



**ACPA**

American Cleft Palate  
Craniofacial Association

# 2022 Impact Report



[ACPACares.org](https://www.acpacares.org)

## Cover

Suzanne Santomieri,  
Coordinator at NC Cleft  
and Craniofacial Center  
with son Dominick



# Letter from John Girotto

Last year was filled with exciting change and growth for ACPA. Perhaps the most important occasion in 2022 was the return to meeting in person at ACPA's 79th Annual Meeting in Fort Worth, Texas.

**Our community depends on ACPA's highly valued education, and we delivered it to nearly 1,000 providers through in-person and virtual programming.**

Our organization has made initial progress in several areas of ACPA's 2022-2025 strategic plan. *The Cleft Palate Craniofacial Journal* reached its highest-ever impact factor. The Board of Directors voted to approve the creation of the Advocacy and DEI Committees, and we've already seen results. Our work will continue in new phases, including a focus on how ACPA can better enable families and affected individuals to advocate for themselves with their providers and insurance.

Parallel to our advocacy work, ACPA joined the coalition of "Face Equality International". Our work in inclusivity, equality, and representation will speed up considerably in 2023, and our team will begin work in changing representation and perception in mass media. Ensuring our patients and families thrive means that we must do our part in-clinic and help remove barriers, so they thrive in life.

I'm extremely proud of our new brand – the new logo, purpose, passion, and promise – and how ACPA talks about itself as an organization. I know our patients will feel a stronger connection to their ACPA Approved Teams because of it. The new website has two distinct areas, one for providers, and one for families and patients, as we seek to make the resources of ACPA incredibly easy to access.

It was an honor to serve as President of this esteemed organization after being a member for nearly 20 years. ACPA is in exceptional hands in 2023 as Dr. John Caccamese assumes the presidency. Our Board of Directors is strong, nimble, outspoken, and passionate about ACPA's ongoing mission. Our community is cutting-edge, compassionate, and altruistic beyond measure. The future is bright.

A handwritten signature in black ink, appearing to read "John Girotto".

**John Girotto, MD, MBA, FAAP, FACS**  
IMMEDIATE PAST-PRESIDENT, 2022

# About ACPA

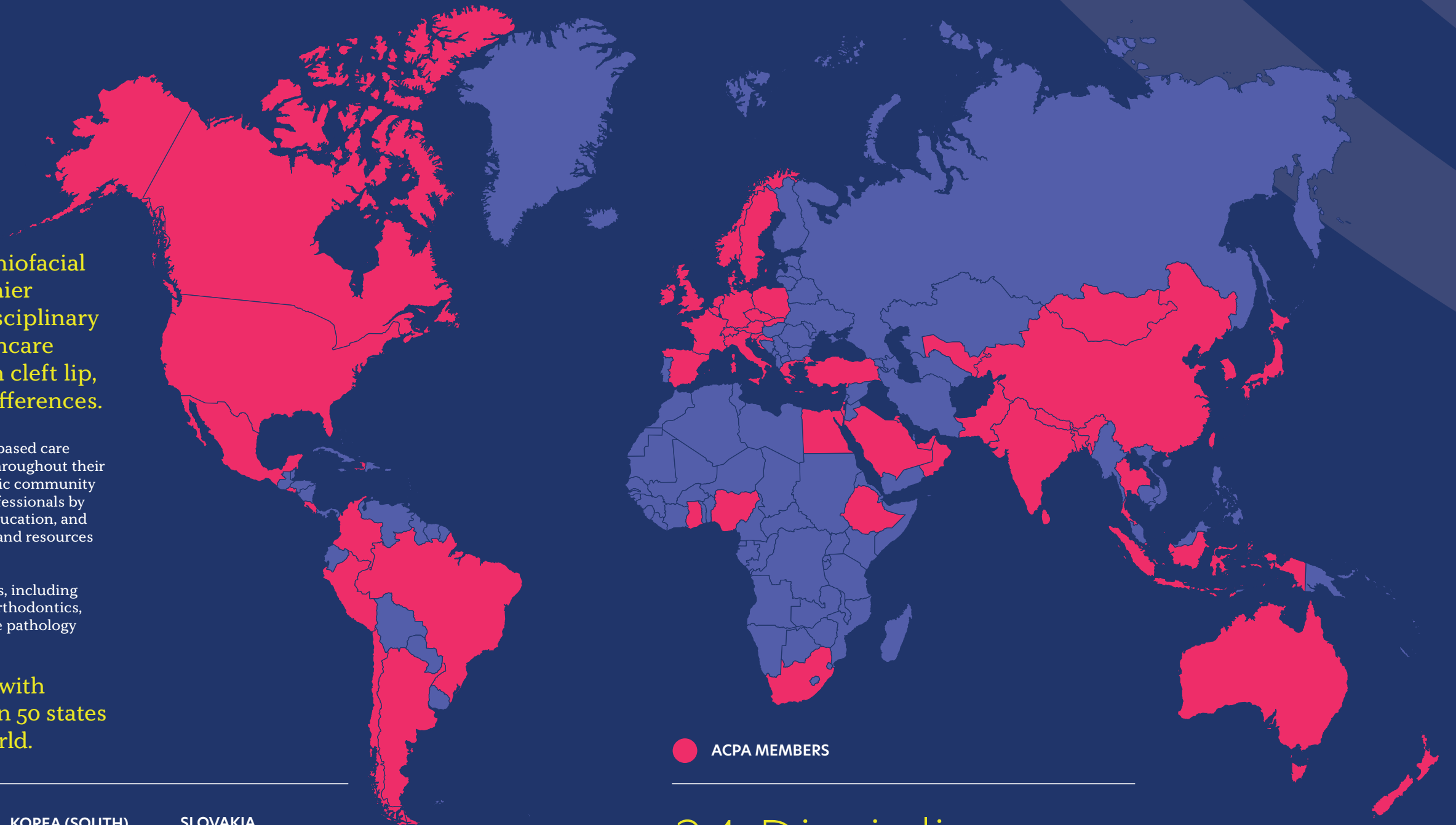
The American Cleft Palate Craniofacial Association (ACPA) is the premier scientific resource and interdisciplinary professional network for healthcare providers serving patients with cleft lip, cleft palate, and craniofacial differences.

At ACPA, we champion a comprehensive, team-based care approach that supports patients and families throughout their unique care journeys. Since 1943 ACPA's scientific community has united cleft and craniofacial healthcare professionals by their passion and purpose with the research, education, and networks to provide evidence-based treatment and resources so patients and families thrive.

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 members work with patients and conduct research in 50 states and 59 countries around the world.

ARGENTINA	EGYPT	KOREA (SOUTH)	SLOVAKIA
AUSTRALIA	EL SALVADOR	KUWAIT	SLOVENIA
AUSTRIA	ETHIOPIA	MEXICO	SOUTH AFRICA
BANGLADESH	FRANCE	MONGOLIA	SPAIN
BELGIUM	GERMANY	NEPAL	SRI LANKA
BRAZIL	GHANA	NETHERLANDS	SWEDEN
CANADA	GREECE	NEW ZEALAND	SWITZERLAND
CHILE	HAITI	NIGERIA	TAIWAN
CHINA	HONG KONG	NORWAY	THAILAND
COLOMBIA	INDIA	OMAN	TURKEY
COSTA RICA	INDONESIA	PAKISTAN	UNITED ARAB EMIRATES
CROATIA	IRELAND	PERU	UNITED KINGDOM
CYPRUS	ISRAEL	POLAND	UNITED STATES
CZECHIA	ITALY	SAUDI ARABIA	UZBEKISTAN
DENMARK	JAPAN	SINGAPORE	



34 Disciplines  
2,141 Members  
50 States  
59 Countries

# Numbers to Celebrate



76,000

### PATIENTS SERVED

The 197 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 difference.



357

### CLEFT COURAGE BEARS SOLD

Since 1989 the ACPA Cleft Courage Bear has become a lifelong friend to children of all ages. With stitches across the upper lip, this fuzzy companion provides comfort and cuddles at every stage of their journey.



\$5,500

### PROFESSIONAL SCHOLARSHIPS & AWARDS GRANTED

ACPA supports patients and families by equipping providers with essential professional resources. Each year ACPA provides professional scholarships for graduate students and young professionals in the cleft and craniofacial field to join ACPA and attend ACPA's Annual Meeting. Awards are granted to recognize dedication to research.



\$20,000

### COLLEGE SCHOLARSHIPS GRANTED

ACPA awards college scholarships to outstanding students born with cleft or craniofacial conditions. In 2022 ACPA was honored to provide scholarships to three deserving students.



6,397

### PATIENT EDUCATIONAL RESOURCES DISTRIBUTED

ACPA works with cleft and craniofacial experts to develop educational resources to ensure patients and families receive research-based and trusted information. ACPA offers more than 30 publications to help parents learn about their child's diagnosis and navigate every stage of their treatment journey.

## Top 5 Most Read Articles on the Website

478

### PAGE VIEWS

Slayton's First Year

<https://acpacares.org/success-story/slaytons-first-year/>

376

### PAGE VIEWS

Sarah's Smile

<https://acpacares.org/success-story/sarahs-smile/>

354

### PAGE VIEWS

CPCJ Author Guidelines Update

<https://acpacares.org/cpcj-author-guidelines-update/>

341

### PAGE VIEWS

Tyler, the Bravest Boy

<https://acpacares.org/success-story/tyler-the-bravest-boy/>

293

### PAGE VIEWS

ACPA Recognizes 2022 Milestone Members

<https://acpacares.org/acpa-recognizes-2022-milestone-members/>

## Financials

All financials are unaudited.

### Revenue:



\*Includes supporter and exhibitor revenue | \*\*Excludes sale of assets

### Expenses:



### Donations Received by Fund:

\$458,472 Unrestricted	\$25,000 Grant	\$4,250 Family Services Endowment	\$3,850 Randall/LaRossa College Scholarship Fund	\$1,200 David Kuehn Speech Scholarship Fund
\$1,000 Young Professional Service Award	\$850 James F. Mulick Educational Scholarship	\$625 Donna Pruzansky Memorial Fund	\$350 Samuel Berkowitz Long Term Study Award	\$300 Subtelny Junior Investigator Award

# ACPA at a Glance

A snapshot of our membership engagement in 2022.

# 2,141 Members

AS OF 12.31.2022

1,350 ACTIVE/ PROFESSIONAL	305 LIFE	215 STUDENT
213 INTERNATIONAL	20 RETIRED	24 ASSOCIATE/ AFFILIATE
10 EARLY CAREER <small>Introduced October 2022</small>	4 TRANSITIONAL	

## 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 or Free Registration Rate for ACPA Online Learning Opportunities
- 4 Access to the ACPA Online Community
- 5 Interest Group Membership

			
976	331	242+	239
ATTENDEES AT ACPA'S 2022 ANNUAL MEETING FROM 59 COUNTRIES	MEMBERS CONTRIBUTED ON THE ONLINE COMMUNITY <sup>*1</sup>	VOLUNTEERS <sup>*2</sup>	ARTICLES PUBLISHED IN THE CLEFT PALATE CRANIOFACIAL JOURNAL

<sup>\*1</sup> The ACPA Online Community is the place for members to ask questions, connect, network, share resources and more. Features include discussion forums, member profiles, resource libraries, blogs, and events.

<sup>\*2</sup> Volunteers support ACPA's mission by serving on the board of directors, editorial board, committees, and special interest groups. Volunteers also evaluate junior investigators, chair sessions at ACPA's Annual Meeting and more.

## Top 3 Most Read Articles From *The Cleft Palate Craniofacial Journal*

- |                     |  |
|---------------------|--|
| 2,547<br>PAGE VIEWS | <b>Systematic Review of Clinical Practice Guidelines for Oral Health in Children with Cleft Lip and Palate</b><br>Volume 59 Issue 6<br><a href="https://journals.sagepub.com/doi/10.1177/10556656211025189">https://journals.sagepub.com/doi/10.1177/10556656211025189</a> |
| 2,489<br>PAGE VIEWS | <b>Validation of Skully Care as a Fast Method for Quantifying Positional Cranial Deformities</b><br>Volume 59 Issue 9<br><a href="https://journals.sagepub.com/doi/full/10.1177/10556656211035022">https://journals.sagepub.com/doi/full/10.1177/10556656211035022</a>     |
| 2,039<br>PAGE VIEWS | <b>Maternal Cigarette Smoking and Cleft Lip and Palate: A Systematic Review and Meta-Analysis</b><br>Volume 59 Issue 9<br><a href="https://journals.sagepub.com/doi/10.1177/10556656211040015">https://journals.sagepub.com/doi/10.1177/10556656211040015</a>              |



# Areas of Impact

## Partnership with MyFace

As part of our commitment to providing professionals and their patients with the best possible information for their care journey, ACPA has partnered with myFace to present the free educational webinar series, *Transforming Lives*.

## New Member-Only Online Community

Our new Online Community makes it even easier for ACPA members to stay in touch with each other. It's a centralized hub where members can ask questions, share news stories, and network with each other. Numerous topics from the latest in medical care trends to personal histories are discussed every day, providing education, color, context, and hope to those who need it most.

## Joined Face Equality International (FEI)

FEI is the first and only global alliance devoted to ensuring the global facial difference community can live freely, without indignity or discrimination. We join other national organizations to advocate on behalf of the cleft and craniofacial community.

## Reached Highest Ever Impact Factor

A growing Impact Factor shows how the research published in the *Cleft Palate Craniofacial Journal* is continuing to grow in citations and overall impact, increasing its viewed importance in the relevant field(s) and throughout several subject categories.

## Hybrid Annual Meeting

ACPA's first hybrid Annual Meeting was held in Fort Worth, Texas ensuring our members had access to the latest research and education to best care for their patients whether in-person or virtually.

## New Committees

The ACPA Board of Directors voted to create the ACPA Advocacy, ACPA DEI, and ACPA Family Resources Committees, embarking on critical initiatives that directly impact the professional lives of our members and the patients they serve.

## Increased College Scholarship Award Amounts

ACPA awards three college scholarships annually to outstanding students born with cleft and craniofacial conditions making college more affordable for their families. Many times, these students are inspired by their own journeys to pursue a career in the cleft and craniofacial field.

In 2022 we increased the award amounts ranging from \$5,000 to \$10,000 to make an even bigger impact.

## Launched Team Care Coordinator Retreat

A virtual event was offered to care coordinators to learn and share knowledge between care teams. The event was attended by 147 professionals, and was free to members.

## New ACPA Brand

ACPA redefined in 2022 to better align with our journey, where we are today, and where we're headed. Our new logo represents the parallel journeys of families, where they intersect with research and science within their care teams. It represents the fact that no healthcare provider, and no family travels in a straight line on their journey. And it's clearly a symbol which represents the compassionate care our members choose to provide every day, and the courage of their patients.

"I am in awe of the impact we have made this year thanks to our dedicated members and generous donors. **We couldn't do it without you.**"

Adam Levy, CAE

EXECUTIVE DIRECTOR, ACPA





## Professional Scholarship Recipients

ACPA strives to support patients and families by helping to equip care providers with essential professional resources.

Each year ACPA provides the opportunity for graduate students or young professionals studying in cleft and craniofacial fields to become members of ACPA and attend the Annual Meeting through professional scholarships.



### Eshan Pua Schleif PhD, CCC-SLP

David P. Kuehn  
Speech Scholarship

Named in honor of ACPA Member David P. Kuehn, this scholarship was established to help current master's or doctoral students enrolled in a communication sciences and disorders or related program the opportunity to attend ACPA's Annual Meeting.



### Kathryn Preston DDS, MS

Mazaheri Young  
Professional Scholarship

Established by ACPA Member Mohammad Mazaheri, this scholarship supports the participation of professionals new to their field the opportunity to attend ACPA's Annual Meeting.



### Imani R. Gilbert BS

Karlind T. Moller  
Cleft/Craniofacial Scholarship for  
Speech Path./Audiology Students

This scholarship helps current undergraduate/graduate students in accredited speech-language pathology and/or audiology degree programs fund research/projects involving patients with cleft lip/palate and/or other craniofacial anomalies.



### Cleo J. Yi DMD, MDS

James F. Mulick  
Educational Scholarship

Established by ACPA Member Dianne Altuna in memory of her father James F. Mulick this scholarship supports the participation of orthodontists in ACPA's Annual Meeting.



### Mary Church BSN, RN

Donna Pruzansky Memorial Fund for  
Maternal and Child Health Nursing Grant

Established by Sam Pruzansky, MD, in memory of his wife who practiced as a nurse in the area of maternal and child health, this grant supports the participation of nurses new to their field the opportunity to attend ACPA's Annual Meeting.



# Professional Awards Recipients

ACPA is proud to present awards that recognize dedication to research, care, and the cleft/craniofacial community.



## Holly Peryer, MSc and co-authors

**SAMUEL BERKOWITZ, DDS, MS**  
**LONG-TERM OUTCOMES STUDY AWARD**

Given annually to the primary author of the article judged to be the best long-term outcomes study published in *The Cleft Palate Craniofacial Journal*.



## Sivakumar Chinnadurai, MD

**CPCJ PEER REVIEWER OF THE YEAR AWARD**

Given annually to the peer reviewer recommended and selected by the Editorial Board who best exemplifies the core values and mission of *The Cleft Palate Craniofacial Journal*.



## Earl J. Seaver, PhD

**DISTINGUISHED SERVICE AWARD**

Recognizes an individual, member or non-member, who has demonstrated exceptional service to ACPA.



## Kazlin Mason, PhD

**EMERGING LEADER AWARD**

Given to an early career professional who is a member of ACPA for at least three years and not more than 15 years, who exhibits exemplary accomplishment and dedication to the issues affecting people with cleft and craniofacial conditions.



## Stephen and Jennifer Len

**FAMILY SERVICES LEADERSHIP AWARD**

Recognizes an individual or group, such as a parent, patient, advocate, or community organization, who has demonstrated exceptional service and leadership on behalf of individuals with cleft or craniofacial anomalies.



## Jeffrey L. Marsh, MD

**HONORS OF THE ASSOCIATION AWARD**

Represents the highest expression of respect and gratitude ACPA bestows. It is granted to those individuals whose lifetime of research, healthcare delivery, or leadership has advanced, significantly and uniquely, the amelioration of physical, behavioral, or social conditions of cleft lip and palate or other craniofacial differences.



## Jean-Charles Doucet, DMD, MD, MSc, FRCDC and Alexis L. Johns, PhD, ABPP

**STEWART ROOD CPCJ SECTION EDITOR OF THE YEAR AWARD**

This award is given annually to a section editor of *The Cleft Palate Craniofacial Journal* in recognition of their significant and substantive contributions to the journal.



## Kari M. Lien PhD, CCC-SLP and Daniel Cho MD, PhD

**SUBTELNY JUNIOR INVESTIGATOR AWARD**

ACPA's Junior Investigator Award recognizes outstanding presentations from investigators either recently graduated or currently enrolled in a training program dealing with cleft and craniofacial evaluation and treatment.

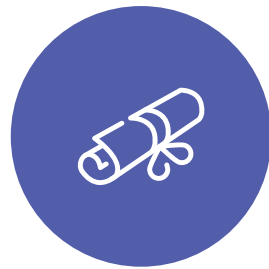


## Aleshia Pringle, ARNP

**YOUNG PROFESSIONAL SERVICE AWARD**

Given to a cleft/craniofacial professional who has been in the profession for 10 years or less and demonstrates exceptional service to: 1) cleft lip and palate/craniofacial team, 2) professional society in a manner of serving or promoting cleft lip and palate/craniofacial interests, 3) community in a manner of serving or promoting cleft lip and palate/craniofacial interests or 4) cleft lip and palate/craniofacial profession.





# College Scholarship Recipients

ACPA awards college scholarships annually to outstanding students born with cleft or craniofacial conditions.

Award recipients are selected 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 recognize the winners of the 2022 Randall/LaRossa College Scholarships.



## Bennett Slaughter

HONORS AWARD,  
RANDALL/LAROSSA COLLEGE  
SCHOLARSHIP

Most people know that a child born with a cleft lip and palate undergoes surgery to repair the birth defect, but they are unaware of the complications with speaking, eating, breathing, and hearing that take an entire childhood to correct. Dealing with self-confidence issues at a very young age stemming from bullying and name-calling, I decided that I would determine my own identity rather than just being the kid with a facial difference.

Every life achievement became my voice to say being born with that difference doesn't make me different at all. Even as my self-reliance grew, I learned to appreciate that someone looked beyond my scars and befriended me simply because of my worth as a human being.

I am so very honored to receive the Randall/LaRossa College Scholarship and to represent such a diverse and underrepresented group of people.

**With this financial support, I will attend the University of Georgia to pursue a Bachelor of Science Degree in Biology with an emphasis in Pre-Medicine.**

As a future physician, I plan to emulate my Craniofacial Surgeon's bedside manner, calm demeanor, and confidence to advocate for children born with a cleft lip and palate. As someone who has personally lived through both the suffering and triumphs, I want to provide a sense of security to children with cleft and their families.



## Julia Decker

GENERAL AWARD,  
RANDALL/LAROSSA  
COLLEGE SCHOLARSHIP

Born in China with a bilateral cleft lip and palate, I lived in an orphanage for my first three and a half years until I was adopted and moved to the United States. I have never forgotten the children I left behind in China. My early life experience motivated me to partner with the non-profit organization Love Without Boundaries. To date, I have been able to sponsor the cleft repair surgeries of seven children living in under-resourced communities in China and Cambodia.

It has been difficult to forget the stares of others and the feelings of insecurity I once had. The many doctor appointments, therapy sessions, and surgeries, however, made me a stronger person. The positive aspects of having a cleft include finding a close-knit community, making true friends, becoming closer with my family, and gaining confidence to be proud of my appearance. I am grateful and honored to have been chosen for this year's General College Scholarship.

**I will be attending Salve Regina University in Newport, Rhode Island to obtain my nursing degree and fulfill my mission of helping children like me.**

I hope to become a cleft nurse specialist and work on a cleft team. By awarding me this scholarship, you have reduced my financial burden, which will allow me to focus on my class work and not worry so much about how I am going to pay for school. Thank you very much for your generosity!



## Braiden Weis

VOCATIONAL AWARD,  
RANDALL/LAROSSA  
COLLEGE SCHOLARSHIP

Being born with a cleft lip and palate has come with many challenges. Although I have had multiple surgeries over the years, I have to learn how to deal with the lasting effects of cleft lip and palate. I hope to become a role model for other kids that are going through the same things I went through.

I was lucky to have gone to Shriners Hospital in Chicago for most of my surgeries and I have met other kids like me over the years which has helped me feel like I'm not the only one born like this. I'm the first born in my family with a cleft lip and palate so there's been a lot of learning over the years. My family has always been very supportive flying back and forth to Chicago for doctors' appointments and other local doctors.

**Getting this scholarship will help me achieve my dreams of becoming a linesman at Pratt Community College.**

Becoming a linesman, I can give back to my community when the power gets knocked out. I like working with my hands building and working on my truck. I'm currently building a dune buggy and hope to work on future projects. Thank you for helping to better my future.



# 2022 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. President's Circle gifts make a tremendous impact at ACPA.

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

CleftStrong 5K (Ray and Chelsea Ortiz)

## PRESIDENT'S CIRCLE GOLD LEVEL (\$3,000-\$9,999)

Stephen* and Patricia* Beals (Craniofacial Foundation of Arizona)	Marilyn C. Jones*
Silvia* and Wescott Blemker	Kathleen A Kapp-Simon*
Lynn* and Brad Fox	Land Realty, Inc.
	Renee M Powell

## PRESIDENT'S CIRCLE SILVER LEVEL (\$1,000-\$2,999)

Anonymous*	Janice F. Lalikos*
Anonymous	Adam* and Rachel Levy
Adriane L. Baylis*	David W. Low*
Michael L. Beckley*	Alexandra MacCracken
Samuel Berkowitz*	Jeffrey L. Marsh*
Thomas Biermann	Timothy J. Marten*
Greg and Kristen Bowden	Aaron C. Mason*
Sebastian Brooke*	Martha S. Matthews*
Richard* and Cheryl Bruun	Samuel M. Maurice*
Richard* and Ann Burton	Krishna G. Patel*
John F. Caccamese*	Jamie L. Perry*
Marilyn A. Cohen*	Michael Petersen
Bernard J. Costello*	Philly Phaces
Canice E. Crerand*	Andrea O. Ray*
Claudia Crilly Bellucci*	Pat Ricalde*
Scott* and Julie Dailey	Carolyn Rogers-Vizena*
Lisa R. David*	Andrew Severance
Amelia F. Drake*	Steven* and Shannon Smiley
John A. Giroto*	Peter* and Jody Spalding
Anna Glazer Simon	Gregory D. Subtelny
Matthew R. Greives*	Douglas Swol
Yvonne R. Gutierrez*	Sherard Austin Tatum*
Tasha E. Hall*	Raymond Tse*
Ron R Hathaway*	Karin Vargervik*
William Y. Hoffman*	John E. Volz*
Banafsheh Hosseinian	Martha Weber
Oksana A. Jackson*	Sasha and Nichelle Weintraub
John N. Jensen	Joseph K. Williams*
Rohit K. Khosla*	Kristina Wilson*
Sara Kinter*	Laura A. Workman*
Katelyn Kotlarek*	Isaac Leake Wornom*
David Kuehn*	

\*ACPA Member

# 2022 Donors

Gifts of all sizes make an impact in the lives of those with cleft and craniofacial conditions, their families, and the professionals who provide their care. Thank you to the following donors for their support of ACPA's programs in 2022. This support helped ACPA to advocate for patients, expand research efforts, provide professional and patient education, award professional and college scholarships, and much more.

## SUPPORTER (\$500-\$999)

Priya Acharya	Aaron DeMaio*	Kristen M. Lowe*
Kristina Aldridge*	Allison M. Dobbie*	Miles of Smiles
Dianne M. Altuna*	Catharine Bradford Garland*	Karlind T. Moller*
Amy Anderson*	Brian and Elyse Gilbert	Gary S. Neiman*
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Maureen Smith Andrews*	Steven L. Goudy*	John and Rebecca Richards
Anonymous*	Kathryn A. Hanson*	Earl J. Seaver*
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Alvaro* and Michele Figueroa	Katharine Ostedgaard*	Peter D. Witt*
Noopur Gangopadhyay*	Robert W. Parsons*	

## FRIEND (\$1-\$249)

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Andrea Accion	Anonymous	Ruth Barta*
Somer Adkins	Anonymous	Joan Barzilai*
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Anonymous*	Joy L. Baltz*	Amanda Berghorst Vanmaanen
Anonymous*	Sarah Bannan	Jessica Berry

\*ACPA Member

**FRIEND (\$1-\$249)**

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 Marcus Bowen  
 Denise Brandon  
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 Kevin Edmonson  
 Dayna Elaine  
 Genevieve Elam  
 Omri Emodi\*  
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 Jay Granadosin  
 Teresita Granadosin  
 John Graves  
 Glen Greenstreet  
 Antonio Guillen  
 Rania A Habib\*  
 Mary Halloran  
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 Michelle Harris  
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 Jodi Hasley  
 Tracey Heiniger  
 James Held  
 Patty Held  
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CDE  
SENIOR MANAGER, DEVELOPMENT  
& STRATEGIC PARTNERSHIPS  
CBell@ACPACares.org



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MANAGER, MEMBER PROGRAMS  
& ENGAGEMENT  
EBrenneman@ACPACares.org



**Lauren Mowles**  
SENIOR ASSOCIATE,  
PROGRAMS AND DEVELOPMENT  
LMowles@ACPACares.org



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SENIOR MANAGER,  
EDUCATION PROGRAMS  
CReinauer@ACPACares.org



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