



children's craniofacial association



2015 Annual Report

## Message from the Executive Director



Saying 2015 was a Wonderful year is no exaggeration. One of CCA's biggest challenges over the years has been public awareness. Then, along came *Wonder*, written by R.J. Palacio in 2012, a book about a 5th grader who is entering public school for the first time, and who has a craniofacial condition. This masterfully written book continued to be a very important public awareness tool for CCA. Schools all over the world are using this book as a teaching platform, educating students about accepting differences in others, and facial differences in particular, and teaching them not to judge others, but to choose to be kind. We continued our *Wonder* book donation and discount program to ensure funding isn't an issue for schools to have access this book. By donating the book to schools in need and selling it at discount prices to others, thousands of students are learning the message of kindness and understanding and to stand up to bullying. We also continued to provide educators with teaching resources and our *Wonder* Reader's Theater script at no charge. In return, we have heard from many teachers that this book has "profoundly changed the lives of their students" and as a result, so will it change the lives of many people with differences.

We are so grateful for all of our individual, corporate and foundation donors who have allowed us to continue our many important programs and services. And again in 2015, we are grateful to the very families we serve, who stepped forward to raise a significant part of CCA's budget by holding fundraisers and approaching their workplaces for matching gifts. However, competition for funding is always a challenge, so guided by our strategic plan, we work diligently to widen our circle of support. In 2015, we focused on social media to open new revenue streams as well as implemented plans to increase corporate sponsorships and foundation support.

Please peruse the rest of our 2015 Annual Report to see how your dollars are making a difference in the lives of individuals and families affected by facial differences.

*Charlene K. Smith*

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 acted for who they are, not how they look.

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## Programs

**Information and Support** – CCA disseminates information to educate craniofacial patients and their families, health care providers, and the general public regarding craniofacial conditions. CCA also 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 Listing** – Children's Craniofacial Association refers to the full members of the International Society of Craniomaxillofacial Surgeons. 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.

**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. Therefore, even families with insurance are often unable to meet the financial requirements to travel to receive quality care for their children. CCA offers these families funds for food, travel, and lodging through its financial assistance program. CCA also helps families locate discounted hotel rates as well as donated airfare.

**Website and Social Networks** – [www.ccakids.org](http://www.ccakids.org) offers another entry point for both parents and the public to learn about craniofacial challenges. More than 340,000 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.

**Newsletter** – A newsletter is published three times a year to inform more than 15,000 readers of CCA activities, as well as educate families, donors, and interested parties of the latest in craniofacial treatment. 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.

**Family Networking** – CCA has a list of more than 700 families who are willing 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.

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**Choose Kind *Wonder* Initiative:** Our fastest growing program is the Choose Kind Initiative based on the bestselling children's novel, *Wonder*, by RJ Palacio, about a 10-year-old boy with a craniofacial syndrome going to public school for the first time. Through this book and our educator-developed-resources, CCA gives middle grade students (and beyond) a platform and excellent resources to become their own best advocates to prevent bullying by increasing self-confidence and self-reliance, and by promoting kindness as an ethical choice. CCA has purchased over 17,500 special edition copies of *Wonder* and we are distributing these texts in schools across the country and pairing our CCA Kids with classrooms to visit in person, via video conferences, and through pen pal activities.

**Education Booklets** – CCA has the most comprehensive library of publications that focus on educating families about craniofacial conditions and associated issues. To date a series of 14 syndrome booklets have been published that explain various craniofacial conditions and their treatment. The booklets, A Guide To Understanding Apert Syndrome, A Guide To Understanding Craniosynostosis, A Guide To Understanding Hemangiomas, A Guide To Understanding Hemifacial Microsomia, A Guide To Understanding Treacher Collins Syndrome, A Guide To Understanding Facial Palsy, A Guide to Understanding Crouzon Syndrome, A Guide to Understanding Fibrous Dysplasia, A Guide to Understanding Moebius Syndrome, A Guide to Understanding Microtia, A Guide to Understanding Pfeiffer Syndrome, A Guide to Understanding Pierre Robin Sequence, A Guide to Understanding Cleft Lip and Palate and A Guide to Understanding Frontonasal Dysplasia are in question/answer format, and are written in easy-to-understand text. In addition, 17 information papers have been published covering issues families dealing with craniofacial conditions experience.

**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 Thursday before the weekend activities begin. 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 condition parents, and siblings. The weekend includes other informational sessions, visiting local attractions, and plenty of time for adults to interact and kids to play. In our research survey a couple of years ago, the families told us this retreat is the most important program we provide. About 150 affected children will attend this year, 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 had public service announcements during American Idol and House, and has been featured twice on the Maury Povich Show, the Tyra Banks 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. In addition, CCA is featured under "Family and Friends" and in various press releases on Cher's official website.

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## Program Impacts

### **Big Potential**

By far our fastest growing program is *Wonder*, with its universal message and our excellent supplemental resources and ability to connect classrooms with "Real Life Auggies" to bring the book to life. In 2015, we distributed over 2,300 books, bringing our total since initiative inception to 7,500 books distributed.

### **Volunteer Support**

29 new volunteers were added in 2015 and 25 volunteers, both families and professionals, volunteered at the 2015 Family Retreat.

### **Financial Assistance**

Assisted 67 families with 91 trips

Average assistance granted per trip: \$510.34

Total amount spent through the end of December 2015: \$46,440.94

### **Booklets and One-Sheet Overviews**

We added 3 new overviews in 2015, all of which were written by Earl Gage, MD-Pediatric Plastic Surgeon, Mercy Children's Hospital, St. Louis, MO

"The 7 Things You Should Know Before Your Child's Surgery/A Surgeon's Tips for a Speedy Recovery;"

"Pain Management in Children: A Surgeon's Perspective;" and "Cyber Bullying"

### **Family Retreat & Educational Symposium**

107 families attended the 2015 Family Retreat & Educational Symposium, including families from 32 states and Australia, Canada, Mexico & Romania. CCA awarded 28 families a Retreat scholarship.

### **New Families**

472 new families added to the membership database in 2016

### **Craniofacial Acceptance Month (CAM)**

National Picnic Day took place on Saturday, September the 12th. Picnics were held in California (2), Florida (2), Illinois, Michigan (2), Nebraska, New Jersey, North Carolina, South Carolina, Texas, Utah and Virginia. Over 200 CAM packets were mailed.

### **Newsletter**

Published three newsletters and added an online newsletter published monthly

### **Ask the Doctor Blog Series**

We launched "Ask the Doctor" blog series. Each month Earl Gage, MD-Pediatric Plastic Surgeon, Mercy Children's Hospital, St. Louis, MO, answers a question from one of our families and we share his answer(s) on our CCAKids Blog.

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## Financial Position

This year for CCA, we had a generous bequest left to us, helping us gain some much-needed footing and close funding gaps. We had several grants come through this year, including a \$20,000 grant from the Steven and Mary Birch Foundation, \$10,000 from the Wheeler Foundation, and \$7,500 from the Tony Stewart Foundation. While we fell short on our Family Fundraisers \$270,000 goal, fortunately we have some well-established fundraisers that increased their revenues again this year and will be looking to add more Family Fundraisers in the coming year.

One area we would like to facilitate is online donations, so we are looking into a system that would make that process easier for the donor to navigate online and for the staff to process. We are also looking to add the capability of handling stock donations, as our account was closed several years ago.

CCA continues to receive the majority of our donations from Individual Contributions, many of those coming from the families we serve. We believe personal contributions and gifts are the strongest indicator of success and the lifeblood of any nonprofit organization. We are grateful for our generous donors.

If CCA intends to grow, as was established at this year's annual Board of Directors Retreat, we must prioritize development activities, including adding more fundraising events and ideally, corporate sponsorships.

## Looking to the Future

CCA intends to grow. By 2020, 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 and have ordered a new special edition *Wonder* book, with updated resources, a forward from two CCA members, and a letter from the author R.J. Palacio. We intend to distribute 10,000 more books over the next two years.

CCA committed to doubling the amount of financial assistance we award to families in 2016. This commitment will address the unmet needs of families seeking qualified care for craniofacial conditions.

CCA will continue to promote public acceptance for all people, based on who they are, not how they look.

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

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# testimonial



**M**y son, **Quinn Johnson**, was born on October 6, 2011, with a wide unilateral cleft lip and palate. We live in a rural area where there is no one who specializes in this condition, so we need to travel.

When I was pregnant, my perinatologist recommended the Children's Hospital of Philadelphia (CHOP). CHOP is three and a half hours away not including stops we have to make traveling with kids. We started going to CHOP when my son was four weeks old.

We then traveled there on a weekly, then monthly basis as Quinn was fitted for a retainer that helped naturally pull his lip together. The retainer needed tightening on a regular basis up until he had his lip repaired at the age of four and a half months.

This got to be very expensive. There were follow-up appointments after that, and he had his palate repaired at ten months old. He continues to have surgeries to place tubes in his ears due to his cleft and has follow-up appointments, and he sees his cleft palate team yearly.

There are a lot of organizations out there that offer resources for your child's condition but none that I have found that will help you with the financial burden of having to travel long distances to get your child the best care possible. That's the last thing you want to think about when you're faced with what to do and where to go, because this is your child and you want the best for them.

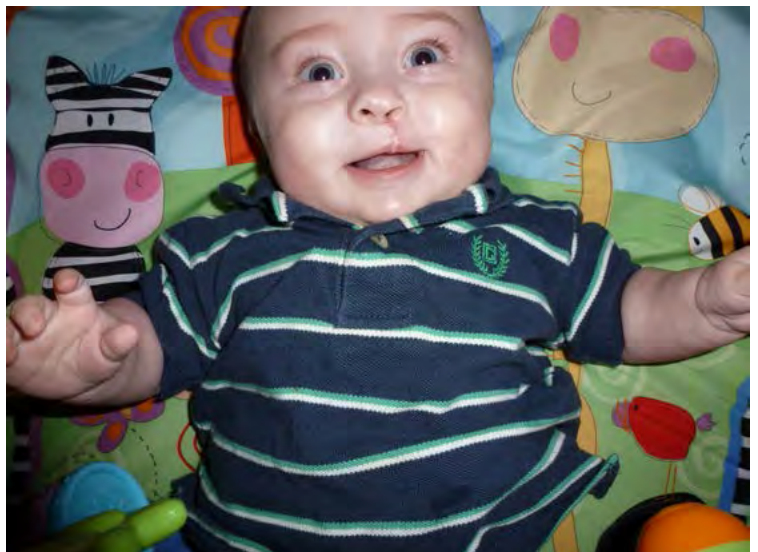
I then found Children's Craniofacial Association (CCA), and Annie is

absolutely wonderful. She is always so pleasant to talk to and willing to help you out in any way she can. CCA has helped us with hotels, food and gas, and it is such a relief to have financial help so you can focus on your child and not how you are going to get him to his surgeries and appointments.

I am very thankful for CCA and appreciate everything they have done for us—without them I do not know what we would have done. I hope one day I will be able to repay them plus more for all the help they have provided to our family, so they can help another family that is in the same situation as we are.

Thank you to CCA and everyone who donates to them and for all your continued support!

Colleen, Lance, Kailee,  
Quinn, Avie – Athens, PA



# testimonial

I was born in 1952 with Sturge-Weber syndrome\*, a birth mark that covers the left side of my face. It looked more like a bruise. The doctors wouldn't let my mother see me for a few days, and because I had such a rare condition the doctors weren't sure what it was.

By the time I was about a year old, my face had turned more pinkish and as the years went on, it became purple. I was diagnosed with glaucoma around age three or four. and although I am sure I probably had seizure activity, because of the type of seizures I have which only last a few seconds, I was not diagnosed with psycho-motor seizures until I was in my mid-20s.

When I hit puberty, the left side of my face, tissue and bones started to grow. In the early 1960's the doctors could not do much for my condition and my parents were told to wait until I had stopped growing before any surgery could be discussed. I was lucky to have my wonderful mom and dad who didn't take that advice lightly and from the time I was an infant continued to search out the best medical updates for the times.

By 1967, there was a procedure called derma-

tattoo. In theory, they were to make pigment to match the color of your skin and tattoo the port wine birthmark with the correct color. Unfortunately, it didn't work; when the pigment was put into the birthmark, the extra blood flow on that side of my face just washed it away.

It would not have been too much of a problem if that was all that happened; however, in my case, my birthmark covers the entire left side of my face and they used 150 thousand needles each time. I had 7 treatments which left a lot of scarring because of all of the needles that were used—there was literally no skin left on my face when they were done and the healing process was horrendous.

Once the skin healed, the initial results showed temporary promise that it was going to work, hence the reason for the additional treatments. But with time, the pigment was washed away; leaving the skin very damaged, scarred and pitted. I had multiple derma-abrasion treatments over the following years but that didn't help very much to correct the scarring.

At the same time, the birthmark and bones were growing and becoming



more of an issue with my nasal passage closing and my breathing. My first rhinoplasty and debulking was scheduled at University of Michigan, Ann Arbor, somewhere around 1968. I lost my left eye to glaucoma at age 21. I have had to have debulking/reconstructive surgeries on the average of every two to three years, sometimes twice a year due to the rate of growth. I lost count of how many surgeries, procedures or laser treatments I have had at 70.

Until 2003, I used doctors in Michigan. Unfortunately, I had a few bad surgeries that caused some complications that

could not all be fixed by local doctors. It is a terrible feeling to be told that no one can help you at the best hospitals in your state or the top doctors that you have been going to tell you that they have done all they can do for you.

In 2003, I found out about **Dr. Milton Waner**, who is based in New York City. Out of desperation, I went to see him on my vacation from work. He accepted me as a patient and told me that with the help of **Dr. Aaron Faye** (based in Boston) they would be able to fix a problem that I had been living with since a disastrous surgery about 10 years prior which



involved a cranial cut and the dropping of my left eye socket. They told me I would need about four surgeries to help correct it. Unfortunately, I lost my job and insurance in August 2004.

I was unemployed and without the funds to get back and forth to New York. I had just started the treatment plan with Dr. Waner and Dr. Faye and could see some promising results. It was then that I started looking for help from agencies that might be able to help with flights for medical purposes, etc. I could find no one that would help an adult—all of the services were for children.

I stumbled across CCA, Cher's organization, and it didn't look like there were any stipulations about adults receiving funds, even though the name was Children's Craniofacial Association. So I called **Annie Reeves** for the first time and was greeted by the sweetest lady who told me to apply and that she could probably help me. With all of the graciousness in the world, I have been receiving help from CCA for my past three surgeries.

I just had surgery in November 2014 and need another one as soon as I am healed. The doctors ask that I stay in New York City about seven to 10 days, where a hotel room

can run between \$200 and \$300 a night. Plus there's roundtrip airfare as well as expenses for food, taxis or rental cars and surgery-related incidentals. And, even though I am an adult, I need someone with me because I cannot fend for myself after a major surgery.

CCA has been generous to give me funds toward my expenses. I want you to know how much I appreciate what CCA has done for me in the past—and to let you know that the child inside of this adult still hopes and prays that the next surgery will be the last surgery, and the one that will make me look "normal."

Thank you all from the bottom of my heart!

Sincerely,  
Leslie Anne Trout

*\*Sturge-Weber syndrome is a rare congenital neurological and skin disorder and is often associated with port-wine stains of the face, glaucoma, seizures, mental retardation. It is characterized by abnormal blood vessels on the brain surface. Normally, only one side of the brain is affected.*

**CHILDREN'S CRANIOFACIAL ASSOCIATION**  
**STATEMENTS OF FINANCIAL POSITION**  
December 31, 2015 and 2014

	<u>2015</u>	<u>2014</u>
<b>ASSETS</b>		
CURRENT ASSETS		
Cash and cash equivalents	\$ 443,682	\$ 359,075
Accounts receivable	6,072	7,645
Inventory	8,626	21,766
Prepaid expenses	4,257	7,350
Total current assets	<u>462,637</u>	<u>395,836</u>
PROPERTY AND EQUIPMENT, NET	1,838	1,589
OTHER ASSET		
Deposit	<u>1,727</u>	<u>1,727</u>
<b>TOTAL ASSETS</b>	<b><u>\$ 466,202</u></b>	<b><u>\$ 399,152</u></b>
<b>LIABILITIES AND NET ASSETS</b>		
CURRENT LIABILITIES		
Accounts payable	\$ 13,499	\$ 12,543
Accrued liabilities	4,877	6,133
Total current liabilities	<u>18,376</u>	<u>18,676</u>
OTHER LIABILITIES		
Deferred lease costs	<u>5,162</u>	<u>6,590</u>
<b>TOTAL LIABILITIES</b>	<b><u>23,538</u></b>	<b><u>25,266</u></b>
NET ASSETS		
Unrestricted	431,191	373,886
Temporarily restricted	11,473	-
	<u>442,664</u>	<u>373,886</u>
<b>TOTAL LIABILITIES AND NET ASSETS</b>	<b><u>\$ 466,202</u></b>	<b><u>\$ 399,152</u></b>

*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, 2015 and 2014

	2015			2014				
	Programs Education and Assistance	Supporting Services Management and General	Fundraising	Total	Programs Education and Assistance	Supporting Services Management and General	Fundraising	Total
Salaries and related expenses	\$ 125,677	\$ 7,144	\$ 31,977	\$ 164,798	\$ 116,481	\$ 6,247	\$ 30,734	\$ 153,462
Bank charges	-	1,500	661	2,161	39	2,332	500	2,871
Depreciation	726	41	185	952	725	42	185	952
Dues and subscriptions	-	129	150	279	-	-	150	150
Equipment rental	1,907	1,453	-	3,360	954	2,661	-	3,615
Event expenses	138,763	-	-	138,763	130,645	-	-	130,645
Fundraising expenses	47,002	-	1,150	1,150	-	-	487	487
Individual assistance	-	-	-	47,002	33,969	-	-	33,969
Insurance expense	-	2,106	-	2,106	-	2,206	-	2,206
Office expenses	2,322	5,429	1,909	9,660	1,547	4,669	345	6,561
Postage	14,547	94	3,175	17,816	16,959	555	9,756	27,250
Printing	16,647	-	10,651	27,298	13,705	586	4,141	18,432
Professional fees	27,211	12,698	9,150	49,059	12,516	12,882	6,644	32,042
Public awareness	16,178	-	1,633	17,811	22,795	-	300	23,095
Rent expense	14,945	3,558	3,803	22,306	15,699	842	4,142	20,683
Telephone	5,027	337	-	5,364	4,863	256	39	5,158
Training	-	250	-	250	250	-	-	250
Travel and entertainment	92	5,482	-	5,574	99	3,739	-	3,838
Volunteer appreciation	-	174	-	174	-	-	-	-
	\$ 411,044	\$ 40,395	\$ 64,444	\$ 515,883	\$ 371,246	\$ 36,997	\$ 57,423	\$ 465,666

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