



caring voice  
coalition

We're Here to Help.

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2015 ANNUAL REPORT

# LETTER FROM THE PRESIDENT



**I**t's an undeniable fact that health insurance today doesn't always cover everything we wish it would cover, at a cost we can afford. The connection between health insurance and earned income is still a harsh reality for many individuals. In 2015, many patients faced massive increases to their health insurance premiums and out-of-pocket costs. Studies show that marketplace benefit designs are shifting a higher percentage of health care costs onto their members. These marketplace dynamics can make life-sustaining therapies essentially unaffordable for many patients without the help of financial assistance programs. As a result, more and more patients are seeking assistance from CVC, and I am proud that CVC was able to impact the lives of over 35,000 patients in 2015 by providing access to copayment, premium, alternate coverage and disability programs—an accomplishment we are only able to deliver with the help of our dedicated partners. We were so grateful to be able to expand our reach to 25 disease states in 2015, while cultivating new partnerships with so many dedicated donors across the country.

As we enter our 13th year of service, it's wonderful to report continued growth in the number of patients we have served as well as our overall budget. In 2015, 99 percent of our total budget went directly to supporting our programs and services for patients. We paid out financial grants totaling more than \$97 million while continuing to provide high-touch, emotional and practical support to patients at an unbelievably difficult time in their life.

As we continue to strengthen our employee relations by living out our core values, CVC was recognized for the fourth year in a row as one of the Best Nonprofits to Work For in the nation. This "exceptional" designation from *The NonProfit Times* differentiates CVC

from many of its peers and demonstrates to the public that employee appreciation equates to program efficiency, respect and fairness. Our belief is that happy and well-trained employees, provided with the proper tools and honest feedback, produce high quality, effective results.

Our newly established Audit and Compliance Department has shifted into full gear ensuring that our programs are continuing to follow strict policies in accordance with laws and regulations governing nonprofit organizations as set forth by the Internal Revenue Service and Office of Inspector General. One hundred percent of our employees are fully engaged in annual certificate programs such as HIPAA/HITECH, Compliance, Ethics and Fraud to ensure the privacy and protection of our patients and donors. Likewise, service levels are audited and continually monitored from a telephonic and systems standpoint.

Our Board and staff remain committed to our mission to help chronically ill patients access needed prescription medications through our programs. As we celebrate our accomplishments for 2015, we look forward to working even more closely with many of you as we continue to expand our services so no one has to choose between life-saving medication, paying a mortgage or feeding their family.

By all measures, 2015 has been another exceptional year. Thank you for standing with us to ensure that no patient has to face their illness alone. Together, we all contribute greatly to improving the lives of patients we serve.

A handwritten signature in black ink, which appears to read "Pam Harris". The signature is fluid and cursive, with a large, sweeping flourish at the end.

**Pam Harris**  
President

# ABOUT CARING VOICE

## Board of Directors

**Pamela Harris**, Chairperson

**Gregory Smiley**, Treasurer

**Tracy Downing**, Secretary

**Cheryl Sullivan Staveley**, Director

**James Rock**, Director

**Bruce Packett**, Director

## 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.

## Leadership

**Pamela Harris**, President

**Samantha Green**, Vice President

**Taylor Scott**, Director of Patient Services

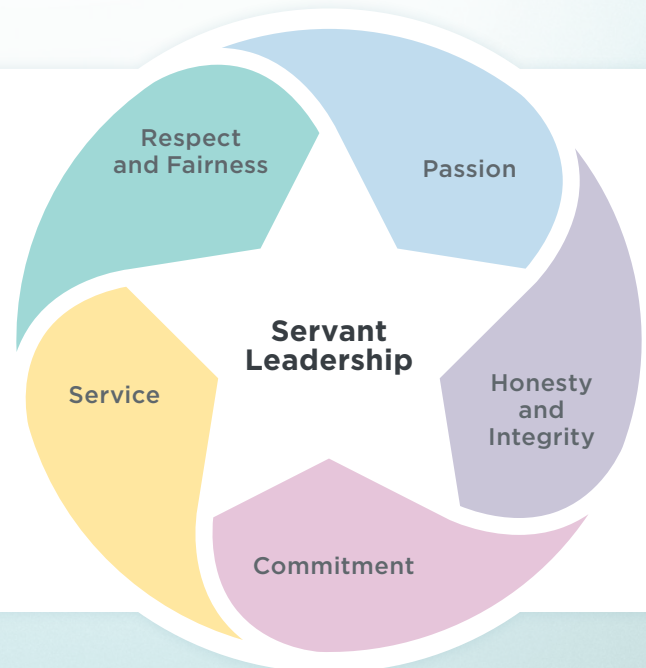
**Rebecca App**, Director of Finance

**Jennifer Previtera**, Director of Communications

**Ron Pizarz**, Director of IT

**Robert E. Mayfield**, Director of Medical Affairs and Compliance

*Caring Voice Coalition 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.*



# OUR PROGRAMS

## Financial Assistance

Patients diagnosed with chronic conditions often face expensive medical costs. CVC provides financial grants to alleviate the burden of medication copayments and insurance premiums, allowing patients to start and remain on their therapies.

## Alternate Coverage

Patients often have trouble finding affordable health insurance plans or may encounter issues they're unable to resolve.

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. CVC is a Certified Application Counselor Designated Organization (CDO) for Marketplace services under the Affordable Care Act (ACA).

## Therapy Appeals

If an insurance company denies coverage of a medication, CVC's patient advocates step in to assist that patient. We coordinate supporting evidence and draft persuasive arguments to appeal the denial.

## Social Security Disability

Our Patient Advocates are dedicated to assisting patients through the various stages of the SSI and SSDI process. CVC recognizes the need for a disability community resource and serves as such for partners and patients regarding preparing and applying for disability benefits.

## Patient Education

Our patient education program identifies public and private services that provide patients with physical and emotional comfort. We connect patients and their loved ones with services that make life easier.



*"I want CVC patients to know they can talk to us... Everyone has a passion for the part they play in CVC's goals and mission to improve the lives of those we serve."*

**Heather Fortune**  
CVC Case Manager

# JULIE NEAL

Caregiver, Lennox-Gastaut syndrome



**B**ailey was born in January 2001. She was beautiful and doing everything normal. Then one morning in June, when she was six months old, I had her on the changing table and all of a sudden her breathing changed. It was like she had the hiccups, but she was staring at the wall and her arms and legs were moving together in an outward motion. It lasted about 30 seconds, then she stopped and cried.

I called the doctor and he sent us to the hospital for an electroencephalogram. The nurses wrote down all of her vitals with a description of what happened. Doctors started her on seizure medication. In hindsight she was probably having seizures long before we ever saw one.

I researched top epilepsy clinics around the U.S. and found a hospital in Houston. I wanted them to start from square one with a fresh look. Their findings were consistent with our original neurologist, which was reassuring, but I had also been hoping they would find something different that could be fixed.

While we were there they performed an MRI. They told us she had scar tissue on her brain, which was the cause of her mental disability. It was the first time we were made aware of this. She

started off so normal, but every year that passed there was more and more delay. This was the first time we heard Lennox-Gastaut syndrome (LGS) was a possible diagnosis.

Bailey has been free of grand mal seizure activity for over five years now. She still has atonic seizures, also known as drop seizures, and myoclonic seizures, which appear as brief, sudden jerks. On a bad day she might have one or two atonic or myoclonic seizures, and they're strong.

Bailey is 14 now, but developmentally she's somewhere between 2 and 4 years old. As she's gotten older, she's also developed behavioral issues, which is common among people with LGS. She cannot communicate to us what she needs or what she wants or what she feels. It's hard because she doesn't always know the words to be able to relay what she's feeling.

Raising a child with LGS takes a village. My son often gets Bailey off the school bus and stays with her until my husband and I get home from work. He takes on the responsibility because he knows that we need his help.

This is what God gave us. We'll keep educating ourselves about LGS, deal with it the best we can and make the best life possible for all of us.

# OMAR ESTEVEZ

Patient, Pulmonary Hypertension

**I** worked three or four blocks away from the World Trade Center during and after the 9/11 attacks. Several years later, I was having a lot of problems with shortness of breath as I walked home from work. I couldn't walk without coughing. I went to my family doctor and he sent me to a pulmonologist. About a month later test results confirmed the sarcoidosis.

When I went to the pulmonologist they took an X-ray and said that a lot of the sacs inside of my lungs, which are supposed to work like a sponge, have debris and dust all over them; they're not working to full capacity.

Later on, it started hurting my lungs a great deal, and it even started hurting my heart. The doctor explained that it's due to a lack of oxygen. A right heart catheterization confirmed the pulmonary hypertension (PH). The doctor told me that this has probably been developing for some time. The PH is all due to the sarcoidosis.

Simple tasks, like climbing a flight of stairs, are daily challenges now. I'm still working, but last year alone I took around 30 sick days. The cold weather in New York hurts my lungs. It's like squeezing an orange. Sometimes I have no other choice but to stay home from work because when I step outside it feels like the cold air freezes my lungs.

I have a lot of problems breathing, even though I have medication.

I feel that a lot of people don't understand these illnesses. They see you going about and they think, what's that person walking around with that machine for? But they don't know how we actually feel inside. People don't realize how my lungs burn so much in the cold weather, and just to stop outside and hold onto a railing makes it worse.

In many ways CVC is the spokesperson for us, they go out there and fight for us. Sometimes when you have a certain problem or condition, you're afraid to talk about it because you feel like you're at the point where you feel like nobody's there to help you. With CVC, I know I'm not the only one with this fight.

My illnesses have taught me that life is short and every day is a challenge, but you have to find a balance, have hope, and have positive friends and family. That will help you greatly.

To cope with my symptoms I often use rest, laughter and medication. My hope is that down the road, with new technology, and more scientific data and new medicines, all of us with this illness will someday be able to have a longer life.



# PUBLICATIONS

## Community Magazine

Caring Voice Coalition's *Community* magazine engages readers in the rare disease community, providing support and education, with health care updates, compelling patient and caregiver profiles, and in-depth interviews with leading physicians, medical researchers, and patient association and support group leaders.

## CVC-e Newsletter

Our monthly CVC-e newsletter is free and provides useful tips, news and relevant articles to patients and caregivers.

## Understanding Your Disability

CVC developed a Disability Guide to help individuals understand the complicated issues involved in proving entitlement for disability benefits. This guide, along with a free wellness journal is available to download at [www.caringvoice.org](http://www.caringvoice.org).

## Social Media

We use social media as an extended unit of support for the disease communities we serve. Our Facebook and Twitter pages have acquired an active and steady following comprised largely of patients and caregivers looking for further support and connection.



**READ** by Patients, Caregivers and Medical professionals

**47,400** Subscribers and growing

**QUARTERLY** published and nationally distributed

*How can you*  
**help save**  
*a patient's life?*

**It starts by making a donation.**

Caring Voice Coalition is committed to meeting the needs of our patients by operating at the highest level of financial responsibility and stewardship. In addition to medical and financial challenges, chronically ill patients face significant obstacles to starting and remaining on therapy. Our programs remove those obstacles. By donating to CVC, you are making a difference in the life of a patient.

**Make your donation today.**



**Give online:**

<http://bit.ly/DonateToCVC>



**Mail your check payable to:**

Caring Voice Coalition, Inc.  
8249 Meadowbridge Road  
Mechanicsville, VA 23116



**Phone:**

(804) 427-6468

Caring Voice Coalition is a qualified 501(c)(3) tax-exempt organization and donations are tax-deductible to the full extent of the law. Our Federal EIN is 26-0058446.



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**CVC is committed to meeting the needs of our partners and patients alike by operating at the highest level of financial responsibility. In 2015:**

**99%**

*OF CVC'S BUDGET  
WENT DIRECTLY TO  
PATIENT PROGRAMS*

**\$97mil**

*WAS PAID OUT IN  
FINANCIAL GRANTS*

**35,000**

*PATIENTS WERE  
SERVED IN 25  
DISEASE STATES*

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## STATEMENT OF FINANCIAL POSITION, JUNE 30, 2015

### Assets

|                             |                             |
|-----------------------------|-----------------------------|
| Cash and cash equivalents   | \$ 58,312,945               |
| Investments                 | 31,915,755                  |
| Contributions receivable    | 4,000,000                   |
| Prepays and other assets    | 222,043                     |
| Property and equipment, net | <u>280,029</u>              |
| <b>Total assets</b>         | <b><u>\$ 94,730,772</u></b> |

### Liabilities And Net Assets

#### *Liabilities*

|                                       |                             |
|---------------------------------------|-----------------------------|
| Accounts payable and accrued expenses | \$ 11,963,826               |
| Long-term liabilities                 | 12,856                      |
| <b>Total liabilities</b>              | <b><u>\$ 11,976,682</u></b> |

#### *Net Assets*

|   |                             |
|---|-----------------------------|
| Unrestricted                            | \$ 3,581,733                |
| Temporarily restricted                  | <u>79,172,357</u>           |
| <b>Total net assets</b>                 | <b><u>\$ 82,754,090</u></b> |
| <b>Total liabilities and net assets</b> | <b><u>\$ 94,730,772</u></b> |

## STATEMENT OF ACTIVITIES YEAR ENDED, JUNE 30, 2015

| <u>Revenue</u>             | <u>Total</u>                 |
|----------------------------|------------------------------|
| Donations and other income | \$ 131,463,596               |
| Investment Income          | <u>1,126,473</u>             |
| <b>Total revenue</b>       | <b><u>\$ 132,590,069</u></b> |

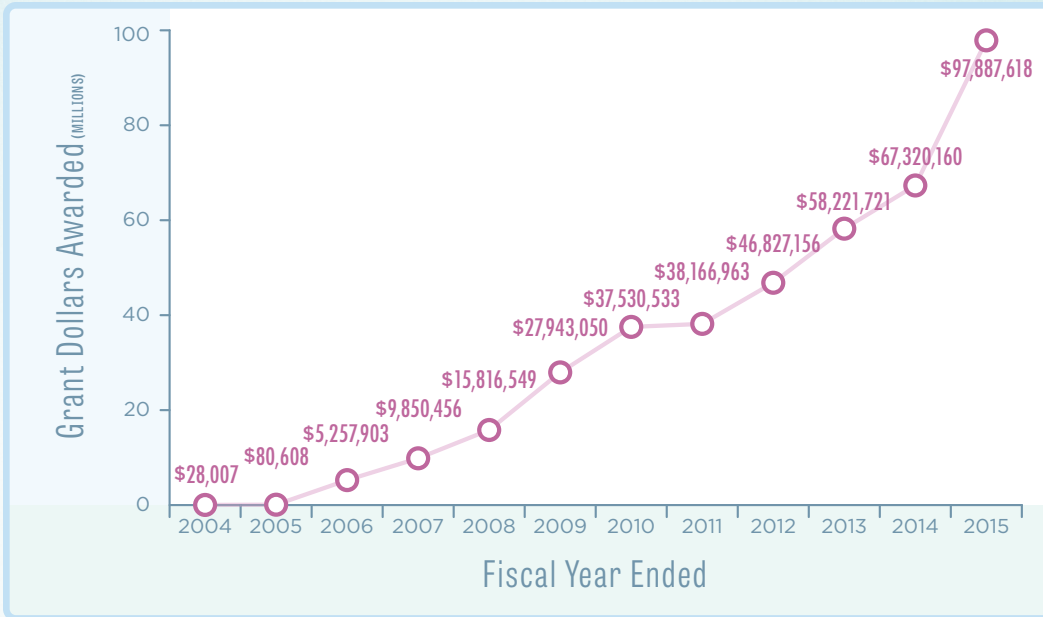
### Expenses

|                               |                              |
|-------------------------------|------------------------------|
| Patient grants and services   | \$ 101,604,913               |
| Administration and management | 690,066                      |
| Fundraising                   | <u>228,384</u>               |
| <b>Total expenses</b>         | <b><u>\$ 102,523,363</u></b> |

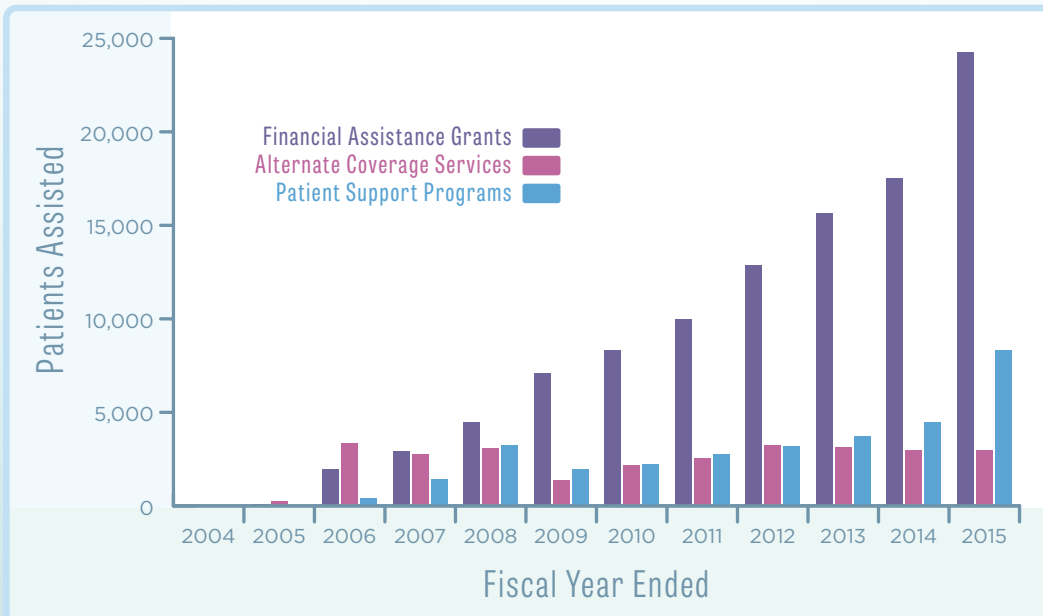
## EXPENSE RATIOS YEAR ENDED, JUNE 30, 2015

|                                      |               |
|--------------------------------------|---------------|
| <b>Patient grants and services</b>   | <b>99.10%</b> |
| <b>Administration and management</b> | <b>0.67%</b>  |
| <b>Fundraising</b>                   | <b>0.22%</b>  |

## FINANCIAL GRANTS AWARDED TO CVC PATIENTS



## PATIENTS ASSISTED BY CVC



8249 Meadowbridge Road, Mechanicsville, VA 23116  
(Toll-Free) 888-267-1440 • (Fax) 888-278-5065  
[www.caringvoice.org](http://www.caringvoice.org)