



2020 Impact Report



**American Cleft Palate–
Craniofacial Association**

LETTER FROM

Patricia Beals

2020 Board President



It has been an honor to serve as your president in 2020. Though this year presented many challenges to all of us professionally and personally, I have had the privilege of watching our organization pull together for the sake of our mission. Despite the pandemic, we navigated difficult circumstances and continued to create a world where people with cleft and craniofacial conditions thrive. I have never been more proud to be part of ACPA and serve together with you.

As I reflect on the last year, it is evident that patients and families remain at the heart of everything we do at ACPA – from supporting professionals in the cleft and craniofacial field with the latest research to providing free educational resources to new parents. As an orthodontist, I saw firsthand the difficulties that many people in our community faced this year, and I also saw those in the ACPA community step up to make a difference. Early in March, many ACPA members volunteered their time to create COVID related resources and guidelines to help us provide COVID safe care for patients. Though the annual meeting was cancelled, we held our first virtual Fall Symposium and continued to host online webinars. We found ways to keep our community alive by connecting with one another virtually and in result, we found a silver lining of hope.

I am excited that we have a new Executive Director. Adam Levy brings experience as well as a fresh perspective that will be exciting for ACPA.

Essentially everyone says “it has been an honor” when they step down as President. The reason for that is that it truly is an honor, and no other word or phrase describes it better. To my fellow members, generous donors and volunteers, and the patients we serve, I say thank you. Your continued support, strength and resilience are remarkable.

As we enter 2021, I am excited to welcome our new president, Lynn Fox, MA, MEd, CCC-SLP, from the UNC Craniofacial Center. She is focused and will develop the new broad strokes we started in response to the challenges of 2020. I look forward to being part of the ACPA family for years to come as we continue to advance our mission.



Patricia A. Beals, DMD, MS
2020 ACPA President

LETTER FROM

Adam M. Levy

Executive Director



There is much to be celebrated about 2020. While that may seem counterintuitive after such a year, I have seen the grit, resourcefulness, and dedication our members, families, and individuals have put forth during this time. Your commitment to providing care for those with cleft and craniofacial conditions has been on full display. I am grateful to have worked with our Immediate Past-President, Patricia A. Beals, DMD, MS, whose leadership guided us through such a wild year. I am thrilled to hit the ground running in 2021 with ACPA President, Lynn Fox, MA, MEd, CCC-SLP.

Looking back, we see that the previous year presented innumerable challenges and tested our endurance. It was a year that we will remember as individuals for a multitude of reasons, but as a community, I hope you will remember that the resilience of ACPA's community was unwavering. There are thousands of individuals whose world is better for your perseverance. ACPA's long-time programs continue to support the cleft and craniofacial community with many thanks to the ACPA Board of Directors, National Office Team, ACPA members, donors, volunteers, patients and families.

We have been stringent in our expenditures, and strict in adherence to best practices in nonprofit financial management, and I am pleased to let you know we continue to operate normally. This will continue to be our short-term goal, as we strive for long-term growth and regain our strong positions.

There are many exciting opportunities on the horizon, such as ACPA's Virtual Annual Meeting and the possibility of new programs for our Family Services. It is an honor for me to serve as ACPA's Executive Director. I look forward to getting to know each of you and hope to meet many of our members and families as soon as circumstances allow.

Thank you to each one of you who continues to help further the mission of ACPA. Your support is moving our collective vision forward.



Adam M. Levy
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 provides support for professionals and hope for patients.

Mission: Creating a world where people with cleft and craniofacial conditions thrive.

MORE THAN 2,400 ACPA MEMBERS
work with patients and conduct research in
50 states and 63 countries around the world.

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



ACPA Members

Numbers To Celebrate



PATIENTS SERVED

The 193 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.



VOLUNTEERS

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



422 ONLINE LEARNING PARTICIPANTS

ACPA provides access to online learning for cleft and craniofacial care providers worldwide. ACPA's webinars received more than 2,500 views in 2020, with select webinars offering professional continuing education credits.



COLLEGE SCHOLARSHIPS AWARDED

ACPA Family Services awards college scholarships to outstanding students born with cleft or craniofacial conditions. In 2020 ACPA was honored to provide scholarships to six deserving students.



PUBLICATIONS CIRCULATED

ACPA Family Services provides patients and families with tools and educational support. Publications are distributed through professionals, by mail and online.



MEDICAL DISCIPLINES REPRESENTED

ACPA members represent 33 medical disciplines, including plastic surgery, oral and maxillofacial surgery, orthodontics, otolaryngology (ENT), nursing, speech language pathology and more.



27,000+ FOLLOWERS ON SOCIAL MEDIA

Although in-person events were canceled to comply with social distancing guidelines, the ACPA community connected virtually throughout the year. ACPA's followers continued to share messages of hope and resources for patients, families, and professionals in the cleft and craniofacial community across various platforms worldwide.



ARTICLES PUBLISHED

The *Cleft Palate-Craniofacial Journal*, an international journal on craniofacial differences, is the official publication of ACPA and the journal of record for the profession. The journal draws from around the world for its interdisciplinary approach to growth, development, diagnosis, and treatment — the provision of optimal clinical services — in all areas pertaining to craniofacial differences. It also keeps readers in touch with the latest research in related laboratory sciences.



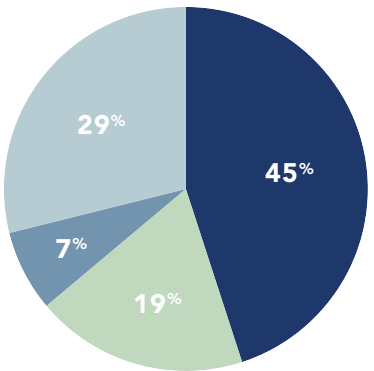
PROFESSIONAL SCHOLARSHIPS AND AWARDS GRANTED

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.

Financials

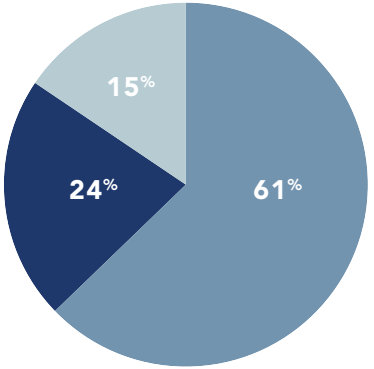
Revenue

Professional Dues	\$450,000
Donations*	\$190,000
Investment Income	\$67,000
Annual Meeting Income	\$0
Other Income	\$290,000
TOTAL REVENUE	\$997,000

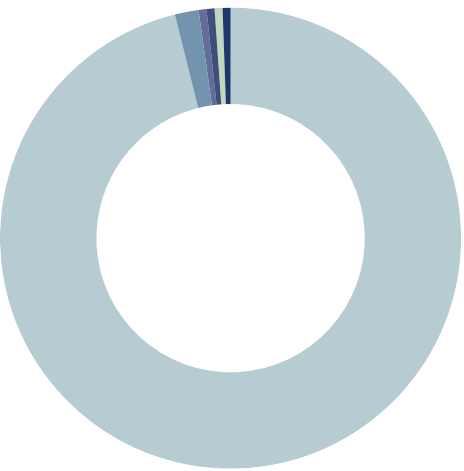


Expenses

Program Services	\$717,000
Management and General	\$286,000
Development	\$178,000
TOTAL EXPENSES	\$1,181,000



*Written off pledges are deducted from donation revenue total.
2020 financials listed are unaudited.



Donations Received by Fund

Unrestricted	\$188,556
Randall/LaRossa College Scholarship	\$6,705
Other.	\$1,209
Family Services Endowment	\$971
Subtelny Junior Investigator Award	\$500
Gip Seaver College Scholarship	\$500

Impact Stories

Gifts to ACPA make an impact in the lives of those with cleft and craniofacial conditions, as well as the professionals who provide their care. Through the generosity of our donors, ACPA continues our mission: to create a world where individuals with cleft and craniofacial conditions thrive. Generous gifts provide scholarships to college students, educational information and support to patients and families, continuing education for professionals, and continues to allow us to spread awareness worldwide.

"Our daughter, Eva Mae, was diagnosed with a unilateral cleft lip at our 20-week ultrasound. At first, we were devastated. Having no experience with clefts, we set out for answers. We discovered many resources, like the ACPA website, and we felt so much relief in the information we found. When Eva was born, we met with Dr. Grant and the ACPA Approved Team at Alabama Children's Hospital. Eva had her lip repair surgery in October. Everything went perfectly and we got to fall in love with her smile all over again!"

—Kristina, Eva's Mother



"Being an ACPA member has allowed me to meet wonderful medical professionals, increased my understanding of the importance of team and coordinated treatment for craniofacial anomalies, and continuously improves my knowledge of how to best serve my patients. Every time I see a child with cleft, I think of my patient zero, my son, and it gives me the drive and energy to provide the support and excellent treatment my family received. I care deeply about the cleft and craniofacial community because it has impacted my own life on a very personal level. I will forever be connected to this community both professionally and personally, and that brings me great joy."

—ACPA Member Walmir B. Da Costa, DMD



"I will be attending Santa Clara University in the fall and I plan on majoring in Neurobiology. After my time in Santa Clara, I plan on going to medical school to become a doctor. All of my doctors have changed my life and I've been so grateful for everything. I just want to give back to others, just as they have given to me. Being born with a cleft lip and palate has only made me work harder. I am also a first-generation college student. I cannot thank you all enough for this scholarship. This scholarship will help ease the burden of affording college for my family. This has allowed me to further pursue my dreams without worry."

—Madeline Bravo, 2020 ACPA College Scholarship Recipient

"We found out that Jeremiah would be born with cleft lip and palate when I was pregnant. Thank you to ACPA for helping us prepare for our baby. ACPA Family Services helped us on our journey by providing great information and sharing stories and experiences that other parents have faced, as well. Thank you!"

—Sadayi, Jeremiah's Mother



2020 Donors

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

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

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Alvin and Margaret Groce	Inova Fairfax Hospital	

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Thank you to all the donors who have generously contributed to ACPA through Amazon Smile, Combined Workplace Giving, Facebook, Online Giving Portals, and United Way. Your support is very much appreciated.

* ACPA Member

2020 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.

Friend (\$1-\$249)

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		Leanne Magee*		

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 all the brave patients and families affected by cleft and craniofacial conditions Leo J Urbinelli*	In Honor of Noah Hill Rebecca Hill	In Honor of Liam Ryan Mark Willens
In Honor of Joy Baltz Loren Elliott	In Honor of Elena Hopkins John Hopkins	In Honor of Jameson Scott Joanne Denison and John Beach
In Honor of David Barnett Neal and Charlene Bell	In Honor of Adam Levy Rabbi, Dan and Miriam Horwitz Susan Stone and Jay Levy	In Honor of Ean & Ellie Smith Alice E. Smith*
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In Honor of Eily Bell Neal and Charlene Bell Judy Mundy	In Honor of Teresa Lykins Jami Carter	In Honor of The Strike Family Deborah J. Strike*
In Honor of Beau Bighill and Family The Wendy Williams Show	In Honor of Scott and Carson McClain Todd Jones	In Honor of Dr. Michael Stroncsek Neal, Charlene and Eily Bell
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In Honor of Colin Brady and Alex Diehl Bonnie* and Johnny Boerema	In Honor of Kayla Nyren Jennifer Lucarelli	In Honor of Noah Suddes Anonymous
In Honor of Nicholas Burgaretta Jillian Burgaretta Barbara King	In Honor of Emma Ortiz Maricarmen Ortiz	In Honor of Anna Taylor Mark and Rita Taylor
In Honor of Ralph M. Daily Jami and Steve Carter	In Honor of Sam Panizales The Face Loft LLC	In Honor of the patients of the Greater Baltimore Cleft Team John F. Caccamese*
In Honor of Dr. Aron Dellinger Neal, Charlene and Eily Bell	In Honor of Madison Pope Josie Pope	In Honor of Wendy Toyama Helen Sharp*
In Honor of Tom DeWalle and Wendy-Jo Toyama Annie Tilden	In Honor of Yuri Rey Regis Lucia	In Honor of Sean Williams Carl and Janet Lust Cheryl Puntil Wilcek Family (Earl, Sisie, Adam, Christy, Betsy, Nick and Evan)
In Honor of Emma Irene Geise Beryl Beaver	In Honor of Elle Rose Richardson Molly Richardson	In Honor of Libby Wilson Mark E. Krugman*

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 Memory of Kameron Beaulieu
Leo J Urbinelli*

In Memory of Dr. Ted Corcoran
Inova Fairfax Hospital Craniofacial Team

In Memory of Mazie Shoffner Coulman
Mike and Julia Coulman

In Memory of Dennis Dible
Anonymous
Patrick J Bakies
B.D. and M.M. Cornelia
James and Nancy Hall
Dean and Nancy Kessler
Sarah and Roger Kloepfer
MacDonald Supply
Andrea, Thomas, and Robert McClure
Larry and Linda Taylor
Vanlue Christ United Methodist Church
Scott and Tania Woods

In Memory of Larry Graubart
Steven and Judith Zimmerman

In Memory of Dr. Ian Jackson
Uldis Bite*

In Memory of Dr. Don LaRossa
David W. Low*

In Memory of Liam
Anonymous

In Memory of Dr. Donald Linck
Anonymous
Nancy Graydon and Team GRF
James P. Green
Sandra Herrick
Robert F. Kennedy
Gayle McNeill
Alvin G. Medvin
Dina Wolkoff

In Memory of Patricia Lockery
Shawn R. Lockery

In Memory of Betty Jane McWilliams
Michelle M. Ferketic*

In Memory of Bodhi Shepard Paska
Gary Miles

In Memory of Florence Puntil
Bob and Linda Currey
Ed and Jan Dorner
Delores Ewoldt
John and Linda Hirschy
Carl and Janet Lust
Julie Miller
Cheryl Puntil
Toni Tantone
Wilcek Family (Earl, Sisie, Adam, Christy, Betsy, Nick and Evan)
Steve and Rosie Wolf

In Memory of Peter Randall
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Uldis Bite*

In Memory of Elizabeth Wright
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2020 ACPA Board of Directors

ACPA’s mission would not be possible without the dedication of our Board members. Thank you for your leadership over the past year. You have directly impacted the success of ACPA.

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Support ACPA

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 or call (919) 933-9044 ext. 204 to learn more about how you can make a difference.



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