




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

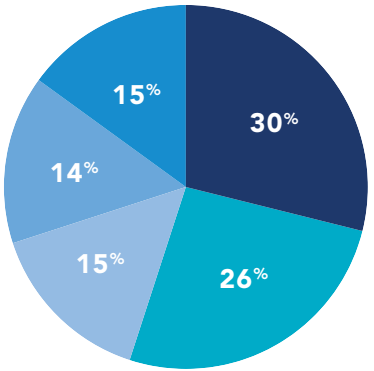
Study Explores Facilitators, Barriers to Standardized Outcome Measurement for Cleft Care
<https://acpa-cpf.org/2021/01/22/study-explores-facilitators-barriers-to-standardized-outcome-measurement-for-cleft-care/>
- 246
pageviews

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

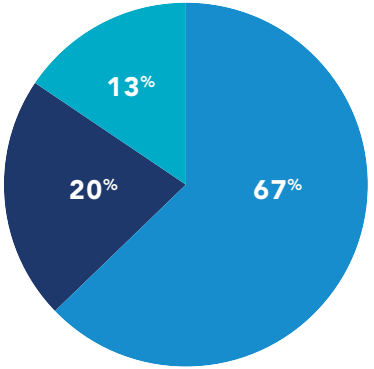
Revenue

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

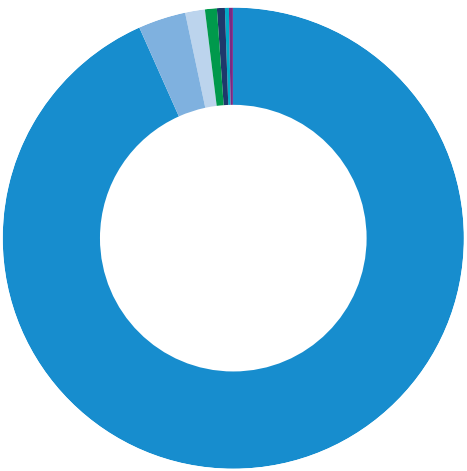


Expenses

Program Services	\$735,839
Management and General	\$215,788
Development	\$141,588
TOTAL EXPENSES	\$1,093,215



* 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

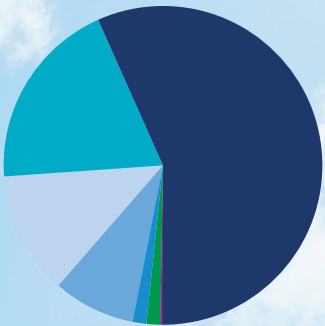
A SNAPSHOT OF MEMBERSHIP ENGAGEMENT IN 2021



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*	

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

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Silvia and Wescott Blemker	Kathleen A. Kapp-Simon*	Alexandra MacCracken
John Clarke	Land Realty, Inc.	Renee and Joe Powell

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

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	Krishna G. Patel*	Isaac Wornom*

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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* ACPA Member

2021 Donors *(continued)*

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Megan Stallbaumer
Vivian Stein
Tommy and Christi Stermer
and kids
Gregory Stewart
Stefanie Nichols Stockberger
Anna Stone
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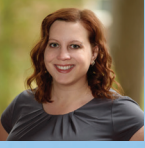
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