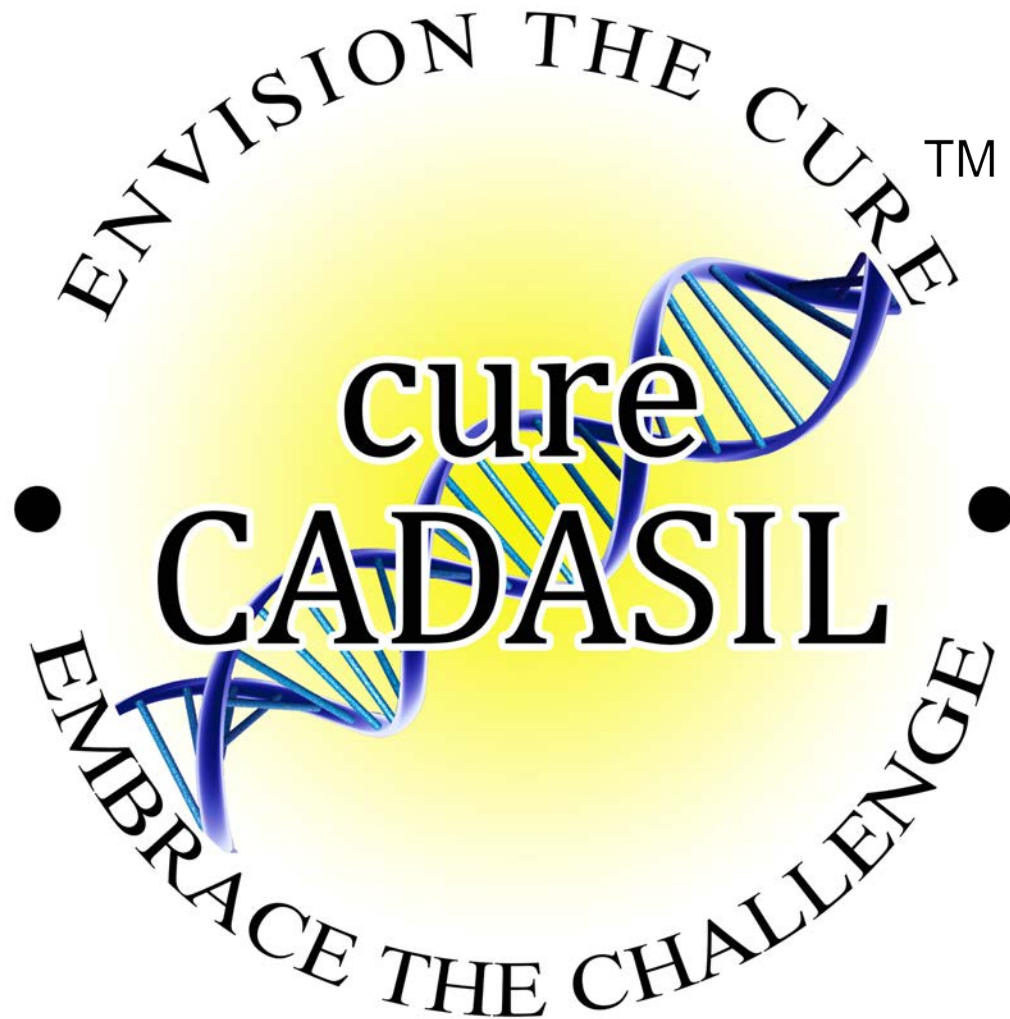


Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy



**cureCADASIL/CADASIL Association  
ANNUAL REPORT 2014**

# 2014 CureCADASIL Annual Report...

## ...A Year in Review

### Organization Overview

CureCADASIL, is a voluntary, non-profit organization. We are a tax-exempt, 501(c)(3) non-profit Corporation in the State of New Jersey. Contributions are tax-deductible within the United States to the extent allowable by law. Our EIN number is 45-5242623. The mission of cureCADASIL is to raise awareness of CADASIL, ensuring it will be universally recognized and understood by the medical community, enabling patients to be correctly diagnosed. We are dedicated to helping patients, families, caregivers, and other supporters touched by CADASIL. We aim to unite patients and the medical community toward the common goal of treatments and ultimately a cure for this rare genetic disease, by promoting **C**ommunication, **A**dvocacy, **R**esearch and **E**ducation. We maintain a worldwide network of support through social media. We promote professional and public awareness through education with our website, newsletter, conferences, meet-ups and webinars We fundraise to raise awareness and support research.

### Board of Trustees, as of December 31, 2014

Anne McGuinness, President

Barbara Hunt, Vice-President/Treasurer

Janet Mills, Interim Secretary, Trustee, Patient Representative

Gail Hunt, Trustee

Christi Lushbaugh, Trustee

Janice Ragazzo, Trustee

Ronnie Bradbury, Associate Trustee

Jennifer Costner, Associate Trustee

Nancy Maurer, Associate Trustee

Pamela Russell, Associate Trustee

Karl Stumpf, Associate Trustee

Robert Davis, Associate Trustee

# Message from the President of the Board

Dear Friends of CureCADASIL,

Reflecting and reviewing the highlights of the previous year has always been for me an important validation of our hard work and dedication. We have accomplished much; but, it's only the tip of the iceberg. CADASIL is a rare disease that gets relatively little attention and funding. Awareness in the medical and patient community must be continued to enhance the likelihood of finding effective treatments and a cure.

We truly are a rare community. Not because CADASIL is a rare disease, but because the CureCADASIL Board of Trustees has an extraordinary group of members with the desire to make a difference in the lives of patients and families affected by CADASIL. This is a rare quality that you can't find in other organizations. People from around the world that are affected by CADASIL are our extended family. We share a common bond on our journey to find treatments and a cure.

We are fortunate to have dedicated board members who give generously of their time. We built a solid foundation to build upon. As we face the years ahead, we'll continue to strive to advocate, educate and fund research. We are committed to providing educational and emotional support to patients and families. We bring patients and physicians together. During 2014, we continued to use YouTube, Facebook, and other Social Media, as well as our website, to promote our educational materials with webinars and educational videos. We remain tireless in our efforts to fund research that may lead to treatments and ultimately, a CURE!

The Registry Committee has been diligently working on a family registry that will help researchers recruit patients for their studies and clinical trials. We expect to launch the registry in 2015. The registry would make it possible for medical researchers to understand CADASIL in ways that never before were thought possible.

I challenge all of the members of the CADASIL community to work together to achieve our vision of a world free of CADASIL. You can join in the fight to support the mission of CureCADASIL in many ways. Embrace the challenge, get involved. CureCADASIL is always looking for members that can fundraise, educate and advocate. We look forward to the day when CADASIL is eradicated and we don't have to worry about future generations inheriting this disease.

Envisioning the Cure while Embracing the Challenge!

Anne McGuinness  
Co-Founder/President  
CureCADASIL  
CADASIL Association Inc.

## Activities and Accomplishments 2014

January 2014, Janet Mills submitted a CADASIL video for the Neuro Film Festival. This can be viewed on the website.

On Tuesday, February 26, 2014, Barbara Hunt, Anne McGuinness, Janice Ragazzo, Karla Smith, and Kathy Phillips attended the Legislative Conference Day organized by the RDLA (Rare Disease Legislative Advocates). The RDLA is a collaborative organization designed to support the advocacy of all rare disease groups. Their goal is to empower the individual to become an advocate. By growing the patient advocacy community & working collectively, the many voices of rare disease patients can be amplified and heard in the State and Federal Government. That evening, we attended the RDLA's 4th Annual Rare Disease Day Documentary Screening and Cocktail Reception featuring the new HBO Progeria documentary, "Life According to Sam" at the Carnegie Institution of Science.

On Lobby Day, Wednesday, we advocated for CADASIL patients on Capitol Hill. We met with Members of Congress and/or their staff to inform Congress about rare diseases and the many different needs of the patient community. We hope to build a lasting relationship with Members of Congress and their staff to ensure that the needs of all rare disease patients are considered in future legislation and policy. Barbara Hunt and Janice Ragazzo met with Senator Gillibrand's staffer. They discussed the need for a Rare Disease curriculum in medical schools. He offered helpful suggestions that they took home with them to get this project off the ground.

On Thursday, February 27, 2014, Anne McGuinness, Barbara Hunt, and Janice Ragazzo attended the Everylife Foundation for Rare Diseases Workshop on FDA Regulatory Law and Policy for Patient Advocates. This workshop focused on the best practices to work with industry and the FDA on expanded access, compassionate use and emergency IND's. It was held at the Embassy of Greece. After the workshop, we headed over to the Capitol Visitors Center on Capitol Hill to attend the Rare Disease Congressional Caucus Briefing. The Rare Disease Congressional Caucus showed just how much the rare disease community's voice is beginning to grow! "Elementary" star Johnny Lee Miller was on the panel. Since learning that a crew member's son was diagnosed with the rare fatal disease Sanfilippo Syndrome, Johnny Lee Miller (Holmes on the TV show) has become an advocate to find a treatment and a cure.

On February 28, 2014, the National Institutes of Health (NIH) celebrated the seventh annual Rare Disease Day with a day-long celebration and recognition of the various rare diseases research activities supported by the NIH Office of Rare Diseases Research, the NIH Clinical Center, other NIH Institutes and Centers; the Food and Drug Administration's Office of Orphan Product Development; other Federal Government agencies; the National Organization for Rare Disorders; and the Genetic Alliance. Rare Disease Day at the NIH was attended by CADASIL Association members Anne McGuinness, Barbara Hunt, and Janice Ragazzo. We had a poster board and exhibit

table. We networked with other rare disease organizations and advocated for CADASIL patients. We wore our favorite pair of jeans to show our support for rare diseases.

In April 2014, Bobby Davis joined the CADASIL Association as an Associate Trustee.

On April 11, 2014, Anne McGuinness and Janice Ragazzo met in person with four neurologists at Capital Health in Pennington, NJ. Michelle McGuinness and Barbara Hunt attended the meeting via conference call. The Capital Institute for Neurosciences is located at the Capital Health Hospital. This meeting was arranged by Michelle McGuinness. The neurologists were very interested in the CADASIL Association and we discussed ways they could help us with our mission. We hope to involve them with a community outreach event for CADASIL Awareness Day and/or Rare Disease Day in the future.

On April 14, 2014, Barbara Hunt and Janice Ragazzo met with Assemblyman Lalor from New York. They discussed with him the need to educate doctors about CADASIL and other rare diseases. He's looking into ways to help them with this project. Barbara Hunt, Janice Ragazzo and Bobby Davis have created a petition to have doctors sign to support this campaign.

On April 21, 2014, the CADASIL Association Board of Trustees approved Mark Graham's application for the CADASIL Association's Research Assistant Scholarship. The amount of the scholarship is \$4,000.00. Mark is highly motivated to work on CADASIL since participating in the 2013 CADASIL Family Conference. Dr. Joseph Arboleda-Velasquez at the Schepens Eye Research Institute/Harvard Medical School will be Mark's mentor during this summer internship. Information about Mark's research can be found on our website.

May 9-10, 2014 Columbia University Primary Care Conference and Expo in NYC. Attended by Anne McGuinness and Janice Ely. Met with Wendy Chung, a Columbia University geneticist. She was added to our Doctor's Directory.

June 17, 2014 Biosimilars Lunch and Learn, Trenton NJ. Attended by Anne McGuinness. Biologics are the next generation of rare disease therapies often providing life-altering benefits for diseases that previously had no treatments. Biosimilars can be used instead of biologics in the treatment of certain diseases. Biosimilars will be just as effective and less costly.

June 18, 2014 Janet Mills was a call-in guest on Gary Garver's "Controlled Chaos" Radio Show in Loma Linda, Ca. (Los Angeles area). Janet shared information on CADASIL and how cureCADASIL.org is striving for a cure. Gary's brother was recently diagnosed with CADASIL. <http://www.kcaaradio.com> Janet Mills was a repeat call-in guest a few months later. She was a great spokesperson!

June 24, 2014 Alisa Jo Middleton and Janet Mills participated in the WEGO Health Rare Disease Chat on Twitter. Anyone who "tweets" and is a member of the global CADASIL

community (patients, family members, friends, doctors), please consider joining these discussions to help promote awareness of CADASIL. The chats are held every Tuesday at 3PM EST at: [twitter.com/wegohealth](https://twitter.com/wegohealth)

July 2014 CureCADASIL awarded Mark Graham with a \$4,000.00 grant to do biomarker research under the direction of Dr. Joseph Arboleda at Harvard Medical School. Please see the research summary in the November issue of EMBRACE. This summer research project identified specific proteins that may serve as biomarkers for CADASIL. In January, an additional \$4,000.00 was awarded to Mark so he could complete his research. Publication of his research should be available soon and will be announced on our Facebook page and website.

July 2014 Barbara Hunt and Anne McGuinness attended several webinars sponsored by NORD and Global Genes related to relationships with Congress.

July 2014 The ULF (United Leukodystrophy Foundation) held its Annual Scientific Meeting and Family Conference. Although no one from our organization was able to attend, CADASIL was mentioned because Dr. Fabrice Dabertrand from the University of Vermont was awarded the ULF's \$25,000.00 CADASIL Research Grant. Much of the money for this research grant came from CureCADASIL members and their families. It took over 5 years for the ULF to get the money for this grant. CureCADASIL is stepping up the pace and hopes to award a grant this year! The amount is yet to be determined. The ULF is planning their next Scientific Meeting and Family Conference in Omaha, Nebraska from July 15-18, 2015. Dr. Dabertrand will be reporting on his work. The ULF plans on inviting additional doctors knowledgeable about CADASIL. There will be a concurrent session during the conference that focuses on CADASIL. We will update our website and post more information on our Facebook page as soon as it becomes available. You can also go to: <http://ulf.org/conferences> for more information.

August 4 -September 5, 2014 RDLA's 1st Annual In-District Lobby Days. The RARE Disease Legislative Advocates (RDLA) schedules meetings for you. RDLA is a collaborative organization designed to support the advocacy of all rare disease groups. By growing the patient advocacy community & working collectively they can amplify our many voices to ensure rare disease patients are heard in State & Federal Government. Members of Congress return home during August to connect with constituents. This is the perfect opportunity for rare disease advocates to strengthen relationships with Members of Congress or build new relationships without having to go to Washington DC. Janet Mills, Anne McGuinness, Ronnie Bradbury, Barb Hunt and Janice Ragazzo attended meetings with their legislators or staffers. Anyone who is interested in attending In-District Lobby Day should email cureCADASIL at [info@cadasilassociation.org](mailto:info@cadasilassociation.org) The RDLA will provide you with a training webinar and cureCADASIL will provide you with information about CADASIL.

Barb Hunt and Janice Ragazzo have been reaching out to legislators for advice on how to educate the medical community about CADASIL. They have also worked with them and other agencies on getting an ICD-10 code for CADASIL. There is no ICD code for

CADASIL. The ICD (International Classifications of Diseases) is the global health information standard for mortality and morbidity statistics. ICD is increasingly used in clinical care and research to define diseases and study disease patterns, as well as manage health care, monitor outcomes, and allocate resources. Having an ICD code for CADASIL is extremely important. This an ongoing project that cureCADASIL is working on. An ICD code for CADASIL will have a huge impact on furthering our mission. . We hope Barb and Janice's hard work pays off and they add CADASIL to ICD-10. CADASIL will be added to ICD-11. ICD-11 comes out in 2017. But, since the USA is dragging behind other countries with ICD-10; it's uncertain if USA be using ICD-11 when it's first rolled out.

September 3, 2014 Janice Ragazzo and Anne McGuinness met with a representative from the Rare Disease Report. We purchased an ad for the 60 page Rare Disease Resource Guide that will be distributed to over 60,000 clinicians and key stakeholders interested in rare diseases. These guides will be mailed to 15,000 physicians and geneticists. An additional 45,000 physicians and nurses will receive it via e-mail. See the ad in the November issue of EMBRACE.

September 8, 2014 Janice Ragazzo accepted a Trustee position for cureCADASIL/CADASIL Association Inc.

September 8, 2014 cureCADASIL was selected as the Community Assist Organization for the New Jersey Devils (NHL hockey team) game against the Arizona Coyotes on February 23,2015.

September 11-13, 2014 Global Gene's 3rd Annual RARE Patient Advocacy Summit and Tribute to Champions of Hope Gala in Huntington Beach, California. Pam Scott, a cureCADASIL member, volunteered to represent cureCADASIL at this conference since no board member could attend. We appreciate her volunteering her time to do this. Thank you Pam! Please read her story in the November issue of EMBRACE.

September 13, 2014 Janice and Tony Ragazzo participated at the Town Community Day in East Fishkill, NY and set up a CADASIL Awareness Booth.

September 17-19, 2014 Janet Mills participated in the Public Health in the Rockies Conference in Fort Collins CO. by donating a basket of her fiction books for the silent auction held during the conference. Brochures about CADASIL were sent with the basket.

September 21, 2014 NINDS (National Institute of Neurological Diseases and Stroke) Non-Profit Forum was attended by Anne McGuinness at the NIH (National Institute of Health), Bethesda, MD This is an annual event and non-profits are able to meet with their NIH Program Director(s). The Forum provided an opportunity for nonprofit leaders to network with colleagues and engage in discussions with the NINDS staff.

September 30 - October 2, 2014 American Association of Critical Care Nurses

Conference in Valley Forge, PA. This was attended by Barbara and Joe Hunt and Anne McGuinness. A CADASIL booth was set up in the exhibit hall. On October 1st, Dr. Sathe gave an ExpoEd session on Differential Diagnosis and Evaluation of Young Cryptogenic Stroke. Barbara Hunt gave a informational lecture about CADASIL at an ExpoEd session.

October 3,2014 Janice Ragazzo and Barbara Hunt joined the Brain Initiative Twitter Chat and tweeted about CADASIL with the NIH.

October 14, 2014 Anne McGuinness attended the BIO conference in Washington, DC.

November 10, 2014 Dr. Shukla from Capital Health in Hopewell, NJ accepted a position on our Scientific Advisory Board.

Jennifer Costner accepted a position as an Associate Trustee.

November 16,2014 CADASIL AWARENESS DAY  
cure/CADASIL was featured on NORD's Home page

Walkway Over the Hudson ~ Hunt and Ragazzo families participated in this event to raise awareness.

December 7, 2014 We have a new address:  
cureCADASIL  
CADASIL Association Inc.  
10 Schalks Crossing Road  
Plainsboro, NJ 08536

December 11, 2014 In-Service education program presented to the staff of Hamilton Continuing Care Center in Hamilton, NJ by Anne McGuinness, Ronnie Bradbury and Jennifer Bradbury.



# CureCADASIL Scientific Advisory Board

We greatly appreciate their guidance and the information they provide. These distinguished specialists contribute their expertise through advice, support and education.

## **Dr. Joseph Arboleda-Velasquez, M.D., Ph.D**

**Assistant Professor, Harvard Medical School, Cambridge, Massachusetts**

<http://www.schepens.harvard.edu/arboleda>

Dr. Arboleda-Velasquez's Current Research Project:

“Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy (CADASIL) is a frequent cause of stroke and cognitive decline in adult individuals with a family history of these conditions. CADASIL is caused by mutations in a gene called Notch 3. The Notch 3 gene is part of a group of genes that help cells communicate with each other. Cells use these social cues from neighboring cells as useful information to make decisions regarding their fate. However, it is not clear how Notch 3 mutations lead to cell-cell miscommunication and how this leads to stroke. In my research, I use mouse models of CADASIL and culture cells derived from these animals to study how CADASIL mutations affect Notch 3 function and how normal physiology could be restored using genetic manipulations and newly developed drugs. This work may lead to the identification of novel therapeutic targets for CADASIL as many drugs that modulate Notch signaling are currently under development for other human conditions.”

Dr. Arboleda-Velasquez, or "Joe" as he prefers to be called, has a question and answer page in Embrace, the newsletter of cureCADASIL.

Joe was the Scientific Director for the 2013 Boston CADASIL Family Conference hosted by cureCADASIL Association June 27-29, 2013.

## **Dr. Angelo M. Santiago, M.D.**

**Neurologist & Owner at Central Wyoming Neurology, Casper, Wyoming**

Trustee Janet Mills credits Dr. Santiago with getting her a correct diagnosis of CADASIL, and for the compassionate manner in which he deals with his patients. Dr. Santiago's expertise is in epilepsy, and many others of his patients have MS/Multiple Sclerosis. He continues to expand his knowledge of CADASIL and other neurological conditions.

## **Michelle A. McGuinness, MS, RAC**

**Regulatory Affairs, Quality & Compliance Leader, Greater Philadelphia Area**

Michelle Mc Guinness is a biopharmaceutical leader with expertise in the quality, regulatory and compliance aspects of pharmaceutical manufacturing & marketing. Ms. McGuinness earned a bachelor's degree in biology/biotechnology from Kean University and a master's degree in Quality Assurance & Regulatory Affairs from Temple University School of Pharmacy. She is a member of the Regulatory Affairs Professional Society and the American Society for Quality. Ms. Mc Guinness proudly volunteers for the CADASIL Association and the Southeastern PA chapter of HDSA.

Ms. Mc Guinness has a passion for rare disease advocacy and awareness. She understands the scientific aspects of CADASIL as well as the impact that a rare disease has on a family. While Ms. Mc Guinness was in high school, her father suffered his first stroke. At the time doctors uncovered that her dad had a variety of risk factors for stroke: high cholesterol, high blood pressure, cigarette smoking, poor diet, etc. A variety of medicines were prescribed to address the risk medical factors, but the strokes and TIAs continued. 15+ years after Ms. Mc Guinness's father had his first stroke, another family member was diagnosed with CADASIL (Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy). We now know that Ms. Mc Guinness's father had CADASIL. Ms. Mc Guinness is committed to advocacy, awareness & finding a cure for CADASIL.

**Dr. Jennifer Majersik, M.D., M.S.**

**Chief, Division of Vascular Neurology, University of Utah Hospital, Salt Lake City, Utah**

<http://healthcare.utah.edu/fad/mddetail.php?physicianID=u0281833>

Dr. Majersik established her vascular neurology practice within the Stroke Center at the University of Utah in 2008. Her clinical practice includes evaluating and treating acute strokes in the hospital and emergency department, managing patients on the inpatient general neurology service, and providing outpatient consultation in the stroke clinic, including urgent referrals.

She has a particular interest in rare single gene disorders causing stroke (such as CADASIL), hypercoaguable states (such as Antiphospholipid Antibody Syndrome), and vascular malformations (such as cavernous malformations and hereditary hemorrhagic telangiectasias). She also provides emergency consultation to stroke patients at community hospitals via the telestroke network.

In 2010, she became Director of the University of Utah Stroke Center in addition to her position as Fellowship Director. Dr. Majersik is currently studying the genetic underpinnings of stroke in large families in Utah and more common polygenetic disorders leading to increased risk of stroke

**Dr. Swati Sathe, M.D., M.S.**

**Rutgers New Jersey Medical School**

<http://pluto.umdnj.edu>

Dr. Sathe was previously the Chief of the Division of Neurology at St. Joseph's Regional Medical Center in Paterson, New Jersey. She was also previously the Assistant Professor of Neurology in the Neurogenetics Division at New York University. She received her medical training at the University of Mumbai and New York University. She has authored several journal articles. Dr. Sathe planned and organized the first ever USA CADASIL Symposium on July 30, 2010 in DeKalb, Illinois with the United Leukodystrophy Foundation.

**Dr. Chirag S. Shukla, M.D.**

**Capital Institute for Neurosciences**

<http://www.capitalhealth.org/find-doctor/shukla-chirag-s>

Clinical Neurophysiology

Electrodiagnostic Medicine

Neurology

Vascular Neurology

## Goals: Education, Support, Resources, Public Awareness

**Website** – Continue to improve our web site during 2015. The website is informational and educational.

**Registry** – The Registry Committee is in the process of choosing a platform for a patient registry. To be launched in 2015.

**Newsletter** – Provides members with organization updates.

**Conferences** – The ULF will have a Family/Scientific Conference in July 2015. Several sessions on CADASIL will be presented.

### **Fundraisers** –

Special thanks to those who organized the following fundraisers on behalf of cureCADASIL and those who participated and donated to cureCADASIL in 2014.

- Shop Rite Fundraiser, Poughkeepsie, NY organized by Janice Ragazzo and Barbara Hunt
- Shop Rite Fundariser, East Fishkill, NY organized by Janice Ragazzo
- Hopewell, NY Awareness Community Day organized by Janice and Tony Ragazzo
- Mansfield Township Elementary School organized by K. Montgomery
- EveryLife Foundation Text to Donate Campaign. Everylife Foundation would have matched up to \$1,000.00 in donations (\$10.00 per text) which means we could have made \$2,000.00 if we got 100 people to donate. We got about half that amount and received \$1,030.00 from the campaign.

**Grants** – Applied for and awarded Wakefern Grant for educational purposes.

# Donors 2014

## **\$1 - \$99**

Mr. and Mrs. S. Anderson  
M. Baez  
V. Bereke  
L. Blunck  
A. Bone  
C. Brennan  
D. Castro  
Mr. and Mrs. J.D. Cody  
Mr. and Mrs. P. Collins  
J. Coutu  
C. Crane  
M. Dalby  
C.J. Deller  
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Mr. and Mrs. P. Donoghue  
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D. Penczak  
Mr. and Mrs. L. Pronnicki  
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S. Sand  
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B. Spinozzi  
L. Strick  
Mr. and Mrs. E. Terman  
Mr. and Mrs. D. Thatcher  
L. Tjøstolvsen  
C. Turner  
F. Wilkowicz

**\$100 - \$499**

Mr. and Mrs. S. Ballina  
R. Bellan  
S. Chapman  
J.D. & L.G. Cody  
Mr. and Mrs. L. Colasuonno  
Mr. and Mrs. A. Culcasi  
East Fishkill Rotary Club, via T. Ragazzo  
Ferolie Corporation, via T. Ragazzo  
Mr. and Mrs. R. Gosar  
Mr. and Mrs. G. Gose  
Halliburton Giving Choices, via Nancy Cotton  
D. Higney  
B. Hunt  
G. Hunt  
K. Hunt  
R. Leslie  
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Mr. and Mrs. R. Matson  
J. McFarland  
Mr. and Mrs. J. McIntosh  
H. McIntosh  
J. Mills  
G. Mitchell  
Mr. and Mrs. J. Montgomery  
A. Neves  
Mr. and Mrs. M. Pool  
M. Powers  
C. Powers  
Mr. and Mrs. A. Ragazzo  
S. Schaefer  
A. Schefer  
C. Schroeder  
W. and R. Sutch  
United Way via K. Dresler

F. Wilkowicz  
Mr. and Mrs. L. Witko  
M. Woodward

**\$500 - \$4,999**

K. Wilber  
Mr and Mrs. D. Lushbaugh  
Mr. and Mrs. E. Maurer  
M. McGuinness  
Pfizer Foundation Matching Gifts Program, via C. Lushbaugh  
Wakefern Food Corporation Grant, via J. Ragazzo  
Yum Brands Foundation Inc., via E. and N. Maurer

**Ongoing Donation Programs**

Thanks to our members and others in the CADASIL community who have used the following programs to donate to cureCADASIL:

Amazon Smile - ~\$187  
Benevity Community Impact Fund - ~\$50  
Goodshop - ~\$119  
iGive - ~\$79

Please continue to support us via these programs!

**Thank You!**

A special thanks to all our members, medical advisors, supporters, and donors for their wonderful support in 2014. "ENVISION THE CURE, EMBRACE THE CHALLENGE"

# Financial Statement

All CureCADASIL board members are unpaid volunteers and therefore we can keep our operational costs low. Any monies earmarked for a particular program or research fund go to that program or fund.

FOR FISCAL YEAR ENDING 12/31/2014  
 (Please use department material change form if your organization's fiscal year ending changes.)

**CADASIL ASSOCIATION** CH  **FOR RENEWALS**

Is this a consolidated financial statement for chapters, branches, or affiliates?  Yes  No

NOTE: In lieu of using this financial statement you may send the IRS Form 990 and all attached schedules of the IRS Form 990EZ and Schedule O.

IRS 990N E-Postcard and IRS 990-PF are not acceptable Financial Statements.

**REVENUE**

1. Federated campaigns: (must provide a list of sources and amounts)	1.	0
2. Government grants: (must provide a list of sources and amounts)	2.	0
3. Program service revenue:	3.	0
4. Membership dues:	4.	0
5. Income from interest, dividends, etc.	5.	0
6. Income from investments & tax-exempt bond proceeds:	6.	0
7. Sale of assets other than inventory:		
a. Gross sales	7a.	0
b. Less sales expenses	7b.	0
c. Net gain or (loss) from sale of assets	7c.	0
8. In-kind contributions (non-cash contributions):	8.	0
9. Royalties:	9.	0
10. Related organizations: (Must provide a list of sources and amounts)	10.	0
11. Net rental income:	11.	0
12. Sales of inventory:		
a. Gross sales	12a.	0
b. Less: cost of goods sold	12b.	0
c. Net income or (loss) from inventory sales	12c.	0
13. Income from fundraising events:		
a. Gross	13a.	0
b. Less: direct expenses	13b.	0
c. Net income or (loss) from fundraising events	13c.	0
14. Income from gaming activities:		
a. Gross	14a.	0
b. Less: direct expenses	14b.	0
c. Net income or (loss) from gaming activities	14c.	0
15. All other contributions, gifts, grants & similar amounts:	15.	19,371.06
16. TOTAL REVENUE	16.	19,371.06

(Add lines 1, 2, 3, 4, 5, 6, 7c, 8, 9, 10, 11, 12c, 13c, 14c & 15)

Statement of Functional Expenses for CADASIL ASSOCIATION CH  **FOR RENEWALS**

ITEMS	(A) Program Services	(B) Management & General	(C) Fundraising	TOTAL for A, B, C
Grant & allocations				
Grant				
Non Cash	\$5,000.00			
Attach schedule				
Assistance to individuals				
Benefits to or for members				
Compensation to officers, etc.				
Other salaries, wages, etc.				
Fees for service non employees				
Other benefits, pensions, etc.				
Payroll taxes				
Professional fundraising fees				
Investment management fees				
Accounting fees				
Management				
Legal fees				
Lobbying				
Office supplies		\$889.49		
Telephone				
Postage & shipping		\$427.55		
Equipment rental				
Occupancy				
Printing		\$233.05		
Travel				
Conferences & meetings	\$1,485.00			
Insurance				
Advertising & promotions	\$1,400.00	\$262.59		
Information technology		\$56.18		
Royalties				
Payments to affiliates		\$100.00		
Depreciation, depletion & amortization				
Other (List Item)		25.00		
Other (List Item)				
Other (List Item)				
TOTAL EXPENSES	(A) 7,885.00	(B) 1,948.86	(C)	TOTAL

**EXPENSES:**

17. Program services expenses, including payments to affiliates (Total of column A)	17.	7,885.00
18. Management & general (Total of column B)	18.	1,948.86
19. Fundraising (Total of column C)	19.	0
20. TOTAL EXPENSES (add lines 17, 18 & 19)	20.	9,833.86

**NET ASSETS:**

21. Excess (or deficit) for the year (line 16 less line 20)	21.	9,497.20
22. Net assets of fund balance at beginning of year	22.	13,822.89
23. Net assets or fund balance at end of year (add lines 21 & 22)	23.	22,304.09