



children's craniofacial association
20 Years of Giving Hope
1989-2009

2009 annual report

Dear Friends,

In 2009 Children's Craniofacial Association celebrated 20 years of empowering and giving hope to individuals and families affected by facial differences. We are proud to be the premier organization addressing a broad range of medical, financial, emotional, psychosocial, and educational issues related to craniofacial conditions.

The 20 year journey has not been without its struggles, but always keeping a keen eye on the needs of our families, we persevered. And, with the help of generous donors, volunteers, and those families we serve, CCA managed to fight through the lean years. Even in this very tenuous economy, we continue to provide important programs and services to all who are affected by facial differences.

CCA touched many lives this year. Among our wide array of programs and services, we added to the series of syndrome booklets and began translating them to Spanish. We continued to publish an informative quarterly newsletter, provide financial assistance so families could receive quality medical care, conducted an educational symposium and held our 19th Annual Family Retreat, providing scholarship funds for more than 20 families to attend.

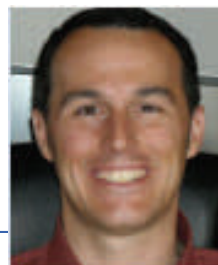
Thanks to many people lending their "time, talent and treasure," CCA will continue to serve our families until we achieve our vision of a world where all people are accepted for who they are, not how they look.

Sincerely,

Charlene Smith
Executive Director



George Dale
Chairman of the Board



cca celebrates 20 years of service



Founded in Dallas in 1989,

CCA's mission is to empower and give hope to individuals and families affected by facial differences.

1989—2009

19th annual family retreat

My name is Kathie and my **eight-year-old, daughter Hannah** was born with hemifacial microsomia and microtia. Hannah struggled with the results of her surgeries and the reaction of her friends to her changes. As a result to their reactions, she came to me and begged me to help her find a friend like her, who understood how hard it is to be a little different from other people and who would just love her for her. After doing some Internet research, that request led us to **Children's Craniofacial Association**.



We were informed of the **Annual Family Retreat** but were unsure whether or not we could afford the trip. Finally we decided that Hannah really needed this group and we had to find a way to get her there. So, on a wing and a prayer, Hannah and I flew to the retreat. There are no words to describe what we felt while we were at the retreat with the CCA kids and families.



I could try to describe the immediate sense of belonging, the shared sense of love and concern for our children, the highs and lows we all face through intense medical care, but I can't seem to find the right words. **I guess we just felt like we were at home. It was wonderful!**

Hannah was able to sing at the talent show, and it was so great for her. She has an incredible love of music, and it was so fun for her to share that with her new friends. The night after the talent show, as I was putting her to bed, she said, "Now all of my dreams have come true. I met new friends just like me and I got to sing on stage!"

I am now a firm believer these children need this retreat! It was perfectly perfect! **I am so grateful to the individuals and organizations donating time and money to make this happen for these kids.** I wish they could have seen them all together, living, loving, laughing – not at all worried about acceptance or appearance. I wish you could read my heart and know how much it means to me that we have a place to go every year, where Hannah can let her hair down and just enjoy being herself, without having to worry about feeling out of place or different.



June 25—29, 2009
Grapevine, Texas



CHILDREN'S CRANIOFACIAL ASSOCIATION
19th Annual Cher's Family Retreat



We have had to go to Boston five times in the past two years, and every time CCA has been there to meet our traveling needs. I know there are more surgeries in my daughter's future, and it's nice to know CCA is there wanting to help families like ours get to qualified medical care. With CCA's help we didn't have to worry so much about the traveling part and we could focus more on taking care of our daughter before and after surgeries.

I continue to be in awe that such an organization even exists! The help CCA has given our family to get our daughter to quality medical care is the most amazing gift we have ever received. **I honestly don't know if it would have been possible without CCA, and I thank God for them every night.** Sydney is now two years old and is the happiest, healthiest little girl I know.

It is difficult to put into words how much CCA's help has meant to us, but I look forward to one day meeting these very special **CCA angels who are now part of our family and thanking them from the bottom of my heart!**



financial assistance

Webinars

Helping Your Child Cope with Teasing

Susan Porter-Levy

Licensed Clinical Psychologist
Dallas, TX

Resonance Disorders

And

Articulation

How Parents Can Be An Advocate for
Their Children While in the Hospital

Amy Smith, CCLS
Dallas, TX

Conducted

three Webinars

in 2009

Craniofacial symposium

"The topics were current and very informative. I learned so much and my kids got to interact with others during the sessions for affected children and their siblings. I hope CCA continues to hold the symposium." Rose

On June 23, 2009 Children's Craniofacial Association held its first craniofacial symposium in 15 years. Dallas-area healthcare professionals presented on topics geared to educate and inform children and adults

affected by facial differences as well as

their family members. **Topics included Family Dynamics, Syndromic Craniosynostosis, Etiology of and Association of Hydrocephalus and Chiari Malformations with Complex Craniosynostosis, Implications of a Compromised Airway, The Use of Anthropometric Measurements, Self-Esteem and Coping and others.** Sessions were lead by physicians and other healthcare professionals.



s y n d r o m e b o o k l e t s



Until Children’s Craniofacial Association started publishing syndrome booklets parents had to try to understand medical journals to find out about their child’s condition.

CCA saw a need and acted. Since the early 1990’s 13 Syndrome booklets have been published

In 2009 Children’s Craniofacial Association translated 5 of its thirteen syndrome booklets to Spanish to meet the needs of our Spanish speaking families. In addition, A Guide to Understanding Cleft Lip and Palate was added to the series of booklets.

Around 15,000 hard copies of the CCA newsletter are mailed quarterly and many more are viewed online. The newsletter contains informative and supportive articles to educate and support families affected by facial differences.

n e w s l e t t e r s



CCA provides various opportunities for social networking for both adults and children.

CCA's Yahoo Group offers families the opportunity to support each other 24 hours a day, 7 days a week.

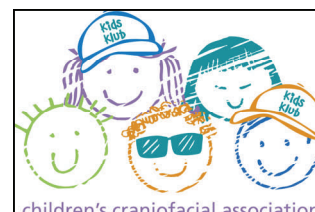
Facebook offers the opportunity for family members to share the lighter side of their daily activities and gives CCA another opportunity to keep families networked and informed.

Care pages is offered as a convenient way for families to keep family members informed of their child's progress when they are in the hospital without making numerous phone calls, thus allowing more time to focus on the child's recovery.

There is a **CCA Kids Klub** for kids of every age group. Kids Klubs are for kids with facial differences, their siblings and even for their friends. Monthly activities allow them to express their thoughts and feelings in creative ways and being part of a club fosters a sense of belonging.

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ccakids.org continues to be the leading website providing on-line resources for individuals and families affected by facial differences. A wealth of educational information coupled with a vast array of resources to provide support and comfort, provide and links to other informative websites, make



Craniofacial Acceptance Month

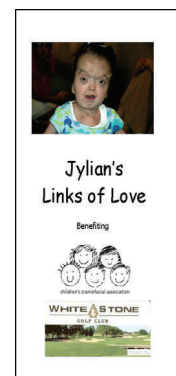
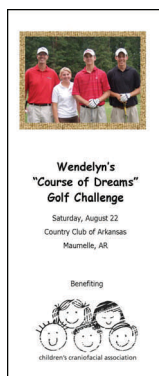
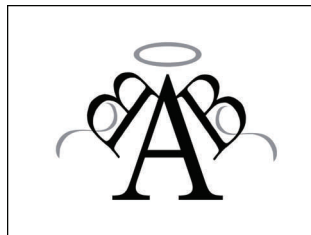
September 2009 marked the Fifth Annual observance of Craniofacial Acceptance Month and the second National Family Picnic Day. In observance, family picnics were held across the country, fundraisers were conducted and special commemorative wristbands were designed and sold, articles were published and 18 governors proclaimed September Craniofacial Acceptance Month in their states.



Our goal is to spread awareness that will foster acceptance of children and adults with facial differences. For the fifth consecutive year, we are *Widening the Circle of Acceptance* through our theme, **"Beyond the Face is a Heart"**, demonstrating that beyond a person's exterior is the 'heart' or the 'real person' within. We envision a world where all people are accepted for who they are, not how they look.



The very families CCA serves are taking a major role in raising funds. Not only are they ensuring the continuation of programs and services, but they are also validating their importance. In 2009 our families raised more than \$150,000 through satellite fundraisers across the nation.



Family Fundraisers

Each year in accordance with stewardship responsibility to stakeholders, Children’s Craniofacial Association contracts an independent auditor to conduct a thorough examination of our financial position.

FINANCIALS

Children’s Craniofacial Association

Statement of Financial Position

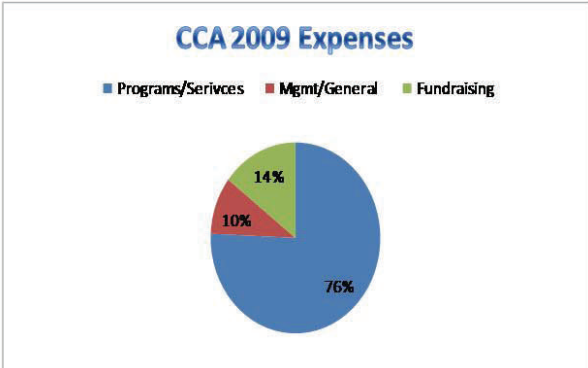
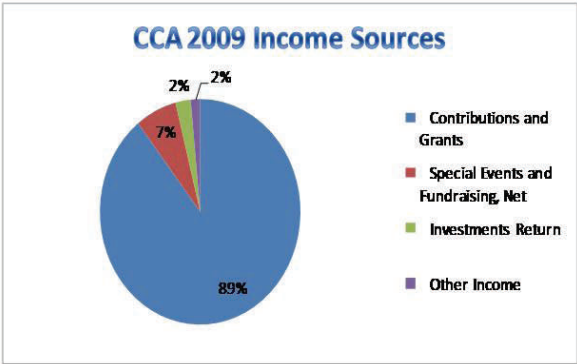
December 31, 2009

ASSETS

CURRENT ASSETS	
Cash and cash equivalents	\$ 400,552
Accounts receivable	90,234
Inventory	1,500
Prepaid expenses	<u>2,095</u>
Total current assets	494,381
PROPERTY AND EQUIPMENT, NET	596
OTHER ASSETS	
Deposit	<u>1,727</u>
	<u><u>\$ 496,704</u></u>

LIABILITIES AND NET ASSETS

CURRENT LIABILITIES	
Accounts payable	\$ 7,605
Accrued liabilities	<u>2,981</u>
Total current liabilities	10,586
OTHER LIABILITIES	
Deferred liabilities	5,171
NET ASSETS	
Unrestricted	<u>480,947</u>
	<u><u>\$ 496,704</u></u>



Leadership

board of directors

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Corning Incorporated
Corning, NY 14831

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Youngstown, OH 44514

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Paula Guzzo
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Pediatric Neurosurgeon
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Emily Youngblood	Rob Gorecki	Janell Nelson	Arlon Tietz
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<u>"CCA Extended Family" (\$500 +)</u>	Ronald & Lori Angel, in memory of John Haycraft	Kathleen M. Dunn in memory of Bill Dunn
Mario Adamo	Anonymous, in memory of Rick Dornier	M.L. & Ann Ekas, in memory of Margaret Ekas Patterson
Anonymous	Anonymous, in honor of John Gorman	Tim B. Elkins, Sr., in memory of Rick Dornier
Martha & James Brown	Anonymous, in honor of Annie Reeves' birthday	Hope Estrada, in honor of Annie Reeves' birthday
Joe Cherry	Anonymous, in memory of Ellery Everett Walker	Jeffrey Fearon, MD, in honor of his colleagues
Roger S. Chin DDS, PS	Lemmu & Sallie Austin, in memory of Ellery Walker	Eric Forseter, in memory of Ellery Everett Walker
Neil & Lori Citrone	Bad Girls Book Club of Austin, in memory of Margaret Ann Ekas Patterson	Patrick & Delores Fox, given in the name of Jeff &
Diana Critchlaw	Yolanda Baker, Austin, TX, in honor of Henry Johnson	Emily Stiers on their wedding day, in honor of Avery Lytle
Jill Gorecki	Thomas & Candace Barton, in memory of Mark Warren	Fred & Judi Freeman, in honor of Michael Esser's college graduation
Tate & April Gorman	Dave Bhavna, in memory of John Haycraft	Friends of Freddie donations, in honor of Fr. Tim O'Neil
Paul & Fran Leatherwood	Kevin & Julie Bonahoom, in memory of Margaret Patterson	Phil & Lynn Gadd, in memory of Ellery Walker
Mary Lytle	Carolyn Bonfanti, in memory of Rick Dornier	Fred & Estelle Gagliardi, in honor of Rick & Janet Gagliardi at Christmas
Susan Martin	Deborah Breslow, in honor of Mrs. Alice Kintisch, Edith Katzourin, Rabbi Elyse	Linda Gaida, in memory of Ellery Walker
Elena Melius	Frishman, Cantor Leon Sher, thanks for helping with	Jeremy Gaige, in memory of Ellery Walker
Mitchell Family	Robbie's Bar Mitzvah preparation	Geoffrey Garin, in memory of Lili Smith
Virginia Moores	Sharon & Thomas Brown, in memory of Pauline Burzio	L. Goodwin, in memory of Ellery Walker
Robert Potts	Brookhall School Staff in name of Janice Stegmann	Sylvia Gonzales, in memory of Ellery Walker
Chase Stehr	Edward Brooks, in memory of Ellery Walker	Erick Gorecki, in memory of Margaret Patterson
<u>"CCA Sponsor" (\$1,000 +)</u>	Christian Callens, in memory of Sidney Goldman	Rob Gorecki, in memory of Johnny Pag
Anonymous	Larry Carpenter, in honor of Cher's birthday	Rob Gorecki, in memory of Margaret Patterson
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Jeffrey Fearon, MD	Rex Coppock, in memory of Ellery Walker	Erin Greer, in memory of John Haycraft
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Kenneth Wilson	Gary & Grace Deily, in honor of Jeremy Dale	Jim & Arleen Heirty, in memory of Kathy Conour
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Hazeldeane Pritchard Bequest		
<u>Memorials / In-Honor Gifts</u>		
Amye M. Adkins, in honor of Cher		

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Margaret Jenna, in memory of Maxine Reed	Jean O'leary, in memory of Sidney Goldman	Charlene Smith, in honor of Annie Reeves' birthday
Doug & Kirsten Jumper, in memory of Margaret Patterson	Johnny Pag, in honor of Robbie Gorecki	Charlene & John Smith, in honor of the birth of Reid Smith
David & Shelly Katz, in memory of Ellery Walker	Greg & Jill Patterson, in memory of Rick Dornier	William & Nancy Suwalski, in memory of Victoria Suwalski
Linda & Rudy Kessman, in honor of Natasha Urban	Greg & Jill Patterson, in memory of Johnny Pag	Lisa Tafolla, in memory of Ellery Everett Walker
Susanne Laird, in memory of Ellery Walker	Greg & Jill Patterson, in memory of Margaret Patterson	Team Margaret, in honor of Margaret Patterson
Beverly & Jack Landry, in memory of Margaret Patterson	Margaret Patterson family, in memory of Mack Hamilton	Doris & Ralph Teneyck, in honor of Tamara Mantlo
Tom & Barbara Lawhon, in memory of Ellery Walker	Jimmie & Gina Pavlu, in memory of Ellery Walker	Neva Tomlinson, in memory of John Haycraft
W. David & Rhonda Leonard, in honor of Casey Deakins	Jana Peace, in memory of Margaret Patterson	Neva Tomlinson, in memory of Jim Weaver
Sylvia & John Loving, in honor of Ryan Holliday	Gloria Pike, in honor of Aidan Skees	Neva Tomlinson, in memory of David Williams
Ann Lucas, in honor of Brody Lucas from grandparents	Carol Porter, in honor of Sydney Rose Ford	Mary & Truman Terrell III, in honor of Justin Prince
Ann Lucas, in honor of Don Lucas for Father's Day	Linda Post, in memory of Margaret Patterson	Timber Ridge Elementary School Collection in honor of Cale Morris
Don & Ann Lucas, in honor of Ann's Birthday	Robert Potts, in honor of John Gorman	Karen VanSchalk, in honor of her wedding
Ann Lucas, in honor of Don's Birthday	Harold & Elvia Prange, in memory of Carolyn Muse	Connie Vegelgesang, in memory of John Haycraft
Emily & Jon Lukowski, in memory of John Haycraft	Mary & Megan Reif, in honor of JoAnn Kopshinsky & Robbie Gorecki	Alicia Vitarelli, in honor of Ava Beeler
Doris Capps Mabry, in memory of Margaret Patterson	Lois Rieck, in memory of Ellery Walker	Dennis & Amy Waid, in memory of Rick Dornier
Janis & Doug Macut Family, in honor of Dr. Sava & Dottie Macut at Christmas	Bill & Donna Rinehart, in memory of Margaret Patterson	Janis Buzzbee Walton, in honor of Rick Dornier
Susan Martin, in memory of Ellery Walker		Lawrence & Ellen Ward, in memory of Margaret Patterson
		Karen Waring, in honor of Megan Cronin

<p>Wesley Healthcare employees honor Fran Cronin Barbara Wiedenman, in memory of Jennifer Walker Mary Wilcox, in the name of Sarah Wilcox Joseph & Rosalia Wilkes, in memory of Sidney Goldman J.B. & Cynthia Wills, in honor of Reed Wills Emily Youngblood, in honor of John Gorman Dave Zucker, in memory of Ellery Walker Michael Zukowski, in memory of Ellery Walker</p> <p><u>Jilly Bean Bunch</u> (Donations given in Jylian Bilbow's name for Financial Assistance to Families) Sponsors of Jylian's Links of Love Golf Event Richard Urso</p> <p><u>Corporate/Foundation Gifts</u> “ <u>CCA Corporate/Foundation Friends" (up to \$1,000)</u> AT&T (Employee Giving) American Express (Employee Giving) American Express Charitable Fund (Matched Gifts of Janell Nelson) Anonymous Aptus Partners, LP (John Romero) Attachemate/NetIQ (Matched gifts of employees) Baby Hands Down by Erin Scott Baker Roofing Company Bank of America (United Way Campaign Employee Giving) Charity Motors (CARS-Charitable Auto ResourceS) Children's Medical Charities (CFC) Cleveland Bakers Local No. 19 Creative Growth Counseling & Coaching, Inc. Danze & Blood Architects DFWBID Dominion Foundation (matched gift of John Charles Larson) Dorroh & Kendrick Deutsche Bank Americas Foundation (Matched Gift of Kent Penwell) Epic Systems, Inc. Five Star Quality Care, Inc. (recommended by Robert Sharrett) Frugal Flower, Inc. (purchases percentage) Funding Factory (Ink/cell recycle rebates) GoodSearch/GoodShop Home Depot (Matched Gifts of Doug Hopkinson) JackTheDonkey.com by David Katz Jefferson Lumber and Millwork by Mary Lytle Johnny Pag Creations Justgive (donors listed separately) Katie's Clothes Bin (by John & Laurie Bovenkamp family) Katsafouros Bequest Legacy Global Foundation directed by the Mitchell family A grant from Kraft Foods Global, Inc. Kroger (purchases percentage incentives)</p>	<p>Neal Oral & Maxillofacial Surgery, PLLC Network for Good (donors listed separately) One Cause (purchases incentives) PASCO (Personal Assistance Services of Colorado) Pfizer (United Way Campaign Employee Giving) Prudential Foundation (Employee/Matching Gifts) Prudential Foundation (Matched Gift of Diana Critchlaw) Random House, Inc. (Matched Gift of Heather Miller) Redwoods Group (Matched Gift of Bill Mecklenburg) Safeway, Inc. (purchases percentage incentives) Saidman & Associates, Inc. Sarah Hall Productions by Sarah Hall Schoolpop, now One Cause (online purchases percentage program) Steam Clean Pressure Wash by Todd Rademacher Schwab Charitable Fund (Donor Advised) A grant from Starlight Foundation, Inc. A grant from Tektronix Foundation (Larry Bolton) Truist for Qwest (Employee Giving) United Way of California.Capital Region (Donor-Directed Donations) United Way of Central Maryland (Donor-Directed Donations) United Way of Greater Milwaukee (Donor-Directed Donations) United Way, Heart of Illinois (Donor-Directed Donations) United Way Mile High (Donor-Directed Donations) United Way New York (Donor-Directed Donations) United Way of Southeastern Pennsylvania (Donor-Directed Donations) United Way of Southern Tier-Corning, NY (Donor-Directed Donations) United Way of Tucson and Southern Arizona (Donor-Directed Donations) WJH Investments Wesley Healthcare (employees of Fran Cronin) Wellpoint Foundation Funds Management (Employee Giving) Wellpoint Foundation (Matched Gifts) Wells Fargo (Employee Giving)</p> <p><u>CCA Corporate/Foundation Sponsors (\$1,000-\$5,000)</u> Association Works by John & Sheryl Paul A grant from the Chatlos Foundation A grant from Lifetime Fitness Foundation A grant from the Perot Foundation The Redwoods Group (Matched Gift of Bill Mecklenburg) Starbucks Coffee Company Vivo Brothers, Inc.</p> <p><u>CCA Corporate/Foundation Partners (\$5,000-\$10,000)</u> A grant from the Max & Victoria Dreyfus Foundation A grant from the Jorge Posada Foundation A grant from May & Stanley Smith Charitable Trust</p>
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Triangle Foundation (Donor-Advised Grants) A grant from Martin Woodall Foundation, Inc.	Snowman Auction / Barbers Hill ISD Gifted & Talented classes / Tracy Tidwell, organizer in honor of Wade White
CCA Corporate/Foundation Patrons (\$10,000 or more)	<u>\$1,000-\$5,000</u>
Cher Charitable Foundation	Be Brody's Angel / Jennifer Lucas & Family, CCA Volunteers CCA Family Retreat Chance Raffle
<u>Fundraising Events & Other Efforts</u>	Cher Convention / Kim Werdman, Judy Didelot, Coordinators
<u>Up to \$1,000</u>	Family Fun Stimulus Package Raffle / Matthew Abernathy, CCA Volunteer w/Jana Peace
Alcan Cable Denim Day for CCA / ARA (Alcan Recreation Association, Employee Group)	Friends of Freddie Firstgiving Page / Rose Seitz, CCA Volunteer
Aptus Partners LP	Jaci's Country Dance Bash / Jaci Samhammer, CCA Volunteer
Baltimore Marathon / Firstgiving Page / Pamela Mishra, CCA Supporter	Johnny Pag Motorcycle Raffle
Brookhall School Staff Collection in name of Janice Stegmann	Dawn Page Firstgiving Page
Carnival of Caring / Avery Lytle, CCA kid	Smiling Through The Mask Dinner / Wendelyn Osborne, CCA Volunteer
Cash Can / Freeman Insurance, CCA Supporter	Starbucks Community Clean-Up / Emily Tipton, Organizer w/Jana Peace, CCA Volunteer
Cash Can / Kim Rogers, CCA Volunteer	Tamale Sale / Booz Allen Hamilton, Houston & Aldine Church Ladies Group- Abigail De Los Reyes, Organizer in honor of Natalie Wardlaw
Janis Cazare's Firstgiving Page	Hopkinson Family, Donation through Awareness Effort
Charity Big Top Show / Erica Mossholder, CCA Volunteer	<u>\$5,000 or more</u>
Cher Charitable Foundation	Alexa's Appeal for CCA / Denise Rast, CCA Volunteer
Ink / Cell Recycle for CCA / CCA Families & Friends	Lily's Dinner for CCA / Tosha Walker, CCA Volunteer
Jewelry Sale / Peggy McDannel	Ryan's Road / Gulich Family; Nicole, Ryan, Ryan Jr., Lauren, Madalynn
Jewelry Sale / Robyn Johnston	Seth's Stride / Swihart Family; Stacy, Mitch, Seth, Gabe, Sydney
Little Fire, Big Hearts Dinner Auction for CCA / Taryn Skees, CCA Volunteer	<u>\$10,000 or more</u>
Tamara Mantlo's Firstgiving Page	Jylian's Links of Love Golf Tournament / CCA & Bilbow Family; Kendall, John, Jylian, Mikey, Ivy
Jana Peace Email Fund Appeal	Wendelyn's Course of Dreams Golf Tournament / Wendelyn Osborne, CCA Volunteer
Orland Park Village Denim Day / in honor of Kate Rogers, CCA kid	<u>\$20,000 or more</u>
Pampered Chef / Jessica Dornier / Bobby Mayo, in honor of Rick Dornier	Chocolate Festival / Rick Chiavari / Aventura Mall
Penny Drive / Angela Marcum / Lincoln Heights Elementary	Friends of Jeremy Golf Tournament / Dale Family; Kristine, George, Jeremy, Tommy, Cody
Permission Men's Skin Care Line	Henry's March / Johnson Family; Rachel, TJ, Lauren, Henry
PetroCasa Energy Chili Cookoff	Heroes 4 Hope Gala / Jorge Posada Foundation / beneficiary, CCA
Solis Women's Health Holiday Collection	
Timber Ridge Elementary School Collection in honor of Cale Morris	
Hannah Steinagel's Firstgiving Page / Kathie Steinagel, CCA Volunteer	
Sammi Wayne's Lemonade Sale for CCA / Samantha & Jennifer Wayne	

CCA Board of Directors, Staff and Families wish thank all of our individual, corporate, foundation and in-kind donors.

2009



children's craniofacial association

13140 Coit Road, Ste 517
Dallas, TX 75240

Phone: 214-570-9099
Toll Free: 800-535-3643

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