



children's craniofacial association



2016 Annual Report

Message from the Executive Director



This past year brought many new opportunities to CCA. We are fortunate that since we began utilizing the bestselling children's novel *Wonder* in our public outreach efforts, we have been able to expand our educational offerings to a completely new audience – middle school students across the country!

Working entirely with volunteers, we've continued to create educational resources for educators that we distribute free of charge. Some of these tools include the Reader's Theater script, lesson plans, our WonderKids interview booklet, and classroom posters. Our "Real Life Auggie" speakers' bureau is by far the most important resource, where our Program Director matches classrooms who have just read the book with a real CCA Kid who will visit the class and give a short talk and host a Q&A. If no one is available in the area, we set up a Skype session and conduct the presentation and Q&A virtually. The success of this program is evident in the confidence and joy it brings to both the speakers and the audience. We are so grateful to have our children, parents, and even some adults participating. Our Real Life Auggies reached over 8,500 students last year and one of our most prolific speakers, 16-year-old Peter Dankelson, was recognized by Global Genes as the Rare Champion of Hope Teen Advocate of the year!

Beyond our public awareness and acceptance campaign, we continued our efforts to help families find the best care for their children. Our staff visited craniofacial teams around the country to update them on our efforts and invite their patients to apply to our expanded financial assistance program. We doubled our financial assistance made available in 2016 and it was utilized to help more patients than ever before! It is absolutely critical that families locate and seek out specialists for their children and CCA stands ready to help them get to those appointments and surgeries.

In closing, 2016 was marked as a year where we forged deeper relationships with our stakeholders and expanded our reach like never before. I am excited to continue these efforts in 2017, continuing to work with our medical professionals and educators alike, to help the world accept one another for who we are, not how we look.

Thank you for your support and your efforts to make the world a kinder place!

Sincerely,

A handwritten signature in cursive script that reads "Erica Mossholder".

Erica C. Mossholder

Executive Director

Mission

The mission of Children's Craniofacial Association is to empower and give hope to individuals and families affected by facial differences.

We envision a world where people are accepted for who they are, not how they look.

Programs

Information and Support – CCA disseminates information to educate craniofacial patients and their families, health care providers, schools across the country, and the general public regarding craniofacial conditions. CCA promotes public awareness of craniofacial conditions and social acceptance of individuals with facial differences. Craniofacial patient families often call CCA to seek emotional support, discuss problems, and identify resources. Through our database we are able to network families with support groups and/or others who have similar conditions and experiences. We also keep a list of helpful resources and are always willing to listen and offer emotional support to family members who need a shoulder to lean on.

Physician Directory – Children's Craniofacial Association provides the listing of the members of the International Society of Craniomaxillofacial Surgeons on our website and to new families who call. These surgeons head teams of specialists specifically trained in the surgical management of problems involving the face and head. Centers with craniofacial teams working together have the advantage of a greater experience to provide comprehensive, quality care, which leads to better results and fewer complications. In addition, ongoing research at these centers offers patients the latest breakthroughs in treatment. As there are relatively few experienced teams, it is quite common for families to travel long distance to get the best care. Furthermore, we have made it a point to gather and share research and interviews from these teams on our website and social media.

Financial Assistance – Since there are relatively few quality craniofacial centers, many families must travel to receive this quality care. The treatment of craniofacial patients may require from one to as many as twenty or more surgeries. Even families with insurance are often unable to meet the financial requirements to travel to receive quality care for their children. CCA offers funds for food, travel, and lodging through its financial assistance program. CCA also helps families find discounted hotel rates and donated airfare.

Website and Social Networks – www.ccakids.org offers another entry point for both parents and the public to learn about craniofacial challenges. More than 420,000 families, healthcare professional, and others have visited this site this year from 176 countries. The website offers up-to-date information about craniofacial conditions, issues related to having a craniofacial condition, esteem-building articles and interactions and information aimed to educate the public and families with a new diagnosis. Our Facebook, Twitter, and Instagram pages were all frequently updated with educational, inspirational, and programming content.

Choose Kind Wonder Initiative – Our Choose Kind Initiative started in 2012 when the book *Wonder* was published by R.J. Palacio. The novel, now a national bestseller, features the story of 10-year-old August “Auggie” Pullman, a boy with a craniofacial condition. This book follows Auggie his first year attending school after previously being home schooled. He experiences the trials and triumphs of most kids going to a new school, and also unique challenges based on his appearance. Our programs that incorporate this book are changing lives in classrooms across the country and teachers send reports of its impact on their students on a consistent basis. The book encourages kids to Choose Kind, meaning choose to be kind, rather than popular or right. While the story is about a student with a craniofacial condition, the message applies to everyone. When this book came out, CCA knew it was an incredible tool for our families, students, and community. We ordered a special edition book with our logo, recommended resources, a special foreword from CCA members, and a letter from the author, Palacio, to CCA Kids. To date, we have ordered and distributed 17,500 books, with an investment of 10,000 books in 2016.

Education Booklets – CCA has the most comprehensive library of publications that focus on educating families about craniofacial conditions and associated issues. To date, 14 syndrome booklets have been published that explain various craniofacial conditions and their treatment and are written in easy-to-understand text. In addition, 19 information papers have been published covering issues families dealing with craniofacial conditions experience.

Newsletter – A newsletter is published three times a year to inform more than 15,000 families and business supporters of CCA activities, as well as educate readers about the latest in craniofacial treatment and support options. The newsletter also addresses issues affecting not only the craniofacial patients but their siblings and parents as well. Subjects such as teasing, grieving, and other psychosocial issues are addressed.

Annual Family Retreat & Educational Symposium – The Annual Family Retreat & Educational Symposium is held each June and is what the CCA families describe as a life changing experience. It provides craniofacial patients, their siblings, and parents an opportunity to interact with others who have endured similar experiences. Children with craniofacial differences, their siblings and parents often feel isolated and alone. The unique weekend retreat allows them to share ideas, problems, and solutions, and make

long-lasting friendships. The informal format of this weekend allows time to build new relationships and bonds of understanding and caring, which will lend support through both difficult and good times in the future. An educational symposium is held on the first day of the 4-day event. Regional craniofacial specialists conduct the symposium. These professionals and health and wellness experts in the field donate their time and expertise to conduct educational sessions for adults, teens, and children who are affected by craniofacial conditions. The event includes other informational sessions, visiting local attractions, and plenty of time for adults to interact and kids to play. In our research survey, the families told us this retreat is the most important program we provide. Over 100 affected children attended in 2016, plus an additional 300 family members.

Public Awareness – One of the most important goals of CCA is to promote social acceptance of children and adults with facial differences. We believe that in order for the general public to accept these and any differences, they must see and understand them. With the support of Cher and many of our families, CCA has been featured in PSAs during *American Idol* and *House*, on the *Tyra Banks Show*, *Maury Povich Show*, and had feature articles in *People*, *Teen People*, *Allure*, *Abilities (Canada)*, *Family Circle*, and *Parade* magazines. Newspaper articles have appeared in *The Washington Post*, *The Dallas Morning News*, *Minneapolis Star Tribune*, *Fort Worth Star Telegram*, *The Atlanta Journal Constitution*, *Rapid City Journal*, and the *Buffalo Chip Gazette*. We are also working closely with the producers of the upcoming film, “Wonder,” which will debut in theatres Fall 2017, which stars Julia Roberts, Owen Wilson, and Jacob Tremblay (*Room*).

Family Networking – CCA has a list of more than 700 families who have volunteered to communicate with families new to CCA. They are eager to connect with these family members to share emotional support, discuss problems, and identify resources. Many families that have a member with a craniofacial condition feel alone and secluded. Being able to communicate with other parents, siblings, or patients can help family members feel part of a larger community with others who are ready to help them through rough times, work through decisions and just “be there” for one another.

Looking to the Future

CCA intends to grow. By 2018, we aim to host 150 families at the Annual Family Retreat and Educational Symposium and we are striving to reach \$1M in revenue by 2020.

We are also working on growing our Choose Kind Initiative to incorporate the film and intend to work closely with the production team, Lionsgate, and the cast.

CCA committed to adding \$27,000 to our scholarship fund for new and lapsed families to attend Retreat in 2017. This commitment will help us grow the program and enrich the lives of families who have never experienced the “four days that last a lifetime” and offer assistance to those who have not been able to attend in several years without a scholarship.

CCA will continue to grow our presence in the lives of the families we serve and use our donor dollars and staff and volunteer resources to empower and give hope to children and families whose lives are affected by craniofacial conditions and facial differences.

Please read on to see testimonials of program participants and CCA's financial statements.

cca retreat: a first-timer's perspective

hi, my name is **Charity Falk**. My daughters, **Cadee** and **Emma**, and I had the privilege to attend the 26th annual Cher's Family Retreat in Fort Lauderdale, Florida. This was our very first retreat and, gosh, was it life changing!

My daughter Cadee has Goldenhar syndrome and was very nervous to go to the retreat. (Heck, we all were.) She made every

us as if we had known them for years.

On our first day both girls attended several symposium sessions. Cadee went to one session about "Becoming My Independent Self," Emma attended a session for siblings called "Hey, Don't Forget About Me," and they both attended a session called "10-18 Year Olds with a Facial Difference and Siblings:

connected with since the retreat!

We had tons of fun! There was so much to do at the hotel that we decided to stay at the hotel almost the entire time. We took a walk down to the pier and got to see a very well-known country music singer's yacht/boat. We went to the pool, played on the swings, laid on the hammock and played ping pong. One day we had an outing to the beach, and it was absolutely beautiful! It was so very different than the beaches we are used to in Louisiana.

That night was the dinner/dance. During the dance, Cadee told me that she never wanted the retreat to end. She was one of the first kids to get on the dancefloor, and she even did the conga line! Her favorite part of the night was dancing with all the little kids.

That night I cried, not because I was sad, but because I saw my daughter not once worry if someone was looking at her or if someone was staring at her face.

The whole retreat I watched her blossom, but that night she was carefree. In 13 years I've never seen her let her guard down around people she had just met a few days before. Her happiness was infectious,



and all I wanted to do was smile and stop time. We took tons of pictures, exchanged phone numbers and emails, and became Facebook friends with so many new friends. I am overwhelmed at how welcoming, caring and accepting everyone was.

On our last day we had to say a fast farewell, because we had an early flight. We took more pictures with everyone, but one of our favorite pictures was with Cadee's fellow Goldenhar kids! This was the first time she has ever met someone with the exact same syndrome as her, and getting that opportunity was priceless! They are all now friends and she has stayed in contact with some of them since the retreat.

It took us a lot of years to get us to go to the retreat, and now we wish that we had gone many years ago—it was the absolute best weekend! I would just like to thank everyone who made this opportunity possible for us!



excuse possible to try and get out of it, but Annie and I eventually got her to go! You see, Cadee is an extremely shy person. Meeting new people and, honestly, sometimes just going to the store, is extremely difficult for her, so she was very apprehensive about going.

Once we got to the retreat and started meeting all the wonderful and welcoming families there, our nerves started to go away, and talking to each new person got easier and easier. Everyone welcomed

How to Be a Friend and Choose Kindness." Again, Cadee was very nervous about going and did not want to be called on during the sessions, but she came out with confidence and a smile. Emma told me that I would have been very proud at how much Cadee opened up and participated.

After the symposiums and dinner we went to the ice cream social and had the opportunity to meet some very special people who we have stayed

“testimonial



hello, as most of you already know, my name is **Genny**. I've been involved with Children's Craniofacial Association (CCA) since about 2004. Before CCA, I had very low self-confidence and was

unable to travel to Texas for 8 years to see my doctors. In those 8 years, my facial structure changed, but the size of my prosthetic eye stayed the same causing me to need two critical surgeries to correct the problem

I made several friends through CCA while attending the Retreats and being able to participate in the golf tournament and annual picnics. I have even had an opportunity to assist the CCA office staff in making *Wonder* packets

and preparing the items for the golf tournament.

Driving to Texas was a financial struggle before I was involved with CCA. In the time I've been involved with them, it has gotten much easier. CCA's assistance with travel and lodging expenses has allowed me to get the quality healthcare not available in Florida. The ability to get to Texas for needed medical care has improved my self image, expanded my confidence, and encouraged me to explore new ideas and new opportunities.



testimonial



We are beyond grateful for the assistance and support that CCA has provided to us. As many parents will agree, each child deserves the best possible medical care that is available. For us that meant traveling to Dallas, Texas, for surgery with **Dr. Fearon** and **Dr. Sacco**. With the help from CCA,

we were able to afford the costs associated with travel and rest more easily as we prepared for surgery.

My son, **Reed**, was born with craniosynostosis, specifically metopic with trigonocephaly. Reed underwent his first surgery at 7 months old in Chicago. Unfortunately, he suffered great blood loss and the outcome of surgery was less than favorable.

When it came time to choose a surgeon for his necessary second surgery, I knew that going out of state was our best chance for a safe, successful

outcome. I also knew that the costs would be much greater. CCA has been a great well of support. Without the assistance we've received, this journey would have been far more difficult to bear.

We are happy to announce that Reed's second surgery was a huge success. He required no transfusions this time around, and the overall outcome is exceeding our expectations. We are so very blessed and thankful to CCA for being an amazing part of our beautiful journey.

Love, Katie and Reed

**CHILDREN'S CRANIOFACIAL
ASSOCIATION**

Financial Statements

December 31, 2016 and 2015

CHILDREN'S CRANIOFACIAL ASSOCIATION
STATEMENTS OF FINANCIAL POSITION
December 31, 2016 and 2015

	<u>2016</u>	<u>2015</u>
ASSETS		
CURRENT ASSETS		
Cash and cash equivalents	\$ 407,095	\$ 443,682
Contributions receivable	74,355	6,072
Inventory	27,164	8,626
Prepaid expenses	5,552	4,257
Total current assets	<u>514,166</u>	<u>462,637</u>
PROPERTY AND EQUIPMENT, NET	1,413	1,838
OTHER ASSET		
Deposit	<u>1,727</u>	<u>1,727</u>
TOTAL ASSETS	<u><u>\$ 517,306</u></u>	<u><u>\$ 466,202</u></u>
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES		
Accounts payable	\$ 12,965	\$ 13,499
Accrued liabilities	4,276	4,877
Total current liabilities	<u>17,241</u>	<u>18,376</u>
OTHER LIABILITIES		
Deferred lease costs	<u>3,045</u>	<u>5,162</u>
TOTAL LIABILITIES	<u>20,286</u>	<u>23,538</u>
NET ASSETS		
Unrestricted	497,020	431,191
Temporarily restricted	-	11,473
	<u>497,020</u>	<u>442,664</u>
TOTAL LIABILITIES AND NET ASSETS	<u><u>\$ 517,306</u></u>	<u><u>\$ 466,202</u></u>

The accompanying notes are an integral part of these financial statements.

CHILDREN'S CRANIOFACIAL ASSOCIATION
STATEMENTS OF ACTIVITIES
For the years ended December 31, 2016 and 2015

	2016	2015
UNRESTRICTED NET ASSETS		
Support and Revenues:		
Contributions and grants	\$ 555,750	\$ 528,718
Special events income, net of direct donor benefits of \$2,842 and \$6,462, respectively	7,430	13,552
Other income	42,689	30,799
Interest income	101	119
In-kind donations	44,975	-
Net assets released from restrictions:		
Satisfaction of program restrictions	11,473	-
Total unrestricted support and revenues	662,418	573,188
 Expenses:		
Programs:		
Education and assistance	487,285	411,044
Support Services:		
Management and general	42,538	40,395
Fundraising	66,766	64,444
	596,589	515,883
 Change in unrestricted net assets	65,829	57,305
 TEMPORARILY RESTRICTED NET ASSETS		
Contributions and grants	-	11,473
Net assets released from restrictions	(11,473)	-
Change in temporarily restricted net assets	(11,473)	11,473
 Change in net assets	54,356	68,778
 Net assets, beginning	442,664	373,886
 Net assets, ending	\$ 497,020	\$ 442,664

The accompanying notes are an integral part of these financial statements.

CHILDREN'S CRANIOFACIAL ASSOCIATION
STATEMENTS OF FUNCTIONAL EXPENSES
For the years ended December 31, 2016 and 2015

	2016				2015			
	Programs	Supporting Services			Programs	Supporting Services		
	Education and Assistance	Management and General	Fundraising	Total	Education and Assistance	Management and General	Fundraising	Total
Salaries and related expenses	\$ 149,804	\$ 10,409	\$ 34,464	\$ 194,677	\$ 125,677	\$ 7,144	\$ 31,977	\$ 164,798
Bank charges	597	252	1,823	2,672	-	1,500	661	2,161
Depreciation	327	23	75	425	726	41	185	952
Dues and subscriptions	75	-	180	255	-	129	150	279
Equipment rental	557	5,293	-	5,850	1,907	1,453	-	3,360
Event expenses	110,036	-	-	110,036	138,763	-	-	138,763
Fundraising expenses	-	-	2,002	2,002	-	-	1,150	1,150
Individual assistance	49,821	287	-	50,108	47,002	-	-	47,002
Insurance expense	-	2,745	-	2,745	-	2,106	-	2,106
Office expenses	9,135	721	3,049	12,905	2,322	5,429	1,909	9,660
Postage	20,259	364	4,780	25,403	14,547	94	3,175	17,816
Printing	20,486	70	3,677	24,233	16,647	-	10,651	27,298
Professional fees	10,399	12,700	8,762	31,861	27,211	12,698	9,150	49,059
Public awareness	78,761	-	2,177	80,938	16,178	-	1,633	17,811
Rent expense	15,229	4,994	3,503	23,726	14,945	3,558	3,803	22,306
Telephone	3,033	2,109	-	5,142	5,027	337	-	5,364
Training	-	-	-	-	-	250	-	250
Travel and entertainment	18,703	1,749	2,274	22,726	92	5,482	-	5,574
Volunteer appreciation	63	822	-	885	-	174	-	174
	<u>\$ 487,285</u>	<u>\$ 42,538</u>	<u>\$ 66,766</u>	<u>\$ 596,589</u>	<u>\$ 411,044</u>	<u>\$ 40,395</u>	<u>\$ 64,444</u>	<u>\$ 515,883</u>

The accompanying notes are an integral part of these financial statements.