



caring voice
coalition

We're Here to Help.

2014 ANNUAL REPORT



Letter from the President

Who would have dreamed that Caring Voice Coalition would one day grow to support tens of thousands of patients with life-threatening illnesses — each and every year? In this report, you will find both our financial highlights and a summary of our ongoing commitment to our patients as well as our stakeholders.

As we enter our 12th 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 2014, we spent 98.5% of our total budget on programs and services for patients, provided over 24,000 grants to the chronically ill, paid out financial grants totaling more than \$70 million while continuing to provide high-touch, emotional and practical support at an unbelievably difficult time in their lives.

It is also my pleasure to highlight the launch of 7 new disease funds in 2014. Idiopathic Pulmonary Fibrosis, Inflammatory Eye Disease, Myositis, Nephrotic Syndrome, Orthostatic Hypotension, Sarcoidosis and Stevens-Johnson Syndrome. We are so grateful to be able to continue expanding our reach while cultivating new partnerships with so many dedicated donors across the country.

Our individual contributions to CVC increased by 33% in 2014. This increase can be directly attributed to our outreach at support group meetings around the country, social media initiatives and our Caring Voice *Community* magazine. We believe that every individual donation is vitally important and is helping us to make a significant difference in the lives of the patients we serve.

As we continue to strengthen our management and staff relationships by living our core values and practicing Servant Leadership, CVC was recognized for the third year in a row as one of the Best Non-Profits 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 and exceptional training equate to program efficiency, respect and trust of leadership. Our belief is that happy and well-trained employees, provided with the proper tools and honest feedback, produce high quality, effective programs.

Our 5th Annual Weekend Wellness Retreat was held again this year in Richmond, VA. This retreat is specifically dedicated to supporting and educating patients about the programs and services of CVC while engaging our team members to interact and learn what it's like to live each day with a severe, chronic condition. As always, the results of the retreat were astonishing for both the CVC team as well as the patients and caregivers that participated.

By all measures, this has been an exceptional year of serving more patients than ever before in vital, practical and tangible ways. 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 the patients we serve.

With my deepest gratitude,

Pam Harris
President

BOARD OF DIRECTORS

Pamela Harris, Chairperson
Gregory Smiley, Treasurer
Tracy Downing, Secretary
Robert E. Mayfield, MD, Director
Mitch Bell, Director
James Rock, Director
Bruce Packett, Director

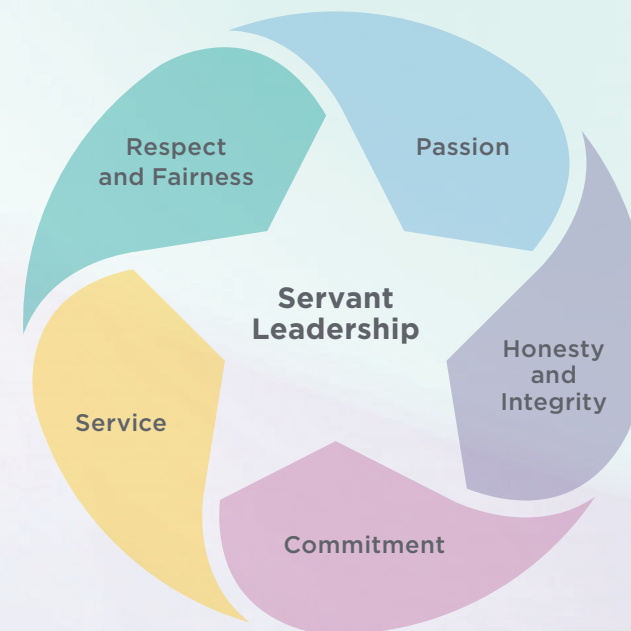
LEADERSHIP

Pamela Harris, President
Samantha Harris, Vice President
Taylor Scott, Director of Patient Services
Rebecca App, Director of Finance
Jennifer Previtera, Director of Communications
Ron Pisarz, Director of IT

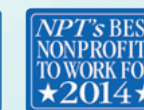
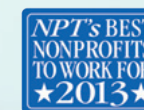
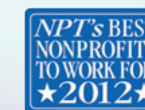
OUR MISSION

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



AWARDS



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. CVC's insurance specialists investigate, review and explain patients' current benefits to them.

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 Social Security Disability program supports patients through the various stages of the SSI and SSDI application process. CVC's patient advocates coordinate supporting evidence, assess eligibility, submit claims for benefits and draft arguments.

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.

OIG Statement

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.

“When I first spoke to CVC I felt like everything was going to be ok. Having a chronic illness is devastating and life changing, but CVC gave me hope and help to get past that and live my life.”

Lisa Mullin
Santa Ana, California

In 2014



CVC denied less than 1% of applications for financial assistance.



98.5% of CVC's total budget went directly to patient programs.



The average speed to answer phone calls in CVC's contact center was less than 30 seconds.



24,000 grants were provided to chronically ill patients.

Did You Know?



27% OF AMERICANS DID NOT FILL A PRESCRIPTION DUE TO COST.*

*Kaiser Family Foundation Health Tracking Poll, 2013

NUMBER OF WORKING-AGE ADULTS IN 2012 WHO SKIPPED NEEDED CARE BECAUSE OF COST*

*Source: Commonwealth Fund

53 MILLION DID NOT VISIT A DOCTOR

50 MILLION DID NOT FILL A PRESCRIPTION

49 MILLION SKIPPED RECOMMENDED CARE



Dennis Redman

Cutaneous Lymphoma Patient

Dennis Redman worked for NASA security for over three years when he stepped in a hole while doing defensive tactics and broke his back from the fall. This was a couple of months before Hurricane Katrina hit, August 29, 2005.

He lost his home to the hurricane and lived in a FEMA trailer for 18 months. While Dennis was rebuilding his home, he had two back surgeries. Since Dennis was out of work for so long, his employment with NASA was terminated. He was physically unable to work because of his back, and received a small settlement that got him through for about two years.

In 2008, Dennis suffered a massive heart attack and underwent surgery to receive his second pacemaker and a defibrillator. Dennis wanted to get back into the work force after a three-month recovery, but found that he was limited in what he was able to do.

Dennis landed a job with the state of Mississippi as a special agent with the Katrina Fraud Task Force. Dennis was only with them for one year, 2010, because the federal grant expired.

In February 2014, Dennis got a job with a security company, working locally, and after three months, he was promoted to lieutenant as a patrol supervisor.

About a year ago, Dennis found out he had cutaneous T-cell lymphoma cancer. A year prior to that, he had a rash on certain parts of his body—mainly under his arms. The painful rash continued to get worse.... with cracking, bleeding, redness, and severe itching. “I called my dermatologist to refill the cream that she had prescribed for me when it looked like an ordinary rash,” said Redman. “She said I needed to come in, because it has been one year since I was there.”

After an examination, his dermatologist requested a biopsy which confirmed that Dennis had T-cell lymphoma cancer, and he was then referred to an oncologist. After the oncologist reviewed Dennis’ reports, they referred Dennis to a doctor at Tulane Medical Center in New Orleans, who specializes in this

type of cancer. This new doctor verified that Dennis did have it and started him on chemo pills and UV light treatments.

After a couple of months on the chemo pills, Dennis found that the pills made him so weak that he was unable to get up once he was down, so the specialist changed his medicine.

“I was very frustrated trying to find the right medicine to work for me and it was also frustrating trying to work out affording the medicine.”

“What is important to me about this diagnosis is that it is not life threatening, as long as I keep up with my doctor and I am not afraid to try new meds, if one does not work for me. My caregiver, my wife, Barbara, is very supportive and is there for me in any way she can be. She knows exactly what is going on and what meds I take and keeps me up to date with my doctor visits.”

“The doctor’s office contacted CVC and a young lady told me all about the program. She is my patient advocate and told me not to hesitate to call her if I had any questions. This was a big relief, because I felt like I was in good hands. I am very grateful for Caring Voice Coalition.”

Dennis enjoys being involved with the Cub Scouts, going to church, socializing, whether it’s at the senior center of Picayune, or in line at Wal-Mart. Dennis also volunteers to play Santa Claus at the Head Start Preschool, when he is able, every year. Most of all, Dennis enjoys spending time with his wife and grandkids.

“We’ve been through a lot in the past nine years. It’s been very difficult a lot of the times, physically, emotionally and financially. After every let down, we always kept the faith and were able to move on.”



Mari Jackson

Pulmonary Hypertension Patient

Mari Jackson was diagnosed with pulmonary hypertension in 2013. While the symptoms started in February of last year, Mari didn’t pay any attention to her symptoms at first.

Mari worked for a mortgage company and drove every day to work—44 miles round trip. Averaging anywhere from 10 to 12 hours a day, and she worked weekends and overtime. Her husband noticed that every time she would go upstairs, Mari would get light-headed and either fall backwards or lose her balance. Every weekend Mari would experience symptoms and pass out.

Upon visiting the ER, Mari underwent several tests. The doctors told Mari, “We don’t see anything, but we do see that you have pneumonia.” The doctors gave Mari antibiotics and sent her home. A month later, Mari was back in the ER. Her blood pressure was 280 over 190 and she ended up having to be admitted. They ran some more tests, and Mari stayed at the hospital for a week.

Doctors performed a lung biopsy and a right heart catheterization. They also performed a crash blood pressure drop, and they would give Mari blood pressure medication three times a day. “I felt like somebody was coming in and beating me,” Mari said.

Once Mari got all the test results back, she met with her pulmonologist. Mari was told she had pulmonary arterial hypertension and that her heart and lungs were not friends. She had no idea that her life was going to change.

“I was devastated. I wanted to go back to work. And I couldn’t. I couldn’t even go up the stairs in my house. I either stayed upstairs or downstairs. To walk from my kitchen to my bathroom, I was gassed out. If I got up too fast, I fell out. If I dropped my head too long to tie my shoe, I passed out.”

Mari was determined to learn more about her condition, so she visited several websites and learned as much as she could about PH. Mari found out that there were things she had to do

differently. She was confined to her room for six weeks because she couldn’t traverse the stairs.

Mari realized that she had to reform her thinking. Her doctor told her that she had to lose weight. Mari thought, “Well, how is that going to happen if I can’t exercise?”

Over time, Mari learned how to cut back on carbs, sodium, and to fall in love with water. “I was 325 pounds, and now I’m 260, and I feel much better than I did a year ago,” Mari says. “My doctor actually told me last week, ‘Compared to how you were last year, you would have never known.’”

Mari has had asthma since a very young age, but she only had one flare up as an adult.

“PAH hides behind asthma, and then it explodes all of the sudden. People with asthma have to be very careful and have things checked out extensively.” For Mari, there were no gradual signs.

“This year is like a complete turnaround,” Mari says. “I have a lot to be thankful for. When I walk, I do so at my own pace. If I get tired, I stop. I do all right. [Recently] I went to the doctor by myself. I walked in on my own. But I took my time.”

Now, Mari just takes everything one day at a time. She doesn’t let anything bother her.

“I keep moving. I want to be able to grab, absorb and use everything Caring Voice Coalition has given me to the best of my abilities.”



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.



The story you did on me in the fall issue of CVC's *Community* Magazine is touching so many. I'm getting all kinds of positive feedback. It's amazing how many are out there living what I live.

— **Sherry Gochenour**
Penn Laird, Virginia

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.






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, Virginia 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.

STATEMENT OF FINANCIAL POSITION, JUNE 30, 2014

Assets	2014
Cash and cash equivalents	\$ 29,728,448
Investments	31,287,584
Prepays and other assets	40,215
Property and equipment, net	430,722
Total assets	\$ 61,486,969
Liabilities And Net Assets	
Liabilities	
Accounts payable and accrued expenses	\$ 8,418,259
Long-term liabilities	18,071
Total liabilities	\$ 8,436,330
Net Assets	
Unrestricted	\$ 3,026,507
Temporarily restricted	50,024,132
Total net assets	\$ 53,050,639
Total liabilities and net assets	\$ 61,486,969

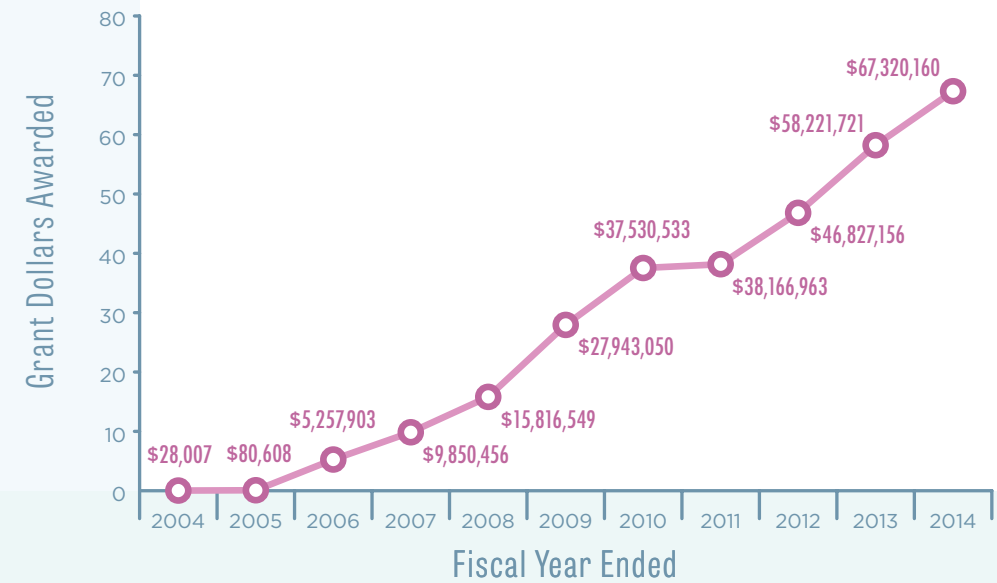
STATEMENT OF ACTIVITIES YEAR ENDED, JUNE 30, 2014

Revenue	Total
Donations and other income	\$ 81,973,294
Investment Income	892,912
Total revenue	\$ 82,866,206
Expenses	
Patient grants and services	\$ 71,208,431
Administration and management	819,874
Fundraising	269,505
Total expenses	\$ 72,297,810

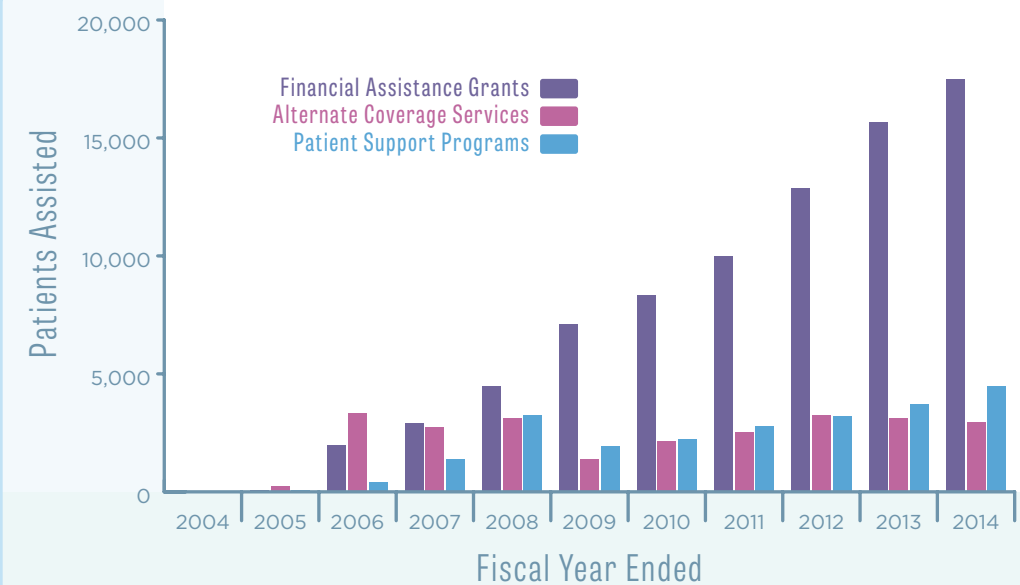
EXPENSE RATIOS YEAR ENDED, JUNE 30, 2014

Patient grants and services	98.49%
Administration and management	1.13%
Fundraising	0.37%

FINANCIAL GRANTS AWARDED TO CVC PATIENTS



PATIENTS ASSISTED BY CVC





We're Here to Help.

8249 Meadowbridge Road
Mechanicsville, Virginia 23116
(Toll-Free) 888-267-1440
(Fax) 888-278-5065
cvcinfo@caringvoice.org
www.caringvoice.org