Caring Voice Coalition, Inc.

2013 ANNUAL REPORT

caring voice coalition

CELEBRATING
10
YEARS
of Saving Lives
2003 2013

LETTER FROM THE PRESIDENT

CVC's tenth year marks exciting new milestones in our mission to save and improve the lives of patients living with rare and chronic diseases. We're assisting more patients than ever before, providing them with much-needed grants and services, and doing so with even greater efficiency and speed.

During 2013, we assisted more than 22,000 patients, awarding them financial grants totaling more than $58 million and providing them with vital alternate coverage services and patient support programs. That represents a 16 percent increase in the number of patients served and a 25 percent increase in the value of grants awarded during 2012. We help meet patients' needs diligently and ethically, with carefully vetted partners whose values mirror our own.

Even as our numbers continue to grow, we're dedicated to helping patients and their caregivers live the best lives possible, with a compassionate, personal touch that never lets them forget that they're not just one of 22,000. They're one in a million.

Pam Harris
President

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AWARDS

Charity Navigator
Three Star Charity

GuideStar Exchange
Silver Participant

NPT's Best Nonprofits to Work For ★2012★

NPT's Best Nonprofits to Work For ★2013★

OUR MISSION

Caring Voice Coalition improves the lives of patients living with rare and chronic illnesses. We accomplish this mission by offering outreach services that provide financial, emotional and educational support.

OUR VALUES

Honesty and Integrity: We commit to being ethically unyielding and honest in our work and inspiring trust among our team.

Passion: We commit our hearts and minds to creating the best results and outcomes.

Commitment: We are dedicated to the overall success of CVC as well as each other.

Respect and Fairness: We commit to valuing and respecting differences in others to create a trusting and open environment.

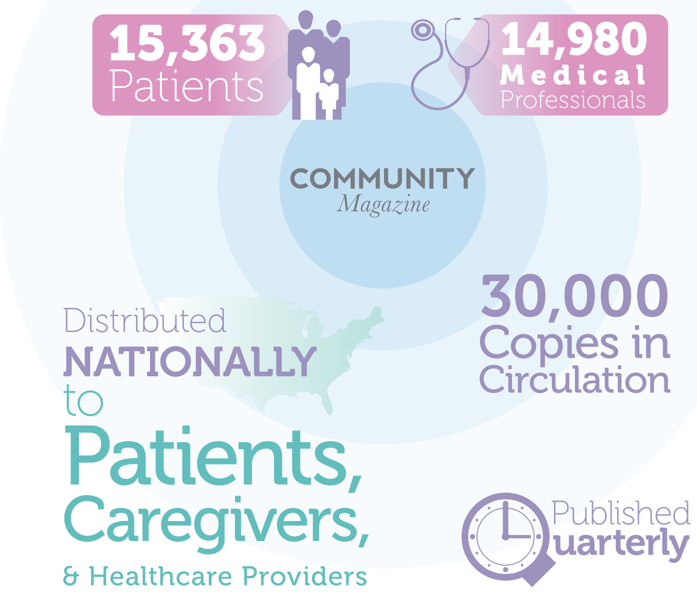
Service: We commit to providing the best service and working to achieve excellence each day.

Guiding Leadership Principle

Servant Leadership: We will focus on serving the needs of the organization and our patients as well as leading by example.

COMMUNITY MAGAZINE

CVC's quarterly *Community* magazine is key to our dedication to communication. *Community* educates patients about living with their disease, physicians about the scope of CVC's services and the general public about what it means to live with a chronic illness every day.



OUR PROGRAMS

Financial Assistance

Patients diagnosed with chronic conditions often face expensive copayments for their prescription medications. CVC provides financial grants to alleviate the burden of these medication costs, allowing patients to start and remain on their drug therapies.

Our grants allow patients to afford copayments for expensive prescription therapies, pay premiums for health insurance coverage and other self-pay responsibilities related to prescription medications or REMS requirements.

Alternate Coverage

Patients often have trouble finding affordable insurance plans or may encounter insurance requirements they are unable to resolve. CVC's insurance specialists investigate, review and explain current benefits to our patients. We work with all insurance types–including commercial, government and exchanges–to resolve issues and help patients identify and explore sources of new or improved coverage.

Therapy Appeals

CVC's Therapy Appeals program exists solely to advocate for our patients. If an insurance company denies coverage of a medication, and a patient is unaware of options, CVC's case managers step in to assist. We coordinate supporting evidence for appeals processes, draft persuasive arguments to the insurance companies to appeal the denials, and follow through to get patients' needed therapies in their hands.

Social Security Disability

Our Social Security Disability program's patient advocates assist patients with various stages of the SSDI application process. Our patient advocates request patient medical records, assess eligibility to apply for disability benefits, review and analyze complex medical documentation, and draft arguments to support disability claims, helping patients effectively communicate with government and health care entities.

Patient Education

CVC's primary goal is to help. We understand what it means to live and cope with a chronic illness. Our patients often experience fear, confusion, frustration, anger–any number of emotions that prevent them from making the best decisions for their physical well-being. Our Patient Education program identifies public and private services to benefit patients' physical and emotional health and comfort. We connect patients and their loved ones with services that make life easier.

STATEMENT OF FINANCIAL POSITION, JUNE 30, 2013

Assets	**2013**
Cash and cash equivalents	$ 18,071,732
Investments	29,424,853
Prepaids and other assets	69,774
Property and equipment, net	744,025
Total assets	**$48,310,384**
Liabilities And Net Assets	
Accounts payable and accrued expenses	$ 6,849,109
Long-term liabilities	27,964
Total liabilities	**$ 6,877,073**
Net Assets	
Unrestricted	$ 1,393,491
Temporarily restricted	40,039,820
Total net assets	**$ 41,433,311**
Total liabilities and net assets	**$48,310,384**

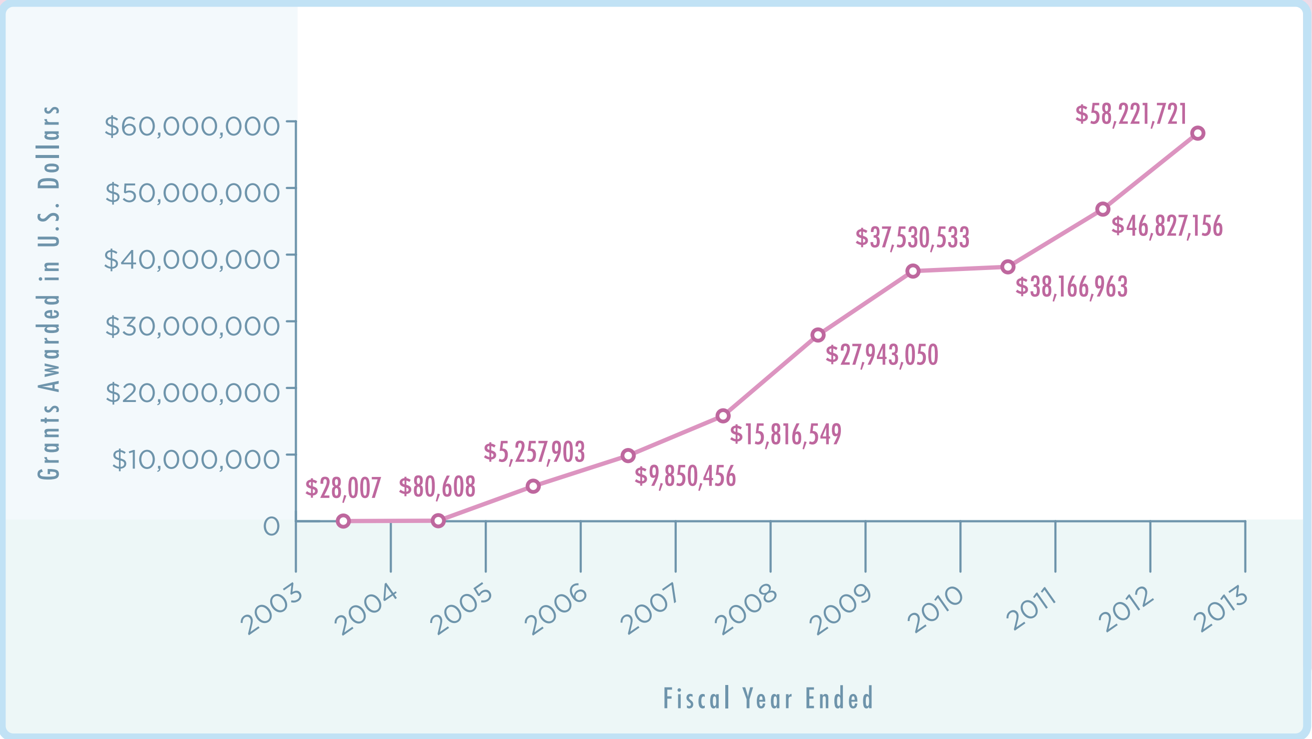
STATEMENT OF ACTIVITIES YEAR ENDED, JUNE 30, 2013

Revenue	**Total**
Donations and other income	$ 57,733,826
Investment Income	153,113
Total revenue	**$57,886,939**
Expenses	
Patient grants and services	$ 62,969,577
Administration and management	659,730
Fundraising	227,554
Total expenses	**$ 63,856,861**

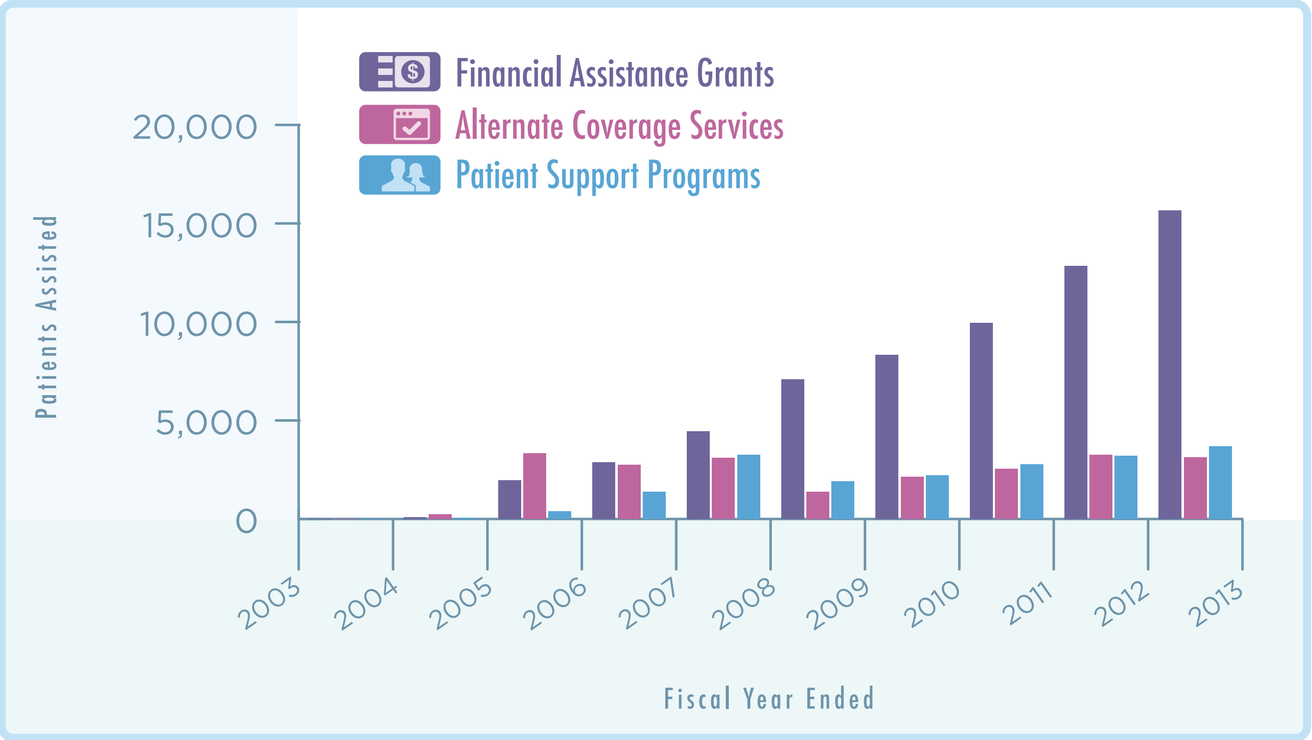
EXPENSE RATIOS YEAR ENDED, JUNE 30, 2013

Patient grants and services	98.61 %
Administration and management	1.03%
Fundraising	0.36%

FINANCIAL GRANTS AWARDED TO CVC PATIENTS



PATIENTS ASSISTED BY CVC



Carrie Beth and Asher Pretto

Carrie Beth Pretto's son Asher was diagnosed with infantile spasms (IS) two years ago, when he was just six months old. Categorized as one of the catastrophic childhood epilepsies, infantile spasms is a disorder that is often accompanied by developmental delays, including cognitive impairment.

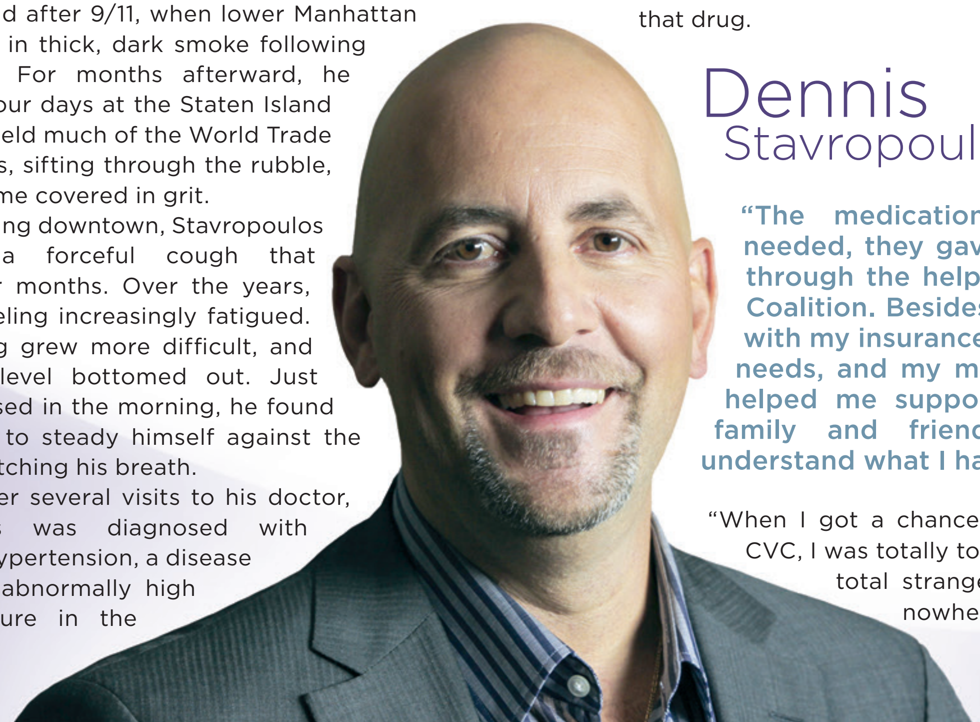
"A week prior to his diagnosis, Asher began having unusual eye patterns and jerking body movements," Carrie Beth recalls. "He would lean forward and then throw his head back and arms out wide.

"As we began to notice this wasn't just a one-time occurrence, we became concerned. Over a week's time, the jerking motions and eye rolling developed into clusters, occurring more often throughout the day.

> **"We are thankful for CVC, its employees, volunteers and donors who sacrifice their time to improve the lives of others and the expression of love and caring for families and individuals in need, not just financially, but emotionally."**

After Asher's IS diagnosis, the doctor stressed the need for starting treatment immediately to prevent prolonged damage to Asher's brain. Now, after two years of multiple medications and doctors' visits, and a year after brain surgery, Asher is seizure-free, a grant from CVC covering a portion of his medication expenses.

"With our weekly schedule of occupational, speech, physical and autism therapy, Asher is thriving despite the setbacks that we have faced over the past two years," Carrie Beth says. "Our little guy, at the age of two and a half, is actively catching up and accomplishing new milestones everyday."



Dennis Stavropoulos

I was always healthy. I could do anything," says former New York City Police detective Dennis Stavropoulos. "I was very active. I played on the softball team at work. I was always a golf junkie. But in 2009, things had really gotten worse for me."

Stavropoulos had helped secure the World Trade Center on and after 9/11, when lower Manhattan was covered in thick, dark smoke following the attacks. For months afterward, he worked 16-hour days at the Staten Island landfill that held much of the World Trade Center debris, sifting through the rubble, returning home covered in grit.

After working downtown, Stavropoulos developed a forceful cough that persisted for months. Over the years, he began feeling increasingly fatigued. His breathing grew more difficult, and his energy level bottomed out. Just getting dressed in the morning, he found it necessary to steady himself against the wall while catching his breath.

Finally, after several visits to his doctor, Stavropoulos was diagnosed with pulmonary hypertension, a disease that causes abnormally high blood pressure in the arteries of the lungs. The disease, which currently affects nearly 30,000 Americans, is often fatal, and has no cure.

He has been taking medication that helps combat his symptoms since early 2010, which he says has greatly improved his overall well-being. "Although I have to take everything a little bit slower, I see such a difference with that drug.

> **"The medication that I really needed, they gave to me for free through the help of Caring Voice Coalition. Besides helping me out with my insurance and my medical needs, and my medication, [CVC] helped me support-wise, because family and friends don't really understand what I have."**

"When I got a chance to meet the staff of CVC, I was totally touched by them—these total strangers who came out of nowhere and helped me out."

Jenn Jopp

Six years ago, Jenn Jopp was diagnosed with alpha-1 antitrypsin deficiency, a rare disorder caused by the lack of a crucial protein that protects the lungs.

"I was scared and confused about this new chronic health condition I was going to have to learn to deal with," Jopp says.

"When people look at me, they don't really realize that I have a disease, but even the smallest incline can be a challenge for me. I have to stop several times because I'm so out of breath, and it's very difficult to live with that.

"Even the outside environmental factors are a huge concern: cold, humidity, the wind, and dust. It's a daily challenge to go anywhere—just to go to the mailbox can be challenging."

In 2009, Jopp was introduced to Caring Voice Coalition. "They were able to support me and send me to educational conferences so I could learn all about alpha-1 antitrypsin deficiency.

> **"They are the most passionate, compassionate people I've ever met in my whole life. They have no boundaries when it comes to the care that they provide to patients. I feel very blessed to have them in my life. As I walk through my journey, they're right beside me every step of the way."**

VIEW MORE PATIENT PROFILES

Use your phone or tablet to scan this quick response (QR) code to hear from patients and caregivers how CVC helps them live the best lives possible.

Cheryl Sullivan Staveley and Meghan Sullivan

Cheryl Sullivan Staveley lives less than ten miles from the health care center where her 25-year-old daughter Meghan lives full time, and visits her almost daily, taking her to special occasions throughout the week and bringing her home to spend time together on Sundays.

Meghan has Huntington's disease, a progressive, degenerative neurological disorder that affects the patient's ability to control movement, as well as mood and cognition, often eventually resulting in the need for 24-hour care.

"In the summer of 2006, we started noticing very subtle symptoms of Huntington's disease [in Meghan]," says Cheryl. "Meghan was 19 when she was diagnosed, but in retrospect, she was probably symptomatic since about the age of 13."

Approximately 35,000 Americans have Huntington's disease, making Meghan roughly 1 of 3,500 people in the U.S. who have juvenile HD. In 90 percent of juvenile Huntington's disease cases, patients have inherited the faulty gene from their father, as Meghan did. Huntington's disease claimed the life of Meghan's father, John Sullivan, in 2008. Meghan's sister, Kaitlin, tested positive for the gene in 2007, but is currently asymptomatic.

"I was very realistic—there was a 50/50 chance that the girls may have the HD gene," Cheryl says. "But because the onset is typically older, I hoped that by the time Meghan was 30, there would be some medical advancement in treatment or even a cure. So to have her juvenile Huntington's disease take hold so quickly really came as a shock."

"Because Meghan is my child, and because she is so young, I wish I could trade places with her. I feel like she deserves to have a full and fun life, and I know that she's not going to have as long of a life as we wish, so my role as caregiver is to be the best advocate for her that I can. To advocate and hope.

"We first heard about Caring Voice Coalition when, in December of 2008, Meghan's neurologist decided that she would be a candidate to try this new drug. It was $6000 a month for the drug, and my Blue Cross paid $2600."

> **"Knowing that Caring Voice Coalition would take care of this copayment was a huge weight off our shoulders. When they say they want to help you, they are truly invested."**

We are grateful for the support and generous donations we receive that ensure our programs and services are always free to patients and their families. Caring Voice Coalition is a 501(c)(3) charitable organization that provides comprehensive support for patients diagnosed with specific chronic or life-threatening diseases. Donations are fully tax-deductible. Please visit our website, **www.caringvoice.org** to make a secure online donation. We also welcome donations by mail. By donating to Caring Voice Coalition, you are making a difference in the lives of many patients and caregivers.

OIG STATEMENT

CVC is a charitable organization, with IRS 501(c)(3) approved status. The Office of Inspector General of the U.S. Department of Health and Human Services has issued a positive opinion (No. 06-04), regarding CVC's financial assistance program for Medicare beneficiaries.

CONTACT US

Office Hours (EST)

Monday – Thursday: 9 a.m. – 7 p.m.
Friday: 9 a.m. – 6 p.m.

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