10,000 +)

Dianne M. Altuna*	Mohammad Mazaheri*
Anonymous	Office of State Senator David Simmons
CleftStrong 5K (Ray and Chelsea Ortiz)	The Paccagnini Family Revocable Trust
Ronald Reed Hathaway*	

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# 2021 Donors

The cleft and craniofacial community has been generously supported through donations to ACPA. We are beyond grateful to everyone who has supported our mission this year.

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# 2021 Donors (continued)

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Shunsuke Yuzuriha\*  
Jeffery Zabodyn  
Alfred Zuno

## Tribute Gifts

A gift in honor of someone special is a wonderful way to support ACPA. Thank you to everyone who chose to make these meaningful gifts.

### In Honor of ACPA Board

Amelia Drake\*

### In Honor of Chris

John Clarke

### In Honor of Mati

Juliana Millon

### In Honor of Nina Yuchnewicz Acuna

Patti Commo

Cynthia Olnhausen-Ramos

### In Honor of Brooke Adams

Renee Livingston Minnick

### In Honor of All of Patients at the Greater Baltimore Cleft Team

John Caccamese\*

### In Honor of Elizabeth Allen

Marilyn Jones\*

### In Honor of Bill Amato

Sue Amato

Danny Gardner

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Eddie Nespoli

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Cindy Anderson

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Heather Fry

Theresa Holleran

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Luis Araujo

Louisa Davenport

### In Honor of Mahala Nicole Barsh

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### In Honor of Charlene Bell

Jim Conklin

Aubrey Burkhart

Judy Mundy

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Lisa Scheetz

### In Honor of Eily Bell

Neal and Charlene Bell

Judy Mundy

### In Honor of Sarah Berghorst

Audrey Barbush

Randi Berghorst

Amanda Berghorst Vanmaanen

Lindsay Chicoine

Lois Fuller

Amy Greba

Barbara Klein

Laura Lien

Kathy Raecke

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Brenda Scott

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Tom Woodworth

Karen Yeldon

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### In Honor of Erin Black

Aaron Black

Bill Hein

Patti Pasquini

Heidi Raber

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### In Honor of Lee Bomhard

Jenny Gee

Chris Turner

### In Honor of Marianna Bowers

Bob Bowers

Marianna Bowers

Christina Garcia

Vanda Gimpel

Taylor Kauer

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### In Honor of Rachel Buckreus

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Cindy Buckreus

Kathy Carman

James Held

Natalie Held

Patty Held

Lauren Hester

Mary Layson

Mary Shupert

Shea Wolfe

Pam Yates

### In Honor of Frank Burgaretta

Lynds Alexandra

Anna Marie Dodrill

Christina Gorini

Delores Lentino

Doreen Ruotolo

Weston Smith

Gregory Stewart

David Woloff

### In Honor of Jillian Burgaretta

Lynds Alexandra

Kevin Barrett

Maureen Barrett

Patricia Cassidy-Dodrill

Rita Cicchetti

Steve Driscoll

Lisa English Sweeney

Christina Gorini

Laura Lynn

Ginny Mayer-Reyer

Doreen Ruotolo

Helen Wasser

### In Honor of Nicholas Burgaretta

Jillian Burgaretta

### In Honor of Rebecca Arcilla Lanon Chavez

Nel Chambers

Jane Miller

### In Honor of Beth Ciresi

Katie Grengig

Kelly Lynn

Terri Richardson

\* ACPA Member

# Tribute Gifts *(continued)*

**In Honor of Karen Le Clair**

Tom Hayes

**In Honor of Odessa Clanin-Minor**

Theron Minor

**In Honor of Darci Marie Clason**

Kathy Taylor  
Brianna Welch

**In Honor of Ellen R. Cohn\***

Michelle Ferketic\*

**In Honor of Tamala Coleman**

Quinn Watson

**In Honor of Shaneka VanShelle Cooks**

Ron Edwards

**In Honor of Canice Crerand\***

Carrie Heike\*

**In Honor of Elliott Marlowe De Walle**

Thomas De Walle

**In Honor of Dasia Dennis**

Linda Cichon

**In Honor of Liz Diller**

Stuart Hupe

**In Honor of Lori Van Dyke-McGregor**

Kim Barrios  
Deborah Cutler  
Marlene Dyke  
Lori Dyke-Mcgregor  
Susie Hu  
Susan Litt  
Joe Mitzen  
Laurie Ray

**In Honor of Harlan Jackson Easterling**

Sue Altman

**In Honor of Heather Edgington**

Beth Harlan  
Heidi Jenkins

**In Honor of Jasmin Elizabeth**

Karen Albamont  
Luke Jaret  
Vivian Stein

**In Honor of Melinda Fairbanks**

Joni Fain

**In Honor of Benedict Jean Fermin**

Aljon Apostol

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Molly Arnett  
Jessica Fitzgerald  
Luanne Freund  
Megan Stallbaumer  
Erin Stueve

**In Honor of Sheryl Flint**

Leanne Brown

**In Honor of Melinda Flores**

Nadine Myer

**In Honor of Francis Fontanoza**

Allen Agcamaran  
Carlo Garcia

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Deb Celio  
Marilyn Cohen\*  
Helen Fox  
Mary Hardin-Jones\*  
Jeannie Loeb  
Cydney Morel-Corton  
Fran Muse  
Christopher Pride  
Jack Ryan  
Robert Shafer  
Ron Strauss\*

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Dawn Franks  
Pam Franks  
Glynn Milam  
Charlotte Vance

**In Honor of Jackie Frazier**

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Maggie Bonecutter  
Sheila Dickens  
Jackie Frazier  
Michelle Haddox  
Monica Hatfield  
Vicky McNulty  
Vickie Pullins  
Nancy Swigert  
Rick Wilton

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Jeana Asay  
Megan Gilbert  
Diane Pooley  
Dale Reynolds  
Emily Schneider

**In Honor of David Givens**

Joann Smith  
Beverly Yeager  
Sue Yoachim  
Alfred Zuno

**In Honor of Goldman School of Dentistry, Orthodontic Faculty**

Michael Bindman

**In Honor of Shelby Lynne Gooch**

Beverly Gooch  
Peggy Mccollum

**In Honor of Heather Howell Goodwin**

Brandy Presley

**In Honor of Aiden Grella**

Lorraine Barr

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Elisa Pettis-Gronau  
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Ariel Hamilton

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Donna Edwards  
Susan Keaveney

**In Honor of Sarah Haydon**

Colleen Adams  
Jordan Clark  
Christine Debruin  
Sarah Haydon  
Judith Hooks  
Evelyn Pentzien  
Christopher Watson

**In Honor of Valonda Hervey**

Lynda Lippencott

**In Honor of Daniel Lee Parker Hodges**

Stephanie Parker-Helmkamp

**In Honor of The Hollrah Family**

Kristina Aldridge\*

**In Honor of Wendell Hosey**

Brandon Barber

**In Honor of Sherry Hudson**

Sherry Hudson

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Iris Sageser\*

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Stephanie Mangum

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Heather O'mara  
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**In Honor of Cassie Lee**

Jason Guiste  
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Dale Lee  
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Anonymous  
Bill Adams  
Lara Cobb  
Tony Decker  
Linda Dehart  
Debra Johnson  
Jeff Lee  
Connie Lee-Kruslyak  
Susan Rourke  
Keke Serio  
Ted Thonn

**In Honor of Hannah Morford and Samuel Liu\***

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Danielle Passon  
Edward Pikulski  
Joanne Rezzino  
Kathy Samoht

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# Memorial Gifts

A gift to ACPA in memory of someone special is a wonderful way to honor their legacy. Thank you to everyone who chose to make these meaningful gifts.

## **In Honor of Luiz Pimenta**

Silvana Barros  
Alice Deforest  
Amelia Drake\*  
Ehsan Khani  
Ronnie Marshall

## **In Honor of Patrick Bosley Poppadabolis**

Anonymous  
Tina Fantozzi  
Nathaniel Johnson  
Tom Neville  
Ruth Strozeski

## **In Honor of Tammy Porter**

Julie Peed  
Raymond Peed

## **In Honor of Justyn Price**

Michael Hayes  
Velda Price

## **In Honor of Dr. Quimby\*, Dr. Collins, and the entire staff**

Melissa Parrish

## **In Honor of Angela Quinole**

Manuela, Christine, Robert,  
and Kenneth Love

## **In Honor of Briana Faith Ramzy**

Briana Ramzy

## **In Honor of Nicole Ratliff**

Pat Baez  
Paulina Balduyck  
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## **In Honor of Carolan Reid**

Jeri Nickels

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Debra Eberhardt  
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## **In Honor of Kimi Dawn Robinson**

Jeri Robinson

## **In Honor of Kay Schexnayder**

Regina and Norbert Allemmand

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Rick Schmidt  
Layne Seeloff  
Mike Vallance

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Nancy Busa & Ron Partington  
Robert Fabry  
The Lucky Outlaw Team from Scientific Games  
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Kimberly Moredich  
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Lynn Walsh

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## **In Memory of Dr. J. Daniel and Dr. Joanne Davis Subtelny**

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## **In Memory of Duane "Van" Vandemark**

Scott\* and Julie Dailey

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Thank you for  
helping patients  
and families  
THRIVE.



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Charitable contributions help ACPA create a world where people with cleft and craniofacial conditions thrive. When you give to ACPA, you are making an impact in the lives of those with cleft and craniofacial conditions, as well as the professionals who provide their care.

To make a donation, visit [www.acpa-cpf.org/donate](http://www.acpa-cpf.org/donate) or call (919) 933-9044 ext. 205 to learn more about how you can make a difference.



**American Cleft Palate-  
Craniofacial Association**

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