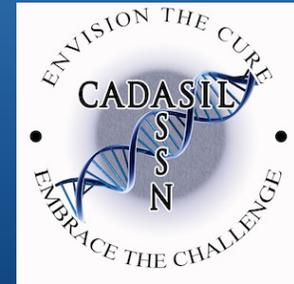


EMBRACE

A bi-monthly newsletter for anyone touched by the rare genetic disease CADASIL

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.



CADASIL Association attends Rare Disease Day in Washington, DC

During the week of February 25th – March 1st 2013, four trustees from CADASIL Association participated in conferences and activities in Washington, DC. We learned so much and made many important connections with others in the Rare Disease Community.

Our busy schedules included:

2/25: Welcome reception and screening of the film “Here.Us.Now”
<http://rareadvocates.org/cocktail-reception-movie-screening>

2/26: Legislative Conference by Rare Disease Legislative Advocates
<http://rareadvocates.org/feb-26th-legislative-conference-agenda/>

2/27: Lobby Day on Capitol Hill – we met with our state representatives in the House and Senate to talk about rare diseases in general, with time allowed for our individual CADASIL stories

2/28 & 2/29: Rare Disease Day at the NIH/National Institute of Health where we hosted a table and bulletin board with information about CADASIL

Please check out our personal summaries of our experiences in this issue of EMBRACE!

March 2013 - Issue 2

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Want to tell your story? Have a question for the doctor? Planning an event? Upcoming newsletters in 2013 will feature CADASIL patients and their loved ones sharing personal stories of living with CADASIL or caring for someone with this rare genetic disease. We welcome your submissions of stories, questions, news, and events. Please email them to: embrace@cadasilassociation.org

OUR STORIES



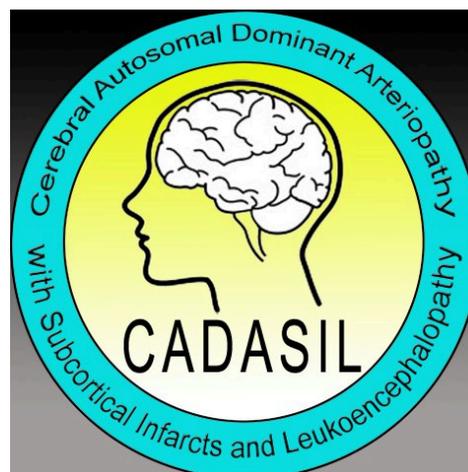
Courtney Colbert
Saucier, Mississippi
Age 21 at diagnosis of CADASIL

My Life with CADASIL

Life with CADASIL is a hard, painful and sometimes lonely battle. I struggle every day with headaches, some of them excruciating. I have dealt with them since I was nine. The hardest thing is moving on with my daily activity. Being a person who had a great memory at one time, I now find myself losing items on a daily basis. Notebooks, memory pads, and sticky notes help for now with my memory issues. But it is fading, it seems, with each excruciating headache. I work through the pain.

I maintain a full time job in between several doctor's visits each month. Counseling, neurologist, eye doctor, etc. are monthly visits for me. I have to inform every person I come in contact with about my rare disease. I seem to drift from family and friends because of the somewhat hardships I have to go through.

I live my life. But in the back of my mind I know I have already had two strokes before age 21, and my memory is fading so it's only a matter of time before it gets worse.



OUR STORIES



Sonia Vernon Prim
Barrie, Ontario, Canada
Age 28 at diagnosis of CADASIL

In 2001 when I was 25, I was working out at a local gym when I started to feel like my arm and legs were falling asleep. I quickly realized that the numbness was moving everywhere on my right side. Scared, I quickly left the gym and got in my car to drive home. I was unable to contact my boyfriend on the phone, so I called my parents to tell them that I felt “weird.” When my mom answered the phone, I could not say anything other than “gym” that made sense. My parents came to get me. At the nearest ER, I was diagnosed with a complex migraine and sent home. My GP referred me to a neurologist who ordered an MRI and was obviously confused by my scan results. To him, my scan showed Multiple Sclerosis, but he did not understand why I did not have any MS symptoms. He referred me to another doctor in Toronto, Canada. Upon meeting me, reading my MRI, and conducting other MS tests such as evoked potentials, the doctor diagnosed me with probable MS. He wanted to confirm the diagnosis by doing a lumbar puncture and set up the appointment for that. About a week before the spinal tap, the doctor called me at home. He told me that he had heard about a “new” disease that could explain the multiple lesions that were evident on the MRI. He also mentioned that the test was less intrusive as it was only a skin biopsy. He refused to tell me the name of the disease and said that he would explain it to me afterwards, if the test proved positive.

My skin biopsy came back positive and then the blood test came back positive for CADASIL. I was so happy that I didn't have MS. But then my doctor started explaining CADASIL. He kept saying over and over: “Sonia, this is rare. Really rare. We don't know much about this disease.” For the past several years, I have heard this repeated and repeated from every doctor where I have searched for answers. It was May 2004 when I received my positive CADASIL diagnosis. I was 28 years old and had been married for one year. Knowing the genetic risks, my husband and I still decided to have a baby. In July 2004, I had my first stroke that paralyzed my right side. While in the hospital, we found out that I was pregnant. I was immediately referred to a special pregnancy “maternal” diseases program in Toronto. There a team of “experts” would help me through my pregnancy. I was followed by an OB/GYN, a hematologist, a pediatrician, an anesthesiologist, a geneticist, and a genetic counselor. Not a single doctor there knew what CADASIL was. They all promised me that they would do research to help treat me. I did research as well. I found one study on-line about pregnancy and CADASIL. It was not helpful according to my doctors. My genetic counselor admitted to me at one appointment that it was obvious that I had a far better understanding of the disease than he did, and that he was not going to be useful to me. Finally the consensus of the medical team was to treat me as a pregnant stroke survivor.

My healthy baby boy was born by caesarean section in March 2005. I had my second stroke 10 weeks later. Thankfully, my son has not shown any CADASIL symptoms – although there is a 50% chance of him having it. I am 36 years old now. Thankfully, I have not had any more strokes. I have about four complex migraines every year. The auras are horrible. I continue my quest for knowledge about CADASIL. The doctor who helped me get diagnosed has agreed to follow me even though he is a MS specialist, because there is no other doctor who knows more than him about CADASIL in my province. According to him, he treats three other people with CADASIL. I have approached the “Best Doctor's” organization as well and have found nothing new. I wear a medic alert bracelet and I carry papers in my wallet that explains CADASIL for when I go to an emergency rooms to get my migraines checked out, to make sure they are not a TIA or stroke. I've actually had one ER experience when I was told to not come back to that ER and that I should drive the hour down to St Michael's hospital in Toronto. I am terrified of the future: of what will happen to me and what will happen to my son.

We CADASILians need a cure. We need a treatment. We need research. We need awareness.

ASK DR. JOE ARBOLEDA



Read more about him at:

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

What can the Boston Conference attendees hope to learn in June?

The attendees will have the opportunity of interacting with physicians and scientists with expertise in CADASIL. They will have ample opportunities to ask questions and also meet and interact with other CADASIL patients and their families. We are also preparing a session to discuss how to overcome challenges towards developing therapies for CADASIL. At this session, participants will interact with representatives from biotech and pharmaceutical companies that have helped develop drugs for other relevant conditions.

Note: Be sure to read our updates about the Boston Conference in this issue of Embrace, and register to attend at: www.cadasilassociation.org/2013-boston-conference

Is a TIA the same as a mini-stroke?

Transient ischemic attacks cause only temporary damage to the brain while a mini-stroke causes permanent damage, even if small.

What test do you think is most accurate for a diagnosis of CADASIL: Blood test or skin biopsy?

The most accurate is the genetic test that is done using blood.

Can you describe the difference between what Multiple Sclerosis looks like on an MRI compared to what CADASIL looks like on an MRI?

There is not a simple way to distinguish CADASIL and multiple sclerosis using MRI only. The MRI information has to be considered alongside family history, clinical symptoms, and the results of the genetic analyses.

Send your questions for Dr. Joe to: embrace@cadasilassociation.org and we will feature them in an upcoming issue!

OUR RDD SUMMARIES



From Anne McGuinness, President of CADASIL Association

Going to Washington, D.C. to be a patient advocate for CADASIL and other rare diseases was truly an empowering experience. Being on Capitol Hill makes you feel that you are really making a difference. Last year, Barbara Hunt and I attended the first RDLA Lobby Day, and we were among about 70 rare disease advocates. This year, we were among 200 advocates. To see how this movement has grown in just one year is very exciting. This year the CADASIL Association had four advocates from four states. We doubled our presence. Next year, I hope we can have even more CADASIL advocates attend. I would like to see a CADASIL advocate from every state. I was very proud to be from New Jersey. I think we had the largest group of advocates, so we had to be split into two groups. We represented about ten rare diseases. Our group included the Pediatric Hydrocephalus Foundation, Sarcoma Foundation of America, EDSers United (Ehlers-Danlos Syndrome), and the CADASIL Association. We all learned about each other's diseases and exchanged ideas about furthering our common cause to find a cure for our disease. Organizations that represent rare diseases share many of the same concerns. It was a great opportunity to tell others about CADASIL. Because we all are in the same boat, the people you meet really understand the challenges we face.

CADASIL Association was one of about 50 organizations represented. The RDLA took out a full-page ad in the DC newspapers "Roll Call" and "Politico." An overwhelming sense of accomplishment came over me when I opened up the newspaper and saw the CADASIL Association listed. The CADASIL Association has been working very hard to increase public awareness of CADASIL. It seems like we are taking baby steps with this endeavor, but little by little the word is getting out.

Rare Disease Day at the NIH afforded us the opportunity to make connections with likeminded organizations and industry leaders. Our table and bulletin board attracted many attendees. Researchers are looking for grants from patient organizations and we received many requests. Unfortunately, we don't have the funds to offer grants at this time. We need to have fundraisers so we will be able to do so in the future. Maybe next year we will have grant money available. We collaborated with other organizations and gained insight on how to grow the CADASIL Association.

From Barbara Hunt, Treasurer of CADASIL Association

It was a great experience to participate in Rare Disease Week in DC for the second time. Last year went so smoothly it was hard to believe it could be done any better. However, the RDLA did make some changes for Lobby Day and they were welcomed improvements of the process. This year there were twice as many advocates as there was last year. Many of those I met last year returned. It was good to see old friends and share stories of the progress we have all made in the areas of awareness, fundraising, and research.



The most gratifying part of the week was seeing an increase in awareness about CADASIL. Last year every time we said the word CADASIL, the response was: "What is that?" This year I heard several times: "Oh, I have heard of that." What a great feeling to have someone who does not have CADASIL recognize it! This tells me that all of the advocating and raising awareness that you all have done is beginning to emerge.

We can continue raising awareness by asking our members of the House of Representatives to join the Rare Disease Caucus. The purpose of the caucus is to bring greater congressional attention to the nearly 7,000 known rare or orphan diseases that currently have no approved therapy, by providing a forum for Members of Congress, families, and advocacy groups to exchange ideas and policy concerns. If you feel that your member of Congress should take up this cause, support laws that accelerate treatments and cures for rare diseases, encourage him or her to join the Rare Disease Caucus today! The link below will help you to contact your state Representative:

rare diseases.org/advocacy/hints-contacting-reps. *Be sure to mention CADASIL specifically.*

OUR RDD SUMMARIES



From Karla Smith, CADASIL Patient and Trustee of CADASIL Association

This was my first visit to Rare Disease Day in Washington, DC. I spent the week by not only figuring out the Metro Train system but was pleased to learn new things and to meet new people who have a rare disease or have a child with a rare disease. Some were experienced advocates and became very helpful to me while meeting with our state Senators and Representatives. Some were there to advocate even if their child was no longer living.

After meeting my one other advocate from Ohio and learning her son's story, I couldn't help but feel sad for what she and her family are going through. Her son is suffering from Gaucher's Disease, which is fatal. Listening to her talk about her dying son yet being very positive and able to speak to anyone about this disease made her very much an idol to me. She brought one of her other teenage sons with her, and after going from meeting to meeting on Capitol Hill, finally a representative asked this young man if he wanted to say anything. He said, "I've been waiting all day to say something." After being asked how he feels about his brother dying, he tried to talk but broke down and started crying. His mother started crying and gave him a hug, and then I started crying. No one should have to go through what this family and many others are going through and have gone through in the past.

I had the experience of meeting another woman who was advocating for her daughter who passed away two years ago from Batten's Disease. Her daughter may be lost, but she is doing whatever she can to inform others and keep her child's memory alive.

For the first time since my diagnosis of CADASIL, I have realized that it is not as bad as those diseases taking our children away from us at such young ages. I am not minimizing CADASIL, as we all know it is a devastating disease. I feel that this experience in DC has humbled me put things into perspective. I know that I would rather have CADASIL over and over instead of seeing my child or other people's children fade away from any disease.

From Janet Mills, CADASIL Patient and Secretary of CADASIL Association

This was my first time in DC, and I had many amazing experiences advocating on Capitol Hill and meeting others in the Rare Disease Community. We are all wanting the same thing: cures and treatments for our conditions. By joining others outside our smaller CADASIL Community, our voices were heard by many state congressional members. Some thoughts:



-So many rare diseases affect babies and young children. It was heartbreaking to hear parents talk about their little ones who have died or are dying. By banding together with others advocating for rare diseases, we can help everyone who suffers, whether they are young or old. We all need one another.

-I was not surprised to be the only advocate there from Wyoming, as my state has a population under a half million. I buddied up with a young father from Florida who lost his 4-year-old son to a rare pediatric cancer, and we spent most of Wednesday, February 27th meeting with our representatives from both states. In the process, my Wyoming reps heard about Rob's son's cancer, and his reps from Florida heard about CADASIL. Partnerships!

-We ARE being heard. Not only did our state representatives in the House and Senate listen to us, they and others we encountered on this trip showed compassion and gave us hope. Please check the link Barbara gave above in her summary, and contact your state congressional reps. If we could ALL ask our members of the House to join the Rare Disease Caucus, we will make an impact. Please, do it.

-Whether President Obama was your choice at the voting booth or not, he acknowledged Rare Disease Day for all of us. A simple but heart-felt thank you to him would go a long way to show our appreciation and further our efforts. Write to him at: 1600 Pennsylvania Avenue NW, Washington, DC 20500 -- or email him at: president@whitehouse.gov **Be sure to mention CADASIL.** Thank you! Together we make a difference!

RECENT NEWS

CADASIL Association welcomes new board members!

We are pleased to have Karla Smith, Nancy Mauer, and Pamela Russell join CADASIL Association in February as Associate Trustees.

2013 Rare Disease Day around the world – February 28, 2013



CADASIL was represented in many locations this year, thanks to the efforts of our members and friends around the globe. Some activities included:

- CADASIL Association trustees attended events in Washington, DC
- Representatives of CADASIL Together We Have Hope attended events at the Texas State Capitol in Austin
- Raising Hands for CADASIL in the UK:
<http://www.flickr.com/photos/rare diseaseday/8515535417/>

Want to share ways you are raising awareness for CADASIL? Please let us know so we can publish it in our next issue of EMBRACE. Email us at: info@cadasilassociation.org

View highlights from Rare Disease Day events for various conditions:

www.rare diseaseday.org/article/news



storify.com/rare diseaseday/international-activities-for-rare-disease-day-2013

<http://www.youtube.com/watch?v=p1AqAeQrwY8&feature=share&list=UU2DPEYfkEZUUpEJuCHwP1fQ>

UPCOMING EVENTS

2013 CADASIL Family Conference in Boston

The CADASIL Association is excited to host the 2013 CADASIL Family Conference to be held in Boston, Massachusetts on June 27-29. Our Scientific director is Dr. Joseph Arboleda-Velasquez.

Guest speakers include: Dr. Joseph Arboleda-Velasquez, Dr. Anand Viswanathan, Dr. Stephen Salloway, with more speakers to be announced soon.

All sessions of the conference will be held at the Constitution Inn.

Call the hotel at 617-241-8400 or 1-800-495-9622 to reserve your room for the discount price of \$125 a night when you mention the CADASIL Conference.

The schedule so far includes:

Thursday June 27, 2013 - Meet & Greet with catered finger foods from 7:00pm - 10:00pm at the Constitution Inn. Please sign in during the Meet & Greet. If you cannot attend, you may also sign in the morning of the conference.

Friday June 28, 2013 - Continental Breakfast from 8:00am - 9:00am at the Constitution Inn. Conference from 9:00am-5:00 pm with a catered lunch from 12:30pm - 1:30pm.

A large part of the conference will be a Question and Answer session, so have your questions ready!

Saturday June 29, 2013 - Continental Breakfast from 8:00am - 9:00am at the Constitution Inn followed by a CADASIL Association Meeting from 9:00am - 10:00am with breakout sessions for patients, caregivers, and those undiagnosed who may be trying to decide if they want to be tested. ALL INVITED! If you are not already a member of the CADASIL Association, please sign up on our [Join Us](#) page on this website, or you may join at the conference. Membership is free.

Registration fees and more details can be found at: www.cadasilassociation.org/2013-boston-conference

Things to do in Boston: <http://www.cityofboston.gov/visitors/thingstodo.asp>

Our thanks to Karl Stumpf for the design of the Boston Conference logo!



MORE UPCOMING EVENTS

CADASIL Association Annual Public Membership Meeting

For: ALL interested

When: Monday, April 15th, 2013 @ 7:30 PM (EST)

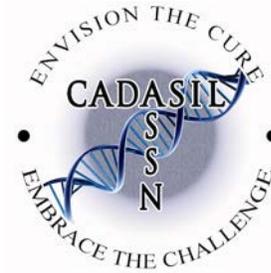
Where: Conference Call

Instructions: Dial 1-605-475-4000

When asked for Access Code, enter: 772160#

You will be told how many others are already on the call, and you will announce yourself

Please note: This is not a free call. If you have an unlimited minutes plan with your cell phone or land line, you will want to use it.



The Ride for CADASIL Fundraiser in St. Paul

When: Saturday, June 8th, 2013

Where: Motorcycle Ride @ Hitching Post Motorsports, So. St. Paul, MN www.hponline.com

Register: 9:00-10:00 a.m. Ride Departs: 10:30 a.m.

Events:

- Motorcycle Ride
- Silent Auction: 5:00 - 7:00 p.m.
- Dogs & Brats: 5:00 - 7:00 p.m.
- Entertainment: 5:00 - 9:00 p.m.



Coordinator/Contact: Bob Leslie (612) 801-0336, WingBob2005@msn.com

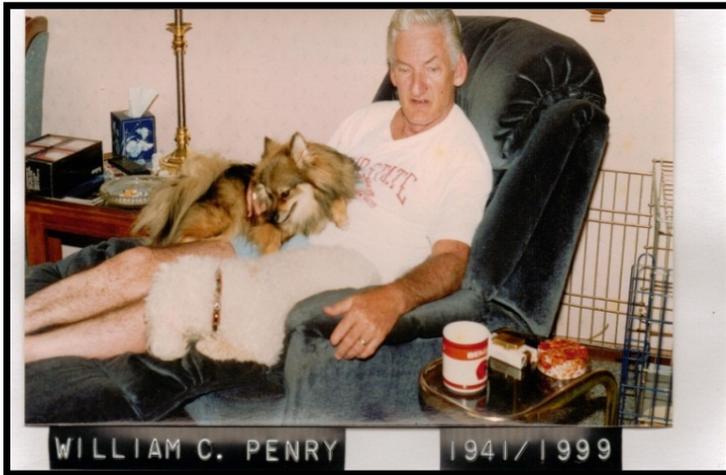
Web Site: www.cadasilrally.org

Facebook: Ride for CADASIL Fundraiser

Proceeds go to Butler Hospital for CADASIL Research

Check out page 12 of this newsletter for ways you can participate to help the global CADASIL community!

MEMORIALS



William C. Penry

1941-1999

Father of Karla J. Smith

Written by Karla: My father passed away from CADASIL one week before my 29th birthday. He was 58 years old. It was not known that he had CADASIL at the time. On his death certificate it stated his cause of death was dementia. We allowed an autopsy to be done, not knowing that we would need that report someday. This report helped to diagnose me. I remember my dad as a very intelligent, strong, stubborn, and hard-working man. My mom, brother, and I watched him getting worse year after year. From what I recall, he started to show signs of CADASIL about ten years before his death. He never had a full stroke, but he had hundreds of mini-strokes. Each time he lost more of his memory, his balance, and other capabilities. We had to put him into a nursing home, and he just got worse and worse. One day the strangest thing happened: I was working a full-time job and something in my head told me to get to the nursing home right away. I told my supervisor that I needed to leave. I went straight to the nursing home and to my dad's room. He had just passed away, and he was by himself. I was too late! For sure, my dad was extremely loved and is dearly missed.



To honor a family member or friend who has died from complications of CADASIL or suspected CADASIL on our Memorials page, please send a story about the deceased (and a photo if you wish) to:
embrace@cadasilassociation.org

OUR WRITINGS

My CADASIL Headaches By Janet Mills



Pressure

Squeezing, intense
Building behind my eyes
Moving across my nose and forehead
A vise grip on my skull

Nausea

Coming from my head,
Not my stomach
Crashing over me in waves
Wish I could vomit

Dizziness

Spinning on a carousel
Light-headed
I feel drunk
So out of it

Pain

Stabbing, throbbing
Light and sound make it worse
An invisible hand twisting my gray matter
Turn off the TV

Fatigue

Sleeping late
Not enough hours to rest
A warm lap for my kitties
I'm a couch potato

Panic

Worrying is a constant
Is this a migraine? A TIA? A stroke?
Silent tears
Another scar in my brain

Strength

I sleep it off,
Like an all-night binge
Tomorrow will be better
I am not alone

Setting: Three friends enjoying lunch at a local restaurant

Janet (smiling hopefully at her friends): We should go see a movie this afternoon.

Kathy: Sounds good. Hey Di, isn't there a new movie out that we *know* Janet would like?

Diane (nodding): Absolutely! The new Twilight movie just started. We know how much she likes vampires and werewolves.

Janet (choking on her soup and breadsticks): Ah, no you don't. I'm not going to another one of those toilet movies with you guys where I have to hide my eyes. You go ahead without me.

(Kathy and Diane trade a perplexed but humorous look.)

Diane: A toilet movie? Kath, did you hear "toilet"?

Kathy: I believe I did. Clearly, Jan doesn't want to see a toilet movie.

Janet (shocked): Why are you saying toilet when you mean Twilight?

Diane: *You* said toilet. *We* said Twilight.

Janet (crossing arms): I clearly said Twilight, and I'm not going.

Kathy: (raised eyebrows) You're not going to the toilet?

Diane: Well, *I* sure need to go before we go to the movie!

Janet: We're not all going to a movie if it's that Twah-liiiiight movie.

Kathy: Can you say "Twilight, toilet, Twilight" fast?

Janet (scoffing): Twilight, twoilet, Twilight, towlight... Ah, geez! I better hit the bathroom!



PARTICIPATE

Please join the CADASIL Association! Membership cards with information about CADASIL and the association will be mailed to every member in 2013. Here's the link again for your convenience:
www.cadasilassociation.org/join-us

Looking for ideas on how to help raise money for CADASIL Association toward our goals and mission? Here are some suggestions. We welcome yours, so please share them with us and we will publish them in an upcoming newsletter.

Gifts: Looking for the perfect gift for someone on your list? Making a donation to CADASIL Association in honor of someone touched by this disease is a loving gesture.

GoodSearch.com: Join GoodSearch to raise funds for CADASIL Association! GoodSearch donates money to your favorite cause when you search the Internet, shop online or dine out at local restaurants! Use GoodSearch.com to search the Internet and they donate a penny per search to your cause. Use GoodShop.com when you shop online and they donate a percentage of every purchase and offer over 100,000 coupons to help you save money too! Sign up for their GoodDining program and they'll donate a percentage of your restaurant bill when you eat at any one of thousands of participating restaurants. It's really easy; it's FREE and turns simple everyday actions into a way to make the world a better place. Please sign up today to help support CADASIL Association! Go to www.goodsearch.com/nonprofit/cadasil-association.aspx to get started.

Make Change for Charity: Toss that spare change from your pocket or purse into a container. Once every few months, locate a Coinstar machine at your local grocery or discount store and donate the cash you receive back to CADASIL Association. This would work well in a school setting as well.

One Thing I can Do: Your days are busy, and if you have CADASIL, sometimes filled with painful symptoms. Instead of thinking of all the many ways you can help make a difference, pick just one and follow through on it. One person doing one thing can help toward awareness and ultimately funding toward a cure.

Know someone who owns a business? Make a call today and ask if the business could host an event to benefit CADASIL Association. Many businesses in our communities are willing to partner with a good cause. One example: An ice cream shop allowed a charity to display their sign next to a receipt fishbowl by the cash register for one day. Patrons "donated" their receipt. The charity was given 5% of total receipts for the day! Another example: A friend who sells products through home parties donated a percentage of sales at a party organized by a member of the charity. Make that call today!

Garage sale: After the holiday season, clean out those closets and pick a date for a spring garage sale! Enlist friends and neighbors who may want to help, and have fun together while supporting CADASIL Association.

Electronic donations are always welcome and greatly appreciated at:
www.cadasilassociation.org/donate

Physical address for donations or other written correspondence:

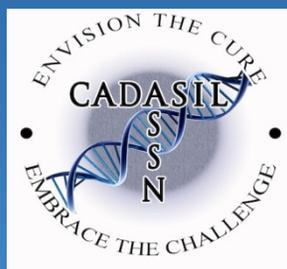
P. O. Box 124, Helmetta, NJ 08828

THANK YOU FOR READING OUR NEWSLETTER -- WE HOPE YOU ENJOYED IT!

**EMBRACE is created and edited by Janet Mills and Karla J. Smith for the
CADASIL ASSOCIATION**

We welcome your submissions of personal stories, questions, news, events, doctor profiles (with permission from the doctor), suggestions for fundraisers, funny or touching creative work, and memorials. We would also love to hear from you with feedback about this newsletter and its contents.

Please email us at: embrace@cadasilassociation.org



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ALWAYS SEEK THE ADVICE OF YOUR PHYSICIAN, OR OTHER QUALIFIED HEALTH PROVIDER, PRIOR TO STARTING ANY NEW TREATMENT, OR WITH ANY QUESTIONS YOU MAY HAVE REGARDING A MEDICAL CONDITION. NOTHING CONTAINED IN THIS PUBLICATION IS INTENDED TO BE FOR MEDICAL DIAGNOSIS OR TREATMENT OF ANY ILLNESS, CONDITION, DISORDER OR DISEASE.

CADASIL Association

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