2019 Impact Report

American Cleft Palate–Craniofacial Association
I would like to thank you all for empowering me to serve as your president in 2019. This was a very successful year for ACPA, which began with the introduction of ACPA’s new mission: creating a world where people with cleft and craniofacial conditions thrive. We have been working for years to serve both our professional and family audiences, and this new direction helped guide our focus on what is most important as we continue on that journey.

As an oral and maxillofacial surgeon, I get the opportunity to work with an ACPA Approved Team at the University of Pittsburgh Medical Center. A multidisciplinary team approach ensures that each patient is treated in a coordinated manner within the framework of the patient’s overall developmental, medical and psychological needs to ensure the best possible outcomes. Every day patients walk into our clinic that have benefited from the good work of ACPA. Patients with cleft and other craniofacial conditions undergo numerous surgeries throughout their childhoods, beginning in infancy and continuing into adulthood, as well as years of therapy for feeding and speech, and appointments for dentistry and orthodontics. Together, with ACPA, professionals walk alongside patients at every stage of their journey.

To have the opportunity to be a leader in an organization with individuals that care deeply about interdisciplinary care, working together, building alliances, and improving the lives of our affected families, is the rarest of gifts. To my fellow members, generous donors and volunteers, and the patients we treat, thank you. It has been my honor to serve as your president this year. As we enter into 2020, I am excited to welcome Patricia Beals as our new president. I know she will do a fantastic job. I look forward to being part of the ACPA family for years to come and continuing our good work together.

Bernard J. Costello, DMD, MD, FACS
2019 ACPA President
Thank you for supporting ACPA in 2019. We are encouraged as we begin our 77th year dedicated to interdisciplinary team care.

As I reflect on the accomplishments we made together, I am filled with gratitude. In 2019 we created the President’s Circle to recognize our most generous donors. We also introduced a new ACPA Cleft Courage Bear to provide comfort to those affected by cleft lip and palate. We have expanded our network on social media and we are sharing more stories from patients and families. We updated and expanded our resources that provide vital information to those seeking answers during vulnerable times. I am pleased to report that we are in a position of fiscal strength and poised for future growth in 2020.

ACPA’s long-time programs continue to support the cleft and craniofacial community. These pages are full of excitement and success stories that would not be possible without the passionate ACPA Board of Directors, National Office Team, ACPA members, donors, volunteers, patients and families. I want to personally thank each and every one of you for your time, commitment, dedication and support.

It takes a team to fulfill our mission of creating a world where people with cleft and craniofacial conditions thrive. Thank you for supporting the cleft and craniofacial community.

Wendy-Jo Toyama, MBA, CAE,
ACPA Executive Director
About ACPA

The American Cleft Palate-Craniofacial Association (ACPA) is a 501 (c) (3) nonprofit medical association representing patients, families and the professionals who treat and perform research on cleft and craniofacial conditions. 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.

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 in 65 countries around the world.
Receiving the news that a child will be born with a cleft or craniofacial condition is often unexpected for parents and at times shocking. Filled with conflicting emotions of confusion and fear, yet also excitement for welcoming the new baby, parents begin searching for information—determined to find answers. Rachel, the mother of a child with a cleft lip and palate, knows the rollercoaster of emotions associated with this type of diagnosis all too well.

It was at her 20-week ultrasound when Rachel learned that her baby would be born with a cleft. At first, many tears were shed; then the search began. To her surprise, she came across ACPA’s website and found resources that gave her hope in the middle of her doubts.

“ACPA’s website was a huge help, especially when reading stories from other families. The website helped us gain so much information when we first learned of the diagnosis. Our gratitude is endless for this cleft community and our cleft team,” Rachel said.

Having access to reliable information and a community of support made all the difference during Rachel’s pregnancy. Her mind was put at ease knowing that she had information developed by professionals in the cleft and craniofacial field that she could trust. She found comfort knowing that other patients and families had experienced the same struggles and made it to the other side.

The ACPA website also lists ACPA Approved Teams as a resource to help families find interdisciplinary care. Before her son was born, Rachel connected with a local cleft team and actively prepared for the birth of her baby with confidence that everything would be alright.

Rachel’s son, Blake, is now one year old with a contagious smile that lights up every room. He has had two surgeries, one for his lip and one for his palate. Though the journey has not always been easy, Rachel and her family have had resources to guide them every step of the way. Today Rachel shares her story in hopes of helping others find the support they need.
# Numbers To Celebrate

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<thead>
<tr>
<th>Category</th>
<th>Number</th>
<th>Details</th>
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<tbody>
<tr>
<td><strong>Patients Served</strong></td>
<td>76,000</td>
<td>The 180 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.</td>
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<tr>
<td><strong>Medical Disciplines Represented</strong></td>
<td>33</td>
<td>ACPA members represent 33 medical disciplines, which includes plastic surgery, oral and maxillofacial surgery, orthodontics, otolaryngology (ENT), nursing, speech language pathology and more.</td>
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<td><strong>Professional Scholarships and Awards Granted</strong></td>
<td>3,000</td>
<td>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 cleft and craniofacial fields to join ACPA and attend ACPA’s Annual Meeting. Awards are granted to recognize dedication to research.</td>
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<td><strong>Abstracts Presented</strong></td>
<td>347</td>
<td>More than 840 professionals attended ACPA’s 76th Annual Meeting in Tucson, AZ, to network and learn about cutting-edge research and clinical innovations. Leading experts in the field presented oral and poster presentations.</td>
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<td><strong>College Scholarships Awarded</strong></td>
<td>8</td>
<td>ACPA Family Services awards college scholarships to outstanding students born with cleft or craniofacial conditions. This year’s awards totaled $8,000.</td>
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<td><strong>Publications Circulated</strong></td>
<td>19,557</td>
<td>ACPA Family Services provides patients and families with tools and educational support. Publications are distributed through professionals, by mail and online.</td>
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<td><strong>Articles Published</strong></td>
<td>191</td>
<td>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.</td>
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<td><strong>Cleft Courage Bears Distributed</strong></td>
<td>1,503</td>
<td>ACPA Cleft Courage Bears touch the lives of children, teens, and adults affected by cleft lip and palate. Whether cuddling a child on a stressful surgery day, bringing a smile to a challenging teenage time, or serving as a happy reminder of life’s achievements and gifts, these timeless bears give the best hugs and bring the biggest smiles.</td>
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<td><strong>Articles Presented</strong></td>
<td>304</td>
<td>Volunteers support ACPA’s mission by serving on the board and committees, reviewing journal articles, evaluating junior investigators, promoting ACPA on social media and chairing sessions at ACPA’s Annual Meeting.</td>
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Financials

Revenue

- Professional Dues ................. $461,000
- Donations* ......................... $496,000
- Investment Income ................. $76,000
- Annual Meeting Income ........... $526,000
- Other Income ....................... $220,000

TOTAL REVENUE ............. $1,779,000

Expenses

- Program Services ................. $1,095,000
- Management and General ...... $235,000
- Development ....................... $202,000

TOTAL EXPENSES ............ $1,532,000

*Written off pledges are deducted from donation revenue total.

2019 financials listed are unaudited.

Donations Received by Fund

- Unrestricted ............................... $422,781
- Mazaheri Young Professional Scholarship .... $25,000
- James Mulick Orthodontic Scholarship ....... $25,000
- Young Professional Service Award .......... $25,000
- Randall/LaRossa College Scholarship ........ $2,878
- Student Scholarships .................... $2,272
- Family Services Endowment ................ $1,350
- Research ................................ $1,086
- Other .................................... $1,860
2019 ACPA Board of Directors

Thank you to our dedicated board members. Your leadership over the past year has directly impacted the success of ACPA.

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Wendy-Jo Toyama: MBA, CAE, Executive Director, National Office Liaison

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 other craniofacial conditions, as well as the professionals who provide their care.

To donate, visit www.acpa-cpf.org/donate or call (919) 933-9044 ext 204.