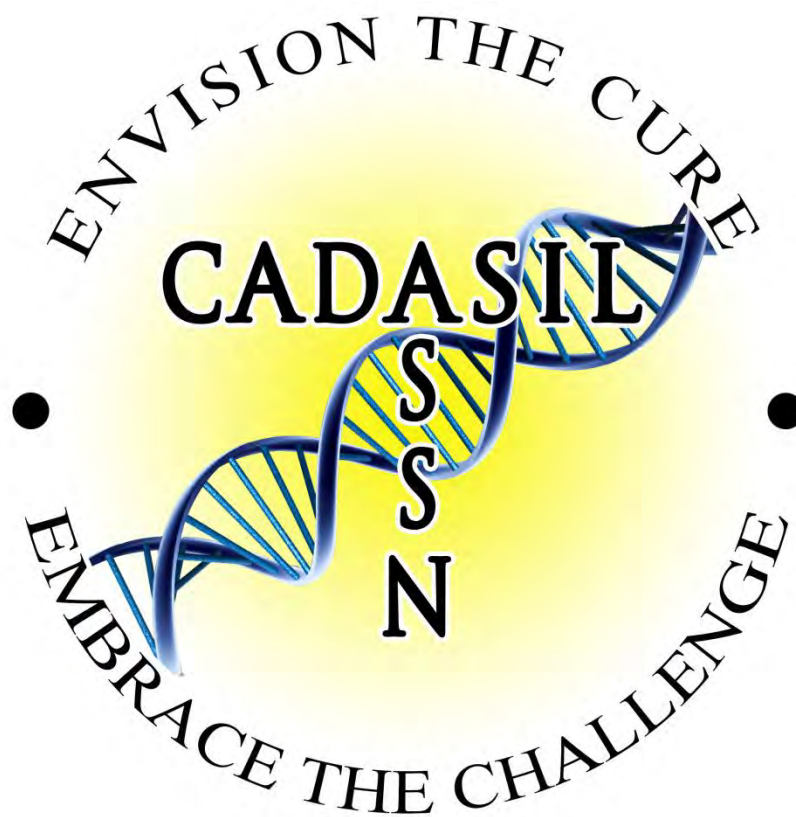
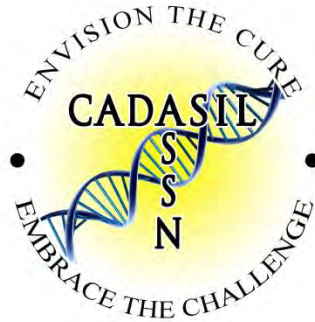

Cerebral **A**utosomal **D**ominant **A**rteriopathy with **S**ubcortical **I**nfarcts and **L**eukoencephalopathy



CADASIL ASSOCIATION

ANNUAL REPORT 2013



Dear Friends,

2013 was the CADASIL Association's first full year as a 501(c)(3) non-profit organization. I am pleased to present to you the CADASIL Association's Annual Report for 2013 (January 1, 2013 through December 31, 2013).

The CADASIL Association relies on a volunteer Board of Trustees to oversee and carry out the operations of the organization. In addition to our talented Board of Trustees we have a group of extraordinary and dedicated volunteers that devote their valuable time to provide the resources necessary to accomplish our goals. It is evident that we are making a difference in the rare disease community through the efforts of our volunteers. I am extremely grateful for their help and want to take this opportunity to express my heartfelt thanks to each and everyone of them. It is our intention to continue building our volunteer network, and I would encourage you to contact us if you have an interest in volunteering. We are dedicated to finding a cure for CADASIL and we have a tough fight ahead of us. Join us in the battle to CURE CADASIL.

Please visit our website at www.curecadasil.org to donate to the CADASIL Association and to find the latest information about resources and upcoming events. We look forward to the future, committed to working together to find a cure for CADASIL.

With hope and inspiration,

Anne McGuinness
President

CADASIL Association



A CADASIL STORY

My husband, Mike, comes from a long line of CADASIL. His grandfather had it, or died of a series of strokes. He was not really diagnosed back then. Mike remembers his father having had strokes. His father would get so angry when trying to speak and express himself that he eventually just quit talking. Mike was only 11 when he lost his father. His father, also, was not diagnosed with CADASIL, but due to the strokes and passing away from stroke related conditions, it was pretty much a given when the children began having same symptoms and being diagnosed. Modern medicine connected the dots. Mike was the youngest of 11 children, 9 boys and 2 girls. One boy died accidentally, so unknown if he carried it or not. All surviving boys had CADASIL. Two of the boys were twins. As time progressed, the family learned of the Familial Stroke Syndrome and how it might relate to them. In 1997, what was left of the family went to Mayo Clinic in Rochester, MN, as they were doing a study on CADASIL, and sponsored different families for the research. All boys, except Mike, were presenting symptoms. Mike was not tested, but the diagnosis was made for most of the other participants. Oddly, they mostly displayed different symptoms. One would cry for all emotions, happy, sad, mad, glad or whatever the event, he would cry, even though it was a happy occasion. Another brother would often laugh, uncontrollably. That is just how CADASIL presented in them. They just could not control the laughing or crying. The same brother that would laugh was also losing his ability for speech. At first it was just difficult to understand him. After several more strokes we could not understand him at all. He was functional otherwise. The twins did not present at all similar. One twin went immediately to the nursing home. He needed more professional care than could be given him at home. The other twin lived considerably longer, and slowly developed dementia over many years. One brother began having strokes at 23 and he is 8 years older than Mike (Mike is 60). He has experienced a sort of fainting spell or light seizures. He had a pretty big stroke, but recovered most functions after a long bout with therapy. He is living at home and, for the most part, doing pretty well. Each of the remaining boys also displayed different results. Probably, because of the strokes hitting in different regions of the brain, AND the differences in personality of each brother. Now, there is only Mike his one brother and one sister living. Neither of the two girls showed signs of CADASIL. One sister died of breast cancer. Mike had said several times, "I don't know how long I am going to be able to outrun this". He was the only one who did not show any signs of CADASIL. Then in January of 2008, we lost the race. Mike had a major stroke. He lost use of his right arm and leg and speech. During the intense therapy in the coming month he was able to regain use of his leg and most of his speech. His right arm was still not functional. Since he was right handed, this created yet another problem. But, he could walk and talk pretty well. We practiced a lot at home and more of his speech returned. Eventually he was able to walk on his own without the cane. There was still a limp. We had to make a lot of adjustments on how we did things, but he was functional again. He could drive, work, walk, sit, stand, dress, slower...everything, just slower. In 2010, we went to Mayo Clinic again and Mike was tested positive. It was no shock or surprise, due to it having been all around him all of his life, and having had the stroke.

After Mike had his first stroke in 2008, he had about an 80% recovery. Our life had pretty much resumed to close to normal. Then he broke his hip in August 2013. He had emergency surgery for partial hip replacement. He has never recovered from the surgery. Had the surgeon researched CADASIL a little further to see if there is a favored anesthesia for CADASIL, perhaps the outcome would be different. About 5 months ago I noticed a gradual mental decline. I began a dreadful

journey within myself discovering feelings and emotions that I never thought could ever be part of me. It is a living nightmare that continues on and on, slowly getting worse. I'm against the wall, nowhere to turn, no help in sight. I am all we have. I am bombarded from all directions, overwhelmed and I don't know what to do.

Most of us, non-professional caregivers, are simply spouses or family members. We have had no formal training or experience of any kind in this field. Overnight we are thrust into a whole new career that we know nothing about, and we may or may not be able to handle it. Plus, we are generally held ACCOUNTABLE for a job we know nothing about, and the welfare of our patient is on us. If the patient gets better, the physician or therapist gets the thumbs up. If the patient gets worse or does not improve, it must be the care they are getting at home. And the nightmare marches on.

Sometimes, when frustrated Mike is able to clearly speak, and when he can it is cuss words or hateful, ugly things that are so terribly uncharacteristic for him. My heart breaks when I see the tears in his eyes when he cannot say what he wants to and the frustration is more than he can bear. With each month he is able to talk less and less, with any continuity. He cannot carry on a simple conversation and is distracted very easily. I try to talk to him, but he just stares at the TV. I feel ignored, yet I know he can't help it. But, it still hurts. The little hits keep coming and the hurt just grows and eats away at my heart, creating an opening for unintended resentment. I cannot include him in any of the decision making. He just is not mentally capable of even making simple decisions. He cannot stand or walk unassisted. I have to transfer him from wheelchair to bed or chair or whatever. Sometimes he works with me and sometimes he seems to just do what is in his head. He gets angry, and justifiably so, but then that puts his safety in jeopardy. I get upset, then angry and it shows, or I mess up and say something less than kind back to him. I see the hurt in his eyes. He knows he is hurting me and does not mean to. It is just the two of us. There is no help unless we have an emergency. No help on a day to day basis. I had to quit a job of 28 years that I loved. It was high traffic, high interaction and a lot of contact with a lot of people who had become friends. But, I loved him more than the job, and I just could not let a stranger take care of him. The last day on the job was a terrible day for me. And I had to do it alone. When I came home, a crying mess, he didn't even notice anything was wrong. He was no longer able to understand things like this, where before he was the rock I ran to and my fixer. He was big enough and strong enough to slay all of my dragons. But, now that man is gone, and I truly miss him. When I tell him something is wrong, he can't remember it for any length of time. If something happened to me and I was out of commission for a few days or weeks, I do not know what would happen to him. I worry so much about this. Sometimes I get so angry at him or so hurt, that I find sides of myself I never knew were there. Trying to contain this anger and hurt only makes me more volatile. I know I have come close to the edge more than once, which creates, yet another, fear and issue. I only sleep a few hours a night due to fear of everything that one can be afraid of. I cannot imagine myself without this man, yet I see the end coming as sure as I sit here. I am generally pretty confident and strong. But, Mike is my one big weakness and seeing him this way with the constant changes, for the worse, I feel parts of me slipping away. On a daily basis I have to cope with the high level of stress, fear, anxiety, lack of sleep, isolation and all of the other deadly emotions that this hideous disease has cursed us with. I watch little pieces of him drift away. I hold tight to whatever thread of hope that is offered me that day, but by nightfall, it is gone. The tiny rays of sunshine are suffocated by the darkness of the reoccurring nightmare, that is actually reality.

I have not even touched on my feelings of guilt. I have this horrible guilt because I am complaining about what I am dealing with, when I know he is the one with the REAL monster. I cannot imagine how I would react to my being in his place. With what he is going through, how can I have the audacity to complain? All I know is that I do have these feelings and emotions and they are real

and running wild. They are part of me and if I do not control them, I will end up inflicting even more misery on him and myself. My attitude will bleed over onto him and his problems will only magnify. Not to mention my sanity becoming confetti in the wind. I can fully understand why there are so many dementia caregivers that are totally dependent on alcohol and/or drugs. They dull the unintended hurt and falsely placed guilt. The physicians do not even think about our wellbeing. In my opinion, the caregiver is just as important as the physician, maybe even more because they love and are always there for the patient. The caregiver should be just as important to the physician for they have such a tremendous impact on the patient. The caregivers mental and emotional state can definitely inject the patient with a negative or positive result in attitude. Caregivers have to live 2 lives. On a 24/7 basis, they have to try to help the patient live their life as comfortable, clean, safe and happy as possible, which is a full time job. In addition they have to live their own lives, which is another full time job of: washing, cooking, cleaning, errands, appointments, groceries, bill paying, keeping up the house, yard, car, etc. Before, it took 2 people to handle all of qqqqqqthese daily chores. Now there is only one.

There is an imperative need for physicians to pay more attention to emotional problems in CADASIL patients. IN ADDITION, it would help so very much if they paid more attention to the caregiver's emotional issues as well. There should be an information source of some kind that goes hand in hand with the patient AND caregiver. The physicians should consider both parties involved. If the patient is angry, aggressive and violent, then the caregiver is going to be the recipient of this turmoil and would need different counseling and/or meds than someone who might have a patient who is very passive and does or says nothing. In this case, the caregiver is alone and isolated. These are only 2 of the countless displays that should be considered by the physicians. BOTH patient and caregiver should have equal time and consideration. Each has such a powerful impact on the other. Sometimes the caregiver is in greater need of mental or emotional help than the patient. Most caregivers are at such a loss with CADASIL, that we are wandering around in the dark grabbing at straws and searching for tiny rays of sunshine. Either free falling or slammed against the wall.

When the physician requires the "New Patient Form" to be filled out, there should be a second form for the caregiver. The physician should consider the caregiver as their patient too. Giving them advise, information and possibly medications. The caregivers may need help coping with traumatic changes in their lives and the lives of their loved ones. Physicians can possibly prevent an additional CADASIL casualty.

For every CADASIL patient there is a second patient, the caregiver.

Donna Martin

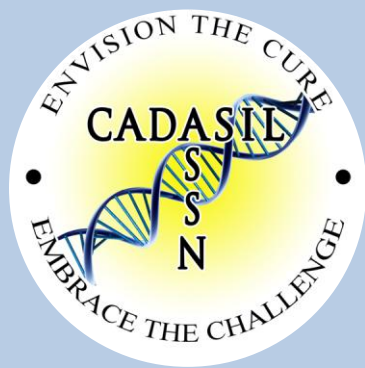
CADASIL ASSOCIATION ANNUAL REPORT 2013

VISION

To have a cure for
CADASIL

MISSION

The mission of the CADASIL Association 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 Communication, Advocacy, Research, and Education.



WHO WE ARE

I am a CADASIL patient who has been told I have an incurable genetic disease with symptoms I endure everyday. . . I am a mother who wonders if my children have inherited this devastating disorder. . . I am a spouse who has watched the love of my life deteriorate physically and mentally as he withered away from me. . I am a mother who watches my child suffer identical symptoms as his father, who is now bedridden and incontinent . . . I am a mother who quivers at the thought of my young child watching her father's health decline, as she thinks, "is it possible this will happen to me"

**We are the Board of Trustees
of the CADASIL Association**

We are busy raising awareness, educating the public and medical community, and communicating with all who are touched by or have an interest in CADASIL.

January 2013, the CADASIL Association Board of Trustees welcomed Karla Smith, Nancy Maurer, and Pamela Russell as associate trustees.

February 2013, during Rare Disease Week, CADASIL Association was represented in Washington, DC by Anne McGuinness, Barbara Hunt, Janet Mills, and Karla Smith. These trustees attended sessions sponsored by the RDLA (Rare Disease Legislative Advocates). Along with more than 120 other patient advocates asked their state Senators to join the Rare Disease Caucus and their representatives on Capital Hill to support special issues that plague rare diseases. They participated in Rare Disease Day at the NIH (National Institute of Health) with a CADASIL exhibit.

March 2013 the new CADASIL Association website was launched by Janet Mills.

April 15, 2013, the CADASIL Association held its first Annual General Membership meeting via teleconference.

April 2013, Christi Lushbaugh attended the [World Orphan Drug Congress USA 2013](#). This conference brought together over 1,000 people to discuss issues facing the development, regulation and marketing of drugs for rare diseases. World Orphan Drug Congress USA is the largest international, commercially focused event for the advancement of rare disease research and orphan drug

development. Christi was able to network with biotechnology companies, pharmaceutical companies, patient advocacy groups, and government agencies.

May 2013, Michelle McGuinness was welcomed as a member of the Scientific Advisory Board.

June 27-29, 2013, the CADASIL Association, with Karla Smith as Conference Coordinator, hosted its first Family Conference in Boston, MA. Dr. Joe Arboleda-Velasquez as Scientific Director brought together a distinguished panel of doctors, researchers, and clinicians to speak at the conference. Please take a look at the program that is posted on our website. The event was a huge success and the feedback from participants was very positive and encouraging. The CADASIL Association held an open meeting on the last day of the conference, for the conference participants. Participants were divided into 3 groups; patients, caregivers, and at risk family members. Sharing issues and concerns with like-minded individuals was rewarding for participants in all 3 groups. This conference brought together CADASIL experts that would continue to work together after the event was over. Dr. Joe and Dr. Stephen Salloway are working on a biomarker study. Biomarkers are very important for clinical trials and need to be defined. One of Dr. Joe's student, Vincent Primo attended the conference. This is a quote from Vincent, "It was not until a recent conference that I experienced an emotional reward that changed my view on life sciences. Our CADASIL research has been presented in many different forums, but never was our work presented in such a meaningful way than at the 2013 Boston CADASIL conference. Unlike most conferences, the CADASIL Association, a non-profit organization dedicated to CADASIL patients and their families, organized this conference. And, what made this conference unique was that our work in advancing the understanding of the Notch 3 mutation and its involvement on CADASIL was being presented and discussed to the very people we were trying to cure as well as their families. Towards the end of the conference, the reactions from CADASIL patients and their families astounded me; they showed great admiration and infinite gratitude for what I do, leaving me with a feeling of integrity and moral value in my career path - something I have never felt before. I've always had an interest in the molecular mechanisms of the CADASIL disease, but this was the first time I had gained an emotional investment in finding a cure. From this moment on, I realized I did not only want to do research in order to satisfy my personal curiosity but also to help bring about a change in medicine." Vincent is furthering his scientific career and pursuing a PhD in biology. As he advances his career, he does so with a special interest in CADASIL.

July 2013, CADASIL Association was accepted as a NORD (National Organization for Rare Disease) member organization, and also as a Foundation Alliance member with Global Genes.

July 2013, Dr. Jennifer Majersik joined our Scientific Advisory Board.

August 2013, CADASIL Association was approved as a bronze level participant in the GuideStar Exchange.

September 10, 2013, Janet Mills joined the FDA Patient Network meeting via webcast.

September 10-11, 2013, Anne McGuinness and Barbara Hunt accepted an invitation from National Institute of Neurological Disorders and Stroke (NIND) to the 2013 NINDS Nonprofit Forum at the National Institute of Health (NIH) in Bethesda, MD.

September 12, 2013, Anne McGuinness attended the Rare Disease Congressional Congress briefing in Washington, DC, while Barbara Hunt was present at the NIH Advisory Council meeting in Bethesda, MD.

September 20-21, 2013, Janet Mills attended the Global Genes Patient Advocacy Summit and Tribute to Champions Gala in Newport Beach, CA.

October 2013, Barbara Hunt received a scholarship to attend the 2013 NORD/DIA Conference on Rare Diseases and Orphan Products in North Bethesda, MD.

October 8-9, 2013, Anne McGuinness and Michelle McGuinness attended the BIO Patient and Health Advocacy Summit in Washington, DC.

October 10, 2013, Anne McGuinness and Michelle McGuinness accepted an invitation to the Rare Voice Awards Gala in Washington, DC.

October 2013, Janice Ragazzo joined the CADASIL Association as an associate trustee.

November 4, 2013, Barbara Hunt and Anne McGuinness attended a New York City Rare Disease Patient Advocate Mixer hosted by the EveryLife Foundation for Rare Diseases.

November 2013, Barbara Hunt and Janice Ragazzo went to Capital Hill in Washington, DC with the Charitable Giving Coalition. CADASIL Association was one of 120 organizations that took part.

November 16, 2013, the CADASIL Association led the way in the CADASIL community for our 4th annual CADASIL Awareness Day. On this same day, member Debbie Friedrich held a fundraiser in Washougal, WA, raising \$3000 for the association. Karla Smith received a proclamation from the Governor of Ohio recognizing CADASIL Awareness Day. Janice Ragazzo and Barbara Hunt received a proclamation for the day from New York's District 6 Legislator Roger Gross, and from the town of Kent, NY.

November 18, 2013, Anne McGuinness met with Rare New Jersey. Rare New Jersey is a coalition of New Jersey rare disease organizations which was formed to work together on rare disease issues in the State of New Jersey.

November 2013, Anne McGuinness, Barbara Hunt and Janice Ragazzo met with Dr. Swati Sathe. Dr. Sathe discussed her move to St. Joseph's Regional Medical Center and the Neurogenetics Program there. She is the director of the program and she is very interested in doing CADASIL research.

December 2013, Barbara Hunt and Janice Ragazzo were invited to speak at the Mending Hearts support group in Brewster, NY.

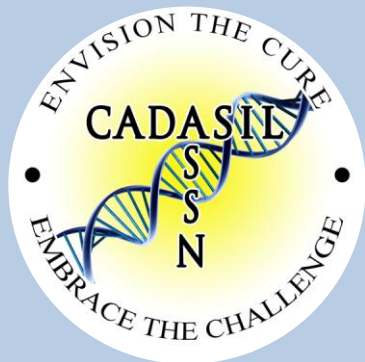
December 2013, Dr. Sathe joined the association's Scientific Advisory Board.

December 2013, Anne McGuinness, Barbara Hunt, Jennifer Costner, Ronnie Bradbury, Janice Ragazzo and Gail Hunt represented CADASIL in supporting Rare New Jersey as they collaborated with HINJ (Healthcare Institute of New Jersey) Dr. Sathe was a speaker at this event, on December 11, 2013. Her speech focused on several rare diseases, one of them, CADASIL.

Many thanks to all who attended these self-financed conferences, while raising CADASIL awareness

PATIENT ADVOCACY AND PUBLIC AWARENESS

CADASIL Association will work together with patient advocacy groups with which we have established relationships, such as National Organization for Rare Diseases, Genetic Alliance, Global Genes, and RDLA. CADASIL Association will continue to maintain connections with important federal agencies, such as the National Institutes of Health/NINDS, FDA and the Social Security Administration, and be aware of their policies which have influence on research and services for its members. CADASIL Association will strive to advocate for patients, caregivers and others touched by CADASIL on public policy issues.



LOOKING FORWARD TO 2014

OBJECTIVES

Explore grant writing options.

Sponsor Student for a research project.

Support planned fundraising efforts by enthusiastic members who take on this task.

Continue to develop a strong volunteer team.

Increase Board of Trustees by adding Associate Trustees to bring new and innovated inspiration.

Continue to seek qualified persons for our Scientific Advisory Board.

Explore funding for research fellowships for graduate students and post-doctoral fellows.

Develop educational materials for patients, caregivers, and healthcare professionals that are accurate, comprehensive and current.

Support patient and caregivers in the CADASIL community. Facilitate the development of local support groups composed of patients, family members, caregivers, and friends of persons with CADASIL

Collaborate with other organizations whose patients deal with similar symptoms and progression such as NMSS, American Stroke Association, ALS Association, Migraines.org, Association for Frontotemporal Degeneration, Alzheimer's organizations and support groups and Together We Have Hope.

Develop strong relationships and work in partnership with major patient advocacy groups including:
Global Genes

RDLA - Rare Disease Legislative Advocates
Genetic Alliance
NORD - National Organization for Rare

Work in coordination with federal agencies including:

NIH - National Institutes of Health and National Institutes of Neurological Diseases and Stroke

NINDS - National Institutes of Neurological Diseases and Stroke

GRDR -Global Rare Disease Registry

ORDR - Office of Rare Disease Research

FDA – Food and Drug Administration, Office of Orphan Drug Development

SSA – Social Security Administration, Office of Compassionate Allowances

Support of a patient registry for CADASIL that will be ready and appropriate when studies and drug trials begin.

Explore and implement the newest technologies, such as social media, to aid in expanding the reach of the organization's message.

Continue with design of website.

Expand and improve the quality of social media by developing media resources such as Facebook and Twitter.

Make use of other media—TV, newspapers, radio, etc.—to share information and to help educate the public about CADASIL including the fact that it is often misdiagnosed as MS or other neurological disorders.

Continue to develop and refine printed materials to maximize impact and effectiveness.

SUPPORT PATIENTS AND CAREGIVERS

CADASIL Association will serve the needs of patients and caregivers managing CADASIL in order to maintain well-being and quality of life. CADASIL Association is a link to a network of support, ensuring accessibility of information, education and counsel for each patient and caregiver touched by CADASIL. CADASIL Association will provide services including patient/caregiver educational resources, support groups, volunteer development, professional collaborations, online resources, webinars, social media, and national conferences. CADASIL Association focuses on symptom management to improve the daily living of people who struggle to maintain dignity, self-reliance and hope. CADASIL Association offers patient care resources about CADASIL to healthcare institutions, organizations, and facilities serving the CADASIL population.



2013 CADASIL Association Board of Trustees

Anne McGuinness
Co-Founder, President

Barbara Hunt
Co-Founder, Treasurer

Janet Mills
Secretary

Gail Hunt
Co-Founder, Trustee

Christi Lushbaugh
Trustee

Associate Trustees

Nancy Maurer
Pamela Russell
Karla Smith
Janice Ragazzo

EDUCATE MEDICAL AND HEALTHCARE PROFESSIONALS

CADASIL Association will provide scientific and clinical information/resources regarding the specific nature of CADASIL— including their diagnoses, symptoms, and treatments to all medical and healthcare professionals, institutions, and similar organizations.

2013 CADASIL Association Scientific Advisory Board

Dr. Joseph Arboleda-Velasquez, MD, PhD

Investigator, Schepens Eye Research Institute, an affiliate of Harvard Medical School, Cambridge, Massachusetts
<http://www.schepens.harvard.edu/arboleda>

Dr. Angelo M. Santiago, MD

Neurologist & Owner at Central Wyoming Neurology, Casper, Wyoming

Michelle A. McGuinness, MS, RAC

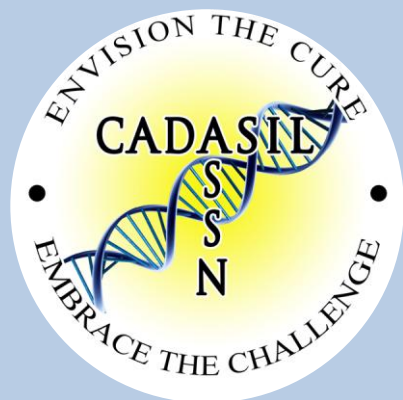
Regulatory Affairs, Quality & Compliance Leader, Greater Philadelphia area

Dr. Jennifer Majersik, MD, MS

Chief, Division of Vascular Neurology, University of Utah Hospital, Salt Lake City, Utah
<http://healthcare.utah.edu/fad/mddetail.php?physicianID=u0281833>

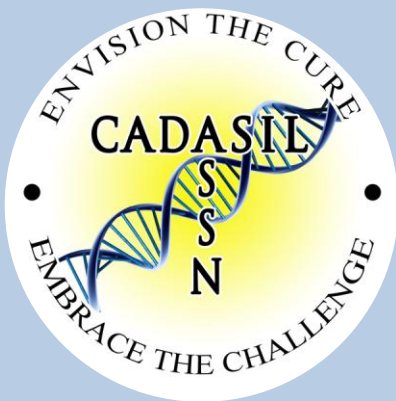
Dr. Swati Sathe MD MS

Director, Neurogenetics Program, Lysosomal Storage and Rare Neurological Disorders, St. Joseph's Regional Medical Center



VOLUNTEER

CADASIL Association is run completely by volunteers. CADASIL Association could not operate without its volunteers. CADASIL Association is thankful for all volunteer efforts big and small and will complement a volunteer's talents appropriately with the needs of the associations. CADASIL Association will be more productive with more volunteers.



HOW CAN I MAKE A DIFFERENCE?

Spread the word

Share CADASIL information with medical professionals, educators, and government representatives by contacting offices, providing brochures, and sharing online resources for CADASIL information.

Support those living with CADASIL

A supportive community helps improve the lives of patients, families, and caregivers of those affected by CADASIL.

Host an event

Events of any size are a wonderful way to raise awareness, build a community, and raise funds for the CADASIL Association.

Donate to the cause

CADASIL Association is a 501(c)(3). Donations to the CADASIL Association are tax deductible. Donations from individuals allow the CADASIL Association to help fund research, spread awareness, and provide support to those in need. To find out more about current research and upcoming events go to: www.cadasilassociation.org

Consider brain donations

Brain donation is essential to the progress of CADASIL research and the search for treatments and for a cure. For more info go to <http://www.butler.org/CADASILSite/support/brain.htm>

Volunteer

Join Us !!! Join the CADASIL Association and lend your expertise - we need volunteers for small jobs to large projects. You will work with other CADASIL families, shape the development of our organization, and help us reach our goals. Plus, learn a lot along the way and have fun. Go to www.curecadasil.org to sign up

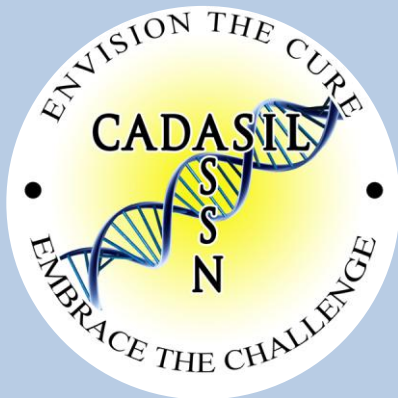
DONORS 2013

\$1-\$99

FUNDRAISING

CADASIL Association realizes that a vital aspect of any patient advocacy organization is fundraising. Fundraising enables the CADASIL Association to persevere in obtaining goals and objectives. CADASIL Association will continue to encourage all volunteers who wish to focus their support in this endeavor. CADASIL Association thanks everyone, who through their donations, have shown support for our vision and mission.

M. Kong
C. B. Tom
Mr. C. Wong
Mr. G. Choy
Ms. C. Leung
Mr. C. H. Lai
Ms. P. Hong
Mr. J. Leung
Ms. D. Leung
Ms. L. Go
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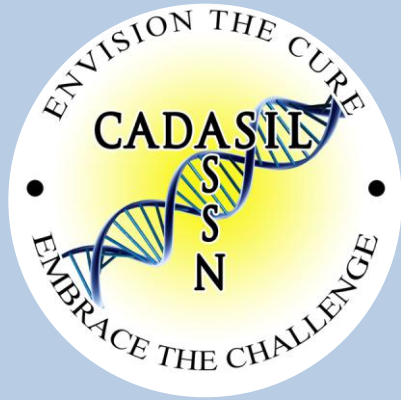
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Yum Brands Foundation Inc.

\$1000-4999

Mr. & Ms. D. Lushbaugh

Pfizer Foundation



Cerebral

Autosomal

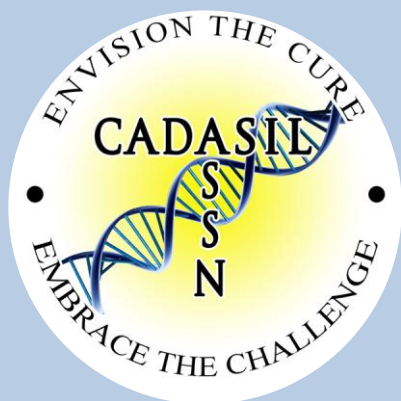
Dominant

Arteriopathy with

Subcortical

Infarcts and

Leukoencephalopathy



VOLUNTEERS

The CADASIL Association gratefully acknowledges and appreciates the effort of the following volunteers and organizations in 2013.

Arizona Ice Tea

Dr. Dev Batish, PhD

Ronnie Bradbury

Jennifer Costner

Ona Cody

Dr. Davidsdottir, PhD

Bobby Davis

Christina Davis

Kristin Davis

Marie Deets

Linda Bagneschi Dorrance

Kristen Dresler

June Dutka

Debbie Friedrich

Beth Fogg

Genetic Alliance

Marcie Glicksman, PhD

Global Genes

Ivana Hansen

Joe Hunt

Katie Hunt

Melissa Hunt

Tim Hunt

Dr. Adrian J. Iverson, PhD

Diane Lucente, MS

Devin Lushbaugh

Ines Maldonada

Kathy Montgomery

Sarah Ruedebusch Morris

NORD

Kathy Philips

Ann Marie Pool

Sonia Prim

Anthony Ragazzo

Carol Schroeder

Billie Duncan-Smith

Bob Smith

Karl Stumpf

Dr. Stephen Salloway, MD, MS Dr.

Peter Saltonstall

Robin Spaur

Sandra Talbird

Dr. Viswanathan MD, PhD

Ray Walker

Dr. Michael Wang

* We have tried to thank everyone. If you have volunteered in any way and we have neglected to recognize you please let us know.

Please note: Expenses to attend conferences and other activities are self-financed by the association member(s) participating.

RESEARCH

CADASIL Association will support research aimed at understanding the disease in a genuine effort to ultimately find a cure

CADASIL ASSOCIATION FINANCIAL STATEMENT

January 1, 2013 - December 31, 2013

Total Assets as of December 31, 2012 \$10,369.42

INCOME

Donations	\$8,602.39
Fundraising	\$1,517.58
Boston Conference	\$2,866.35
Miscellaneous income_	<u>\$11.71</u>

Total Income \$12,998.03

EXPENSES

<i>Funds spend on Programs</i>	\$4,462.22
NJ filing fee	\$25.00
Postage	\$124.22
PO Box	\$54.00
Office supplies	\$205.86
Insurance	<u>\$1,400.00</u>

Total Expenses \$6,271.30

Total Assets December 31, 2013 \$17,096.15

Barbara Hunt
Treasurer

