The Vision of Children

OUR MISSION:

To cure hereditary childhood blindness and other vision disorders, and to improve the lives of visually impaired individuals and their families.

DUAL BOCELLI EVENTS RAISE OVER \$700,000

Live at Madison Square Garden...

Volume 9, Issue 1

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Once again, The Vision of Children partnered with internationally renowned Italian tenor Andrea Bocelli for "An Evening With Andrea Bocelli", this time with an added bonus... a second show in New York City on November 30th! Together the two events helped raise over \$680,000 for the Foundation's sponsored vision research!

Nearly 100 guests gathered in New York City's Madison Square Garden for a pre-concert auction and reception prior to and following the sold-out concert. Although Andrea Bocelli has partnered with The Vision of Children Foundation a total of five times, this was a first for New York City.

Guests were treated to champagne and hors d'oeuvres prior to the concert, followed by a coffee and dessert reception after

Bocelli's performance.

Bidders at the reception were able to choose from an exciting B-24 Bomber Flight experience, a Weekend for 2 in San Diego, and exclusive invitation for 2 to Garth Brooks' Teammates for Kids Party in Las Vegas, and impossible-to-get tickets to Jersey Boys. The auction was so successful that an additional bomber experience and San Diego trip had to be added!



East Coast Family Network Members: from left, Karen Primak, Hillary Portnoy, Lorenza Triebenbacher with Co-Founder Vivian Hardage

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Meanwhile on the West Coast...



Sam Hardage, Andrea Bocelli, Vivian Hardage, and Congressman Darrell Issa

Two-hundred guests gathered again on December 10th for a pre-concert auction and twilight reception in the Four Season Aviara Resort's new "Laviana" Ballroom in Carlsbad, California. Babbo in New York City, prepared a beautiful Italian menu

for guests who dined and sipped fine wines while Vision of Children Founder and Chairman, Sam Hardage, presided over the evening's auction. Thanks to the many generous donors and sponsors, bidders were offered some Chef Bruce Logue, formerly of very exciting packages including a New York City Theatre trip for 2,



A Message from our Founder

Dear Friends,

It my pleasure to introduce our newly designed Vision of Children Newsletter. With all of our exciting news and event information, we found it hard to include everything in just these eight pages!

Our Foundation was honored to host two evenings, one in Anaheim, CA and another in New York City, with Andrea Bocelli. Together, the events raised over \$700,000! Because of your overwhelming support, we are able to continue funding research projects leading to our ultimate goal of finding a cure for genetically caused vision disorders and blindness. As you will read about in the following pages, the Vision of Children Foundation recently hosted our 6th World Symposium on Ocular Albinism. We sponsored 20 researchers and scientists from around the world to join us here in San Diego to present their recent discoveries and discuss progress during the three-day event. We were delighted to invite Family Network members to the conference. Many traveled from across the country to be a part of this year's Symposium. We hope to meet many more of you at the next event!

Our Family Network fundraising has been remarkable during this past year! We are proud to tell you about the incredible ways our extended family has created to raise funds to support the Vision of Children. The Foundation also received a record setting, largest single donation of \$100,000, thanks to the generous support of Dimension One Spas!

We are truly blessed to be associated with such outstanding and devoted supporters. I recently read an article quoting a philanthropist, Bob Wilson. He said, "If you give for a student, you give for a lifetime. If you give for a teacher, you give for more than a lifetime. If you give for research, you give forever." The work we are so passionate about today will, without a doubt, benefit not only the children of today, but also future generations to come. Thank you for helping to make that "vision" come true. We could never succeed without your support!

Warmest personal regards,

Iam Lenfoya

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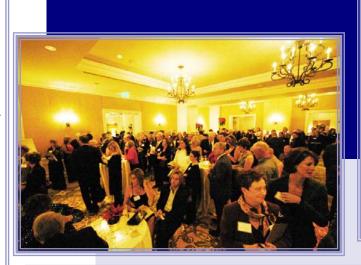
Jolene Leonard Executive Director

jleonard@visionofchildren.org

12671 High Bluff Drive Suite # 300 San Diego, CA 92130 T. (858) 799-0810 F. (858) 794-2348 www.visionofchildren.org

DUAL BOCELLI EVENTS RAISE OVER

\$700,000...cont.





Wine Country Tour for 8, B-17 Bomber Flight Adventure, a Seabourn Cruise, and even a new Dimension One Spa!

Guests were then transported to Anaheim's Honda Center via limousines where the celebration continued while Bocelli's just released DVD "under the Desert Sky" could be experienced en route. Once in Anaheim, the group was escorted to limited premiere seats for Andrea Bocelli's only California performance this year.

A private champagne reception was held immediately following the concert where Mr. Bocelli himself greeted guests. Sam and Vivian Hardage presented Mr. Bocelli with a double magnum of Sonoma-Cutrer's Founder's Reserve as a token of appreciation. The Vision of Children Foundation wishes to thank all of its generous supporters, sponsors, donors, and family network members for their help in making our 2006 Bocelli events such a huge success!

A special note of thanks to George and Lorenza Triebenbacher and our East Coast Family Network Members who took on the tall task of promoting this event and making the entire evening one we will always remember!



SPOTLIGHT ON OUR SPONSORS...

The Vision of Children Foundation greatly appreciates all of our generous sponsors. Your involvement is an important part of the success of our special events, such as our Bocelli Concerts, World Symposiums, as well as our continuous research studies that are being conducted around the world. With your help, we are moving closer to our ultimate goal of enabling all children to have clear, focused The Henry Wine Group Woodfin Suites vision of the world around them. SONOMA-CUTRER Wirage H HOTEL HEALDSBURG TEAMMATES FOR KIDS Vicki Soble Contare Lori & Tink Jill Davis FOUR SEASONS RESORT Accience, North Sien Diego **Kevin & Tamara** BARRATT Sae Higgins Kinsella Joy Skorick SEABOURN Johnson Johnson Stella Morelli PHARMACEUTICAL RESEARCH George & Lorenza Triebenbacher DIMENSION ONE SPAS Mood Distributors JETAIR Barbara Kelsey O'CONNOR DAVIES MUNNS & DOBBINS, LLP Ron Freshman FOUR SEASONS HOTEL

Diane Walker

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Sasan Scott Foundation

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Harriet E. Pfleger Foundation

CHUAO

New York Digital Divide Fund

Dimension One Spas Pledges \$100,000.00 to VOC for Vision Research!



Our Founders, Sam and Vivian Hardage were honored to be guests as Dimension One Spas celebrated their 30th Anniversary in January of this year. The Hardages were overwhelmed by the generosity of owners Bob and Linda Hallam as well as their 300 guests whose combined contributions totaled \$100,000.00 to the Vision of Children Foundation! This is the largest single donation in our history!

Dimension One Spas matches its commitment to its customers with its commitment to supporting VOC's research and outreach efforts. It is clear they have a passion for service both in business and philanthropy by including their employees in such fundraisers as the Vision Cartridge Program, Race for Sight, and is now currently working with the Vision of Children on other opportunities.

Sam, Vivian, and VOC's new director, Jolene, joined Dimension One at their March breakfast meeting where they presented Bob and Linda Hallam with the first ever "Visionary Award" for their steadfast support of our foundation.

Thank you Bob and Linda Hallam and Dimension One Spas, our "Vision Heroes"! We look forward to continued success in 2007!



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Sixth World Symposium on Ocular Albinism





The Vision of Children Foundation hosted our Sixth World Symposium on Ocular Albinism on March 1-3, 2007 in San Diego. The Foundation invited 20 of the top vision research scientists from around the world to meet for three days to share their latest re-

search, explore findings, and examine further options to achieve our goal of finding a cure.

We began early on Friday and Saturday mornings with back-to-back presentations given by researchers. VOC Board Members and staff along with Family Network members were fortu-

nate to listen in on these highly technical sessions and gained valuable insight into the important work our scientists are doing on our behalf.

A few of the topics discussed were:

- Photoreceptor and Retinal Pigment Epithelium (RPE) Structure and Function in X-Linked Ocular Albinism
- Gene Therapy for Severe Inherited Photoreceptor Disease
- Gene Correction in an Albinism Model
- Can We Use Microvesicles to Reactivate Quiescent Stem Cells in the Adult Eye?
- Pigmentation and Proliferation: The Regulation of Cell Number and Cell Class
- Unraveling the Downstream Pathway of OA1: New Insights from the Study of OA1-KO Mouse Melanocytes



At the conclusion of the conference, we brainstormed ideas and asked our scientists for guidance as we plan for the future.

We are pleased with the outcome of this World Symposium. The Vision of Children Foundation is truly appreciative to all of our generous supporters for making these conferences possible. We would also like to thank our wonderful researchers for their dedication and tireless efforts in the search for a cure. Together, we will make the dream of clear eyesight for millions of children a reality.

Dr. Richard Lewis was kind enough to give a private seminar on "Genetics 101" to Family Network members attending the Symposium. We have copies of the video taped session. If you would like a copy, please contact Jolene Leonard at (858) 799-0810. Thank you again Dr. Lewis!!

Iwamuras Donate "Net" Proceeds to VOC



Brenda and Gary Iwamura purchased tickets to the Evening with Andrea Bocelli in Anaheim, but unfortunately could not attend the event. The Iwamuras decided to donate both of their tickets to the raffle at the United States Tennis Association's Santa Luz Open during the November 2006 tournament. Thanks to the generosity of the Iwamura family, the Vision of Children gained an additional \$2275.00 towards vision research!

Nothing Is Impossible At Space Camp

On September 23rd, 2006, Tyler Olson was the first kid to be launched into an exciting new adventure sponsored by The Vision of Children and the Space Camp for Interested Visually Impaired Students. For the entirety of one week, Tyler spent his time in Space Academy at the United States Space and Rocket Center located in Huntsville, Alabama.

There, he was spun around recklessly in a multi-axis trainer, experienced a zerog environment, and was even put through simulated shuttle missions! He reported back to us that, simply stated, "Space Camp was amazing!"

Tyler's wonderful display of enthusiasm certainly exhibits that Space Camp has undoubtedly satisfied his limitless desire to learn about science, math, and outer space. Tyler tells us, "I strongly recommend Space Camp for anyone, including visually impaired people, who want to learn about the history of America, as well as its future in space."

Space Camp is definitely a wonderful experience and supportive of visually impaired children in their belief that nothing is impossible. As stated by a Space Academy Graduate, "Just because I can't see the stars, doesn't mean I can't reach for them."

In the coming years, VOC hopes to be able provide more children with the chance at experiencing Space Camp, and its limitless possibilities.



"Just because I can't see the stars doesn't mean I can't reach for them."-Space Academy Graduate

Scholarship Recipients Check In with VOC ...

Last year, VOC provided two educational scholarships to aspiring college undergrads: Danny Christopher and Angela Benyon. Transitioning from high school into college is a relatively difficult encounter for some, so VOC has followed up with these two to see just how much they are loving college-life!

Danny is currently an undergraduate student studying Technical Journalism at Colorado State University. He seems to enjoy college-life and the new experiences that come along with living in college dorms.

"Well, college life is pretty much everything I expected it to be. There is always something to do; there are always places to go, and new people to meet everyday. The only contradiction between stories I've heard about college and the real thing is that the dorms are supposed to be terrible, but it's one of the best parts about the experience! It's relatively easy to adapt to the small space, the boring dorm food, the lack of sleep, and

living with people you don't know or necessarily like, because with all of that you get the freedom that comes with college life.

Classes aren't much different than they were in high school, except they are literally about ten times larger. There are still eccentric teachers and complaints about homework. The whole college experience is basically a scaled-up version of high school, complete with social cliques, football games, and of course, the schoolwork."



Our other scholarship recipient, Angela Benyon, currently attends Stetson University, where she plans to study Rehabilitative Health for a future career in physical therapy. Her college experiences are filled with time in school-based clubs and her church youth group.

"The day I was born, I began a lifelong journey to compensate for an uncorrectable visual impairment. I am almost



- Angela Benyon

entirely independent when it comes to finding ways around my impairment. I always do as much as I can on my own but I'm (also) not afraid to ask for help when I can't find another way. Even though my eyesight has improved since I was young, it will never be completely normal. Despite the difficulties I will face, I am not hesitant to accept all the rewards and challenges life has to offer. Although my visual impairment is a part of me, it doesn't define who I am or what I am capable of achieving."

- Danny Christopher

Vision of Children is delighted to have been able to help these two individuals in their continuing educational careers and on future goals. We hope only for the best for both Danny and Angela in the coming years!

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Focus on Family Network Fundraising...

Family Network members around the country made 2006 the year to fundraise. Vision of Children was delighted to hear of numerous events happening nationwide. Read on to see how these families affected by genetic vision disorders made a difference in their community as well as our Foundation . . .



Sam Hardage with The Stasi Family

Natalie's Way Annual Golf Outing

For the past six years, the Stasi Family from Staten Island, New York has held an annual "Golf Outing" to raise money for vision research and their charity, Natalie's Way Foundation. In 2006, Sam Hardage traveled to New York to accept a \$25,000 check on behalf of the Vision of Children Foundation. We salute the Stasi family for their ongoing commitment for vision research!

Johnson & Johnson PRDFG Serve at the Somerset Patriot Concession Stand to Raise Money for VOC

Cheryl Wolf and her coworkers joined together at the local minor league baseball park in Bridgewater, New Jersey in honor of Cheryl's son, Ryan, who has Ocular Albinism. Cheryl wrote about her experience:

"Our department has a volunteer group that arranges events for employees to participate in. The team arranged for us to work the concession stand at the local minor league baseball park, The Somerset Patriots, on three different dates. All profits from the nights would be donated to the organizations of our choice.

When I heard about this program, I asked to have one of the night's earnings to be donated to the Vision of Children Foundation. I have a tie to VOC because my son has been diagnosed with OA. From the day we were told by the doctors of

his condition, I began researching organizations that assist children with OA and their families. That is when I found VOC. I read about Vision of Children and finally felt reassured that someone did care and was willing to help not only my son, but others with OA.

OA.

The baseball event was a lot of fun. We had all levels of employees participate, from our CFO, directors, managers, analysts, administrative assistants, to anyone in between. It was a wonderful experience, it didn't matter what level you were or who your boss was in the office, we were all having fun. Our CFO was serving beer and taking out the trash, while others rang on the registers, ran orders, cooked and packaged food. We had a lot of laughs and an all around good time with a extra-special reason for it. For me, the night was very meaningful. I was able to be with my co-workers and friends working together for a cause that is part of my everyday life was absolutely wonderful."



Cheryl Wolf and co-workers working the concession

Bruskotter Annual Holiday Party



Joe & Emily Bruskotter with Son, Charlie

For the third year in a row, the Bruskotter Family of Galena, Ohio turned the holidays in to a season of giving and awareness. Over 200 of their family, friends and coworkers joined them for a party to benefit the Vision of Children Foundation. On hand was literature and information on VOC as well as genetic vision disorders such as OA. The Bruskotters have organized this annual party in honor of their son Charlie who has Ocular Albinism.

Ross's Read-A-Thon



Gail Rubinstein-Hozman sent in checks from her friends and family who donated money during her son, Ross's Read-A-Thon. She hopes that research efforts continue to succeed in finding a cure for hereditary visual impairments.

East Coast Charity Ball



Feidhlim and wife, Roben with sons, Finnegan and Oscar

Feidhlim Boyle is involved with a charity organization that organizes an annual fundraiser, East Coast Charity Ball. Feidhlim was able to get Vision of Children designated as a charity beneficiary and receive a portion of the Ball's proceeds. The East Coast Charity Ball is a Charity Ball in the springtime in Toronto, Canada that raises money for children's charities. Several hundred of Toronto's finest revelers dress up

and shake it down until the early hours. Last year's Charity Ball was the first to involve VOC but we look forward to a continuing relationship and thank them for their generosity.

To find out more about The East Coast Charity Ball, check out their website at: www.eastcoastcharityball.com

Families Join Together In The Race For A Cure

Jennifer and Mark Stachowicz ran in the OUC half marathon in Orlando, Florida to raise funds for Vision of Children. Jennifer sent a letter to all her coworkers encouraging them to donate and informing them that their company will match all donations. We asked her to tell us about the race and her ongoing support of VOC:

1235 420

"Hello! My name is Jennifer and I have two sons who have been diagnosed with Ocular Albinism and Nystagmus. Our sons, Blake (6 years) and Mark Andrew (7 months old), both have the genetic visual disease called Ocular Albinism (OA). My husband, Mark and I ran our first half marathon and decided to make it a fundraising event for Vision of Children. Those two little boys are what motivated us to cross that finish line on December 2, 2006! They are so confident in their lives and they gave us the confidence we needed to finish the race.

Jennifer and Mark Stachowicz

We signed up to run the OUC half marathon on December 2^{nd} in Downtown Orlando. The fee which we paid to run in the marathon was to benefit charities, educational institutions, and the quality of life in Central Florida. What motivated us to run the 13 miles was for our two sons, my father, and my two uncles' who are all affected by OA. We raised funds for Vision of Children to assist in finding a cure for the eye disease which they have and the many other eye diseases out there that effect many others.

What was even better about our own personal fundraiser is that my company matched the funds which we collected 100%!

Don't be afraid to think outside of the box when trying to raise money and awareness of OA. Think up ways which you can raise money – bake sales, charity events which you turn into your own fundraiser, garage sale funds, etc. Don't be afraid to share with others what OA is all about. When strangers make comments to us such as "Your son is just so busy looking all over the place", I stop them and explain to them that he is OA and what they can do to help. I point them in the direction of the Vision of Children website in hopes that their hearts would be opened to making a donation to finding a cure of OA!

Next on our personal agenda – training to commence for the Disney full marathon in January 2008. Once again, we are going to set up our own fundraising event for Vision of Children and make up t-shirts to wear as we run which provides little details about OA and Vision of Children. My goal is to do 2-3 mini fundraisers per year for this cause. If we all pitched in and did the same, we could really make a difference!"

Hanna Kecskes ran the San Diego Rock N' Roll Marathon in honor of her son Alex with all donations benefiting the Vision of Children Foundation. The following is from a letter Hanna sent us explaining her experience:

"On June 4th, 2006, I ran the San Diego Rock 'N' Roll Marathon. This was my first marathon and it was an exhilarating experience! I decided to use this chance to raise awareness of albinism and to raise financial support for research that benefits people with albinism. I wrote to family and friends asking them to pledge their support through prayer and/or a financial contribution to the Vision of Children Foundation. The response was great! Enclosed you will find checks from friends and family totaling \$2315.00.

I wore a photo of Alex on my back with the words "Running for Alex" across the top. Sometimes people would shout out "Go Alex!" This would give me a boost of energy and bring a smile to my face. I felt good the whole race and thankfully never "hit the wall." The highlight of the race came a hundred feet before the finish line when I saw Ken, Cameron & Alex cheering and waving. Ken handed Alex to me and I carried him across the finish line! He took it all in stride, looking around at everyone wondering: "What is everyone so excited about?"



Hanna Kecskes with her son, Alex

During the race, I thought of all the prayers and the words of encouragement friends and family had written to me. (These will be kept for Alex in a keepsake box.) I also thought about how generous they had been with their financial support for the VOC. This really made the marathon meaningful to me. Take care, Hanna"



Jack Houston and his mom, Kathleen

Kathleen Houston ran the LaSalle Bank Chicago Marathon in support of Vision of Children and in honor of her son, Jack. Jack wrote to VOC to tell about his amazing mom and his circle of supporters:

"Hi! My name is **Jack Houston** and I am five years old. Two years ago, I surprised my family when I was diagnosed with Ocular Albinism. They were shocked, scared and had so many unanswered questions. Since that time, the Vision of Children Foundation and their website have been a huge source of comfort for my family. Now they want nothing more than to find a cure for myself and the other children just like me.

Feeling the need to help in some way, my mom decided to raise funds for VOC by running the 2006 LaSalle Bank Chicago Marathon. Through the generosity of our friends and family, we were able to present the VOC with a contribution of \$3219.11!!

We hope our story will inspire other families affected by OA to do the same. With everyone's help, the chances of finding a cure for us will be that much greater!! Thank you Vision of Children for all that you do for me!!"



The Vision of Children Foundation

12671 High Bluff Drive Suite 300 San Diego, California 92130 Phone: 858–799-0810 Fax: 858-794-2338

E-mail: jleonard@viisionofchildren.org

We're on the Web! www.visionofchildren.org



New Executive Director Jolene Leonard (right) & Sister Michelle (left)

Welcome Jolene Leonard!!!

We are thrilled to welcome our new Executive Director Jolene Leonard! Jolene comes to VOC with a special connection and passion...her 9 year old nephew Zach. Jolene's sister, Michelle has been part of the VOC family from the time Zach was a few months old. This kind of family connection not only prepared Jolene for her new role but also gives her a unique perspective of the issues facing our OA families today. Under Jolene's direction the Foundation hopes to maximize its family network outreach, fervently gain grant and corporate sponsorship as well as grow our team and donation program to fuel ongoing research. Jolene has already met each of our researchers and is looking forward to working closely with them!

Welcome Jolene!

Attention Family Network Members...Vision of Children is creating its first *Wall of Fame* and hoping to include each and every one of its amazing "Children" to showcase in our office!

Please send or e-mail your favorite photo to Jolene to be included in our collage!