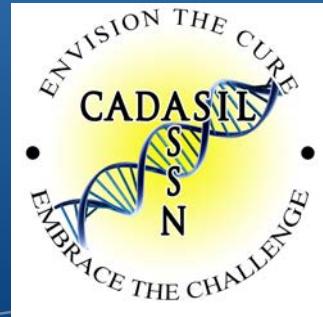


EMBRACE

A 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.



Dr. Swati Sathe joins CADASIL Association's Scientific Advisory Board! Dr. Sathe is known to many people in the CADASIL community. Welcome, Dr. Sathe!



Please consider an end-of-the year contribution to CADASIL Association. We wish to raise money to finance one or more graduate students to do research for CADASIL under the supervision of a doctor/researcher conducting vital research.

Go to: <http://www.cadasilassociation.org/donate> for details.

Please consider signing up for Amazon Smile, where your Amazon account benefits will remain the same, and 0.05% of each purchase all year goes to charity. **CADASIL Association** is a recognized charitable organization of Amazon Smile.
Go to: <http://smile.amazon.com>

Welcome to
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You shop. Amazon gives.

December 2013 - Issue 5

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Take action! Here's how!

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 PLEA FOR 2014

Won't you join us? If you are receiving this newsletter but have not yet become a member of CADASIL Association, we truly need you to be a part of our growing team. We gain credibility in the rare disease community with every member we add, and we gain motivation and strength with every person we reach. Please join us at: <http://www.cadasilassociation.org/join-us>

Below is the End-of-Year 2013 letter that was recently mailed to every CADASIL Association member.

Dear Member,

It has been a short 20 months since the CADASIL Association was formed, and we are so thankful to members like you who have joined us in the journey! We are an organization built with dedicated members like you. Our members include patients, patients' families, friends, caregivers, and other supporters whose lives are touched by CADASIL. Without grassroots members we would not be an organization today!

The CADASIL Association is an IRS approved 501c3 non-profit organization. We are run by an all-volunteer Board of Trustees. Our mission 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 uniting 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. Our passion is to help our dedicated members like yourself make a difference by giving you the support, tools, and opportunities you need to raise awareness, host fundraising events, or volunteer your time in any of our ongoing or new activities. To quote Margaret Meade: "Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has." With your help, we are that group for CADASIL!

Your support has accomplished:

- Our first ever CADASIL Conference in Boston, Massachusetts. This event brought both patients and physicians together. Speakers included Dr. Joseph Arboleda-Velasquez, MD, PhD (Harvard Medical School), Dr. Stephen Salloway, MD, MS (Neurology, Brown Research), Dr. Anand Viswanathan, MD, PhD (Neurology, Massachusetts General), and Dr. Adrian J. Ivinston (Director, Harvard NeuroDiscovery Center). We are pleased that DVDs of this conference will soon be available on our website.
- A volume of increased knowledge! Your support and encouragement inspired various board members, at their own expense, to attend multiple conferences on behalf of the CADASIL Association. They strive at each event to raise awareness of CADASIL and gain knowledge regarding research and funding opportunities for the CADASIL Association. This allows us to continue to grow stronger as an organization and improve how we serve our members.
- Continued growth as an organization, reaching others through our website, Facebook page, Twitter, Embrace newsletter, and handout materials. Many members find us at a time of stress and determination. One such member found us after her 22-year-old daughter had a stroke, leading to a diagnosis for not only her daughter, but also for her husband. We were able to be there for her family and give them a way to make a difference. She is now an active volunteer who shares CADASIL Association information with anyone who will listen, and raises funds along the way.

OUR PLEA, continued

Please consider a donation of any amount to the CADASIL Association in your giving this year. Our organization is supported solely by public contributions and volunteer hours at this time. Your involvement is critical to our work toward increased awareness, accurate diagnosis, and treatments for CADASIL patients. You can make a difference in our fight against this disease. And we are here to help you. Please let us know how you are willing to contribute.

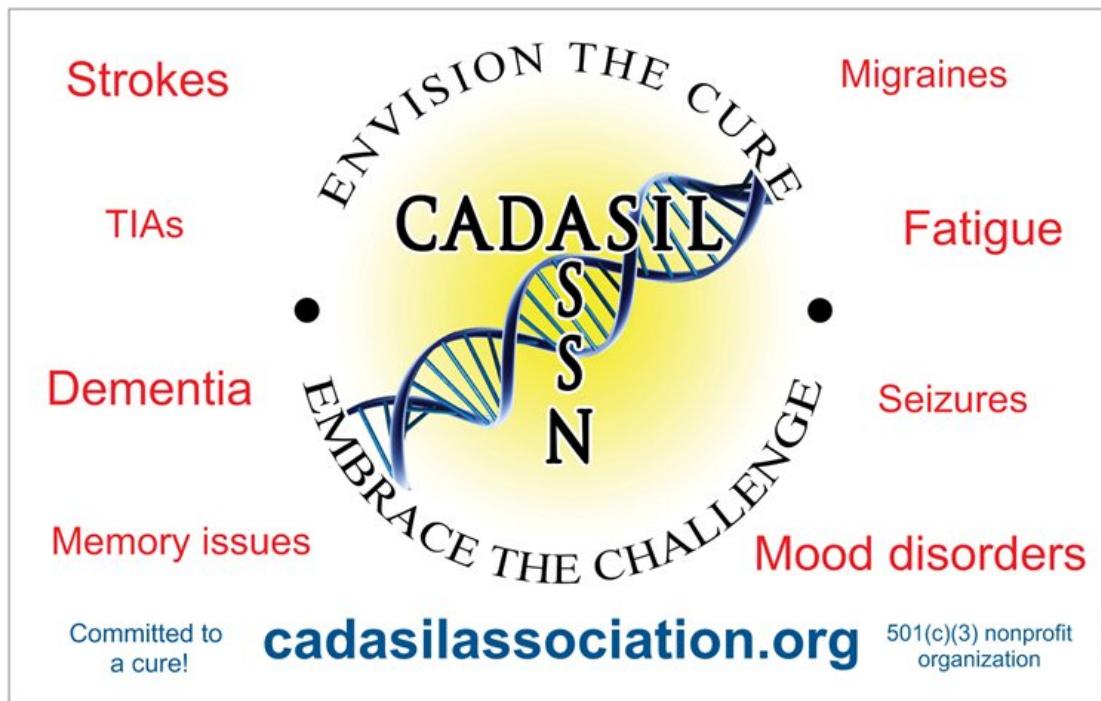
Sincerely yours,

CADASIL Association Board of Trustees

When and where is the next CADASIL conference?

YOU can help answer that question! The CADASIL Association is seeking a family or group of people to organize the next get-together. It can be an informal meet-up of people in the CADASIL community, or it can be more scientific, with medical professionals from the area as speakers and panelists.

Please let us know if you are interested in bringing the next conference to your area.



OUR STORIES



**Wilhemina Finlaw
Kingsville, Ohio
Age 45 at diagnosis of CADASIL**

I was 45 when I was diagnosed with CADASIL. One day I came home from work and my fingers started to tingle and went numb. At first, I thought that maybe I got some acid cleaner on them. Then my face started to feel the same and I thought maybe I touched my face with my fingers and got some cleaner on my face. Within a few minutes my whole arm was feeling the same and I got the worst headache I have ever had. I told my daughter that I had a headache and was going to go lay down and sleep for a little bit. When I woke up later the headache was gone and everything was back to normal. We wondered at the time if I had a mild stroke or something like that.

A few weeks later I went to the doctor and he sent me for an MRI because of my family's history of strokes. When he got the results he said my brain had a lot of lesions and looked like a 75 year-old brain. He sent me to a neurologist at the Cleveland Clinic. He said he would test me for several things including MS and CADASIL. When he described what CADASIL was, I thought that was what I had just from the symptoms he described and what my mother had gone through. [Please see the Memorial for Wilhemina's mother, also in this issue of EMBRACE.] When we left his office I told my husband that I had CADASIL. He said that we were not sure until we got the results back, but I just knew.

Growing up there were times that I felt different, like I didn't belong anywhere. I would walk down the hall at school, and all of a sudden I would feel like I just woke up and wondered why I was there. I always felt I should be home with my brothers and parents on the farm. I would get a headache from running a little ways or from laughing too much. I never told anyone because I figured it would sound strange. Who gets a headache from laughing? I always felt that someday they would find that I had a strange disease or something like that.

While I was going through the testing for CADASIL, my 17 year-old daughter was also having problems and also had an MRI because she got a lot of migraines. [Please see Angelina's story, also in this issue of EMBRACE.] Our doctors decided to find out what was wrong with me first and then go from there. When we got my positive result for CADASIL, I was not surprised at all. Once my results were in they said they could test my daughter but she didn't have to know the results if she didn't want to.

OUR STORIES

Wilhemina Finlaw's story, continued

She figured if she was tested she would know the results anyway, because if she was negative they would still have to find out why she had lesions also.

When we left the doctor after I got my results she looked at me and said that she knew that she had CADASIL also. When I heard her say that I knew exactly how my husband felt when I had said the same thing to him. I was heartbroken to think that at 17, my daughter would have to accept that she also has what is considered a terminal brain disease. My daughter said that we are all terminal here anyway, so this disease shouldn't affect how we live our lives and it shouldn't stop us from doing what we want.

After a few months my 20 year-old son decided that he also wanted to be tested. Since there was a 50/50 chance of passing this to my children, I was so sure that he would test negative. I was so shocked when his results came back positive. In my mind it didn't make sense that both of my children would be positive. Even with a 50/50 chance, both of my children have it.

Now five years later I feel that we have all accepted what we have and are dealing with it quite well. I don't see this disease as a death sentence. I believe I can still live my life as I would if I didn't know I had CADASIL. I'm just a little more health conscious. I don't have to die from this disease. I could get hit by a milk truck or something else. I am very sorry that I have passed this on to my children but I do not for a second wish that I had not had them.





Angelina Finlaw
Kingsville, Ohio
Age 17 at diagnosis of CADASIL

Growing up, I loved learning new things. I was like Johnny Five on *Short Circuit*, going around saying, “need input,” and reading books, observing people, and watching television shows. I loved learning new things. But my attitude towards learning changed as I reached high school. Although I still liked learning and had ease learning many concepts, I began to lose focus sometimes. Some days I felt like I was in a fog. I couldn’t concentrate and nothing would sink into my mind. After a few days I would go back to normal. I could focus again and learn what I was supposed to. This frustrating process went on throughout the first three years of my high school career, finally hitting its peak in my junior year. I began missing school when my mental fog began to be accompanied by dizziness and headaches. Finally I went to see a doctor.

I had an MRI done which showed unexplained chunks of lesions. I was referred to a specialist. Just as I was shocked when I heard about my brain, this new doctor was as well. He confessed that he had never seen anything like it before in someone my age. He did promise to do his best to find the cause, though.

By looking into my family history, especially my mother’s health, my doctor found that I could have a rare disease called CADASIL, or Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy. This of course meant absolutely nothing to me. All of those big medical terms the doctor said just floated right over my brain-damaged head. The doctor explained that I have an incurable, inherited disease that causes strokes, migraines, dementia, and is eventually terminal. This made a little more sense, but it was also much more shocking. They took my blood and I had to wait a month until the results came back.

During that month, I started to get anxious. Finally the call came and the waiting was over. My mom answered the phone and started talking to the doctor while I stood watching her anxiously. Although I knew my mom would tell me what the doctor said, I was still tempted to go find the other phone to eavesdrop on the conversation. But I had tried eavesdropping on phone calls in the past and always seemed to get caught. The people on the phone would hear me breathing and I didn’t think I could hold my breath long enough for this conversation. Also, lack of oxygen would probably give me even more brain damage – I thought I had plenty of that for the moment.

OUR STORIES

Angelina Finlaw's story, continued

Eventually my mom hung up the phone and looked at me. All she said was, "Well, you have it." I wasn't all that shocked to hear that the test was positive. I had told myself that there was a high probability that it would come back positive, so, in a way, I was prepared for it. It was a Friday when I heard the results of my blood test.

That Sunday I was leaving to spend a week at church camp. Those friends who knew me best and knew God and His love surrounded me the whole week. After one of our campfires we were allowed to stay after if we needed to. I stayed to pray and think. Eventually, I told the camp director what I was going through. He reminded me of a verse that I'd heard before many times but it really stuck this time. It was Jeremiah 29:11. "I know the plans I have for you, declares the Lord, plans to prosper you and not to harm you. Plans to give you hope and a future." This verse was the beginning of my healing, not physically, but emotionally. I began to realize that it didn't matter if I have a brain disease because God is in control. He must have a purpose for it so I have to trust him.

In trusting that God has a purpose for my brain disease, I have decided that I was created with it and it is a part of me. Although I look forward to the day that there is a cure, I also know that this disease has impacted my life in good ways too. I know it can cause devastating symptoms but it also has allowed me to appreciate my life while I can still live it to the fullest. Yes, there are some days that I can't do as much. But this disease has caused me to see the fragility of life. I know how short and fleeting this life can be but this knowledge gives me the freedom to truly live. It's given me the courage to do things that I don't think I would have. People often use the excuse that they will do something when they're older or retired. I may not be able to physically or mentally do some things when I am that age. This gives me the courage to do everything now.



MEMORIALS



Gertrude

1927-2003

Mother of Wilhemina Finlaw

Grandmother of Angelina Finlaw

Written by Wilhemina Finlaw

Growing up, my mom was a very fun and loving person. She was friendly to everyone. She would spend a lot of time with us children. We would go on trips, although we did get lost a lot. We would go bowling and skating and lots of things like that. Or we would just walk in the woods or pick flowers in the field. Once she took us to pick blackberries and all of a sudden she told us to turn around and not look. She had been standing on an ant hill and had to take her pants off and shake out the ants. She didn't get upset at all. She was laughing just as much as we were, while we sang, "Mom has ants in her pants." She really had a great sense of humor.

As I got into my teenage years, I started to notice a slight change in her personality. She would get depressed at times and confused and would lose things. She even called the police once when she thought someone stole her car. They found it in the parking lot where she was shopping. We would still have great times but things were different. Sometimes she would call me and say she felt like she was crazy and something was wrong in her head, and she said she was going to go drive her car into the lake. I would go see her and she wouldn't really remember saying that and she would seem fine. Some of the family said that she was just trying to get attention, but I knew that wasn't true. She did start to go to counseling and it seemed to help some.

When she was about sixty, she started to have worse strokes and we had her move in with us. My children were small then and she seemed better when she was with them. She loved spending time with them. Once she took my son to the garden to pick some vegetables and saw a small snake. She was really afraid of snakes, but that time she felt so happy that she kept her cool and just picked up my son and carried him into the house. She said she had saved his life.

MEMORIALS

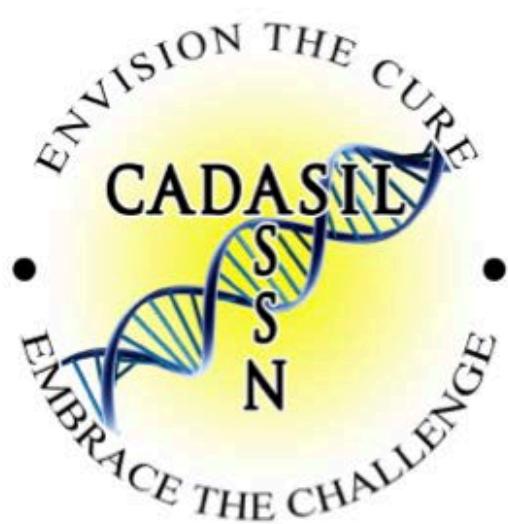
Gertrude's Memorial, continued

She lived with us for about a year, then she had a couple severe strokes and lost her ability to walk , talk, and even eat, so we had to put her into a nursing home. I felt so bad about that but I knew I couldn't take care of her on my own. When my children were learning to read we would take books with us to visit her, and the kids would read to her and we would play cards with her. Sometimes we would take the dog with us and she would lay on my mom's bed with her head on Mom's shoulder.

We did not know at this point that she had CADASIL. She was given some meds that we now know are not good for someone with CADASIL. She also smoked for years and we now know that was not good for her either. I do wish very much that my children had known her like she was when I was growing up. She sometimes felt like she was going crazy, and I think it may have been good for her if she had known she had this disease. Then at least she would have understood her feelings were not because she was crazy. Now I just remember her as she was when I was growing up and remember the fun we had.



To include 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



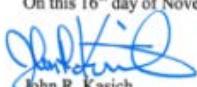
CADASIL Awareness Day November 16th

Many people in the CADASIL community raised awareness in November. If you would like your efforts published in an upcoming issue of EMBRACE, please email us at: info@cadasilassociation.org

NOW, THEREFORE, I, John R. Kasich, Governor of the State of Ohio, do hereby recognize November 16, 2013 as

CADASIL AWARENESS DAY

On this 16th day of November, 2013;


John R. Kasich
Governor



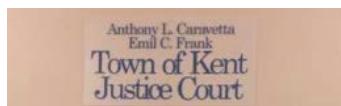
Trustee Karla Smith received a document that the governor of her state of Ohio recognized CADASIL Awareness Day



Trustees Janice Ragazzo and Barbara Hunt received a proclamation recognizing CADASIL Awareness Day from New York's District 6 Legislator Roger Gross



Member Debbie Friedrich held a fundraiser for CADASIL Association on November 16th in Washington state



Co-Founder and Treasurer Barbara Hunt received a proclamation from the Town of Kent, New York recognizing CADASIL Awareness Day



MORE AWARENESS ACTIVITIES

In November, Co-Founder and Treasurer Barbara Hunt and Trustee Janice Ragazzo were interviewed by a Putnam Examiner (New York) newspaper reporter. Their story made the front page!

Read the entire article here:

<http://www.theexaminernews.com/a-current-and-a-former-resident-fight-to-shed-light-on-mysterious-disease/>

Business of the Week
page 8

Daniels
FREE
twitter.com/examinermedia

Somers Stopped in State Quarters 34-7 See Sports page 19

November 19 - November 25, 2013

Small News is Big News

Volume 5, Issue 243

Residents Fight to Shed Light on Mysterious Disease

By David Propper

The symptoms can range, some being more severe than others, but the diagnosis is puzzling, or most of the time completely off the mark.

Patients stricken by CADASIL syndrome can face a frustrating collection of signs before the disease is recognized. Some of the symptoms can be somewhat pedestrian like numbness or tingling and dizziness or nausea to more serious warnings like severe migraine headaches and even strokes.

Still, Cerebral Autosomal-Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy (or CADASIL for short) largely goes unnoticed and untreated. There is currently no cure for it, though not surprising considering many doctors are unfamiliar with the syndrome.

But Putnam County resident Barbara Hunt and former county resident

Janice Ragazzo are looking to change that. Both are part of the CADASIL Association and both fully understand the impact the syndrome can have.

Hunt, who lives in Carmel and is the co-founder, vice president and treasurer of the CADASIL Association, said her husband for years would complain about numbness in his fingertips and them on the left side of his face.

Her husband's sister and brother had been diagnosed with Multiple Sclerosis so when he was also given that probable diagnosis, Hunt found it odd that would be the case.

At that point, he ignored the possibility of having MS and simply went on living his life. Finally in 2010, after it was discovered another relative actually had CADASIL, it was confirmed that's what Hunt's husband had as well.

"It's considered so rare that doctors

don't even look for it most of the time," Hunt said. "We've had doctors say to us 'I thought I'd never see a case of it in my lifetime, in my career.'"

As for Ragazzo, she is personally connected because her daughter suffers from the devastating vascular disorder in the brain. At just 24-years-old, Ragazzo's daughter suffered a stroke.

After being taken to the hospital and eventually having a bunch of tests run on her she was diagnosed with CADASIL. Ragazzo's daughter, who is a teacher, still suffers from debilitating migraines that can last for

continued on page 2

PROVIDED BY BARBARA HUNT
Hunt and Ragazzo stand outside the A&P along Route 22 in Brewster with fliers and informational cards to raise awareness for CADASIL.

November 19 - November 25, 2013

The Putnam Examiner

Residents Fight to Shed Light on Mysterious Disease

continued from page 1
multiple days.

The syndrome is incredibly rare and Hunt said just five years ago it was estimated only 1 in 100,000 people suffered from it. Currently, new figures state it is now 2 in 100,000 people. And she believes as time goes by and more doctors become aware of CADASIL that number will jump even more.

"They say it is such a rare disorder that how was it that (Hunt and myself) lived within 15 minutes of each other," Ragazzo, who now lives in Dutchess County, said. "So we started saying it can't be that rare if look how close we are."

The CADASIL Association was started in 2012 and has about 100 members that stretch over all 50 states. It is a non-profit organization whose president is Anne McGuinness, who resides in New Jersey.

The two have done much since meeting up to inform people of CADASIL. They'll talk to anyone who will listen.

This past Saturday was CADASIL Awareness Day, in which Hunt handed out brochures and education cards and for those who took a further interest she was ready to tell her personal story.

Hunt also goes to different locations and always carries educational material

for the people she runs into. Recently, Hunt spoke with a public health nurse at the Putnam County Department of Health and gave her information to pass along to others. She has also been to the Visiting Nurse Service on Route 22 and Putnam County Hospital, too.

Even when she dropped her twin

Ragazzo and Hunt are leaving for Washington, D.C. Tuesday to urge organizations to keep the funding at a reasonable level for CADASIL so doctors and researchers can keep studying the syndrome, even if the money is minimal.

"It hasn't had the exposure that people know about it," Ragazzo said. "Or even know to ask doctors."

And like most diseases that don't have a cure, finding one is the ultimate goal, even if one for CADASIL is still far off into the future.

"Once we have the awareness out there," Hunt said. "Maybe we can start really looking harder at research."

For more information on CADASIL, please go to www.cadasilassociation.org or email CADASIL Association members at info@cadasilassociation.org.

**Advertise in
The Putnam Examiner**

- 914-864-0878 •
- SMALL NEWS IS BIG NEWS •

FUNDRAISERS

Opportunities for you to help the Association!

Tax-exempt donations are always appreciated and acknowledged by the CADASIL Association.

Some ways the association is planning to use funds raised and donated in the near future include:

- Developing educational materials for patients, caregivers, and healthcare professionals that are accurate, comprehensive and current. We are preparing a full-color tri-fold brochure to be printed for distribution.
- Sponsoring one or more college students for a research project during the summer of 2014. Dr. Joe Arboleda outlined the costs of this at the conference in Boston, where we met students working with him and with Dr. Viswanathan. It takes \$3000-\$5000 to sponsor one undergraduate student for a summer semester, and \$16,000-\$20,000 to sponsor one undergraduate student for one year.
- Providing awareness materials to anyone interested in helping educate the public about CADASIL. We have banners to loan for events, business cards and denim ribbons to hand out, informational letters, and donation request letters available. Please contact us about any of these items.

Please consider signing up for Amazon Smile, where your Amazon account benefits will remain the same, and 0.05% of each purchase all year goes to charity. **CADASIL Association** is a recognized charitable organization of Amazon Smile. Go to: <http://smile.amazon.com>



CADASIL Association is also a recognized charitable organization of GoodSearch and its affiliates. Go to:

www.goodsearch.com/nonprofit/cadasil-association.aspx

Once you sign up and choose the association as your designated charity, every time you do a search with GoodSearch or use GoodShop, GoodDining, or their other choices, CADASIL Association earns money. Consider joining GoodSearch instead of Google or other search engines. You can bookmark the weblink or put it into your browser's toolbar so it is easy to find every time to want to search or do a little online shopping!

Please note: A number of CADASIL Association Trustees travel to conferences and events to promote awareness of CADASIL, to learn more about this condition, to network with others in the rare disease community, to meet with elected officials and medical professionals, to attend workshops and seminars, and for various other reasons important to our mission. ***These trips are funded entirely by the trustee involved. No monies from the CADASIL Association are used for travel expenses.*** In some cases, organizations such as RDLA (Rare Disease Legislative Advocates) and Global Genes offer limited travel stipends, funded by corporate sponsors, for rare disease advocates to attend events. CADASIL Association encourages all members to participate in the same manner when possible. We will provide informational materials for your use upon your request.

RECENT NEWS



September 10, 2013: Janet Mills attended (via webinar) the FDA's Patient Network Annual Meeting entitled **Demystifying FDA: An Exploration of Drug Development**.

September 10 & 11, 2013: Anne McGuinness and Barbara Hunt attended **Progress through Partnership: The 2013 NINDS Nonprofit Forum** at the NIH in Bethesda, MD.

September 12, 2013: Anne McGuinness attended the **Rare Disease Congressional Congress briefing** in Washington, DC, and Barbara Hunt attended 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. From Symptom to Cure: The Journey of a Rare Disease Advocate ~ Equipping Patients to Make a Difference.

October 7-9, 2013: Barbara Hunt attended 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: The Power of Partnerships**, in Washington DC.

November, 2013: Barbara Hunt and Janice Ragazzo were on Capital Hill in Washington, DC with the **Charitable Giving Coalition**. 120 organizations took part, including CADASIL Association.



Anne McGuinness and Michelle McGuinness chatted with Dr. Emil Kakkis in October in Washington, DC.



Anne McGuinness, Dr. Swati Sathe, Barbara Hunt, and Janice Ragazzo met in New Jersey in October to discuss CADASIL Association's goals.



Janet Mills attended the Global Genes Patient Advocacy Summit in California in September.

MORE RECENT NEWS

In July, CADASIL Association was accepted as a NORD (National Organization for Rare Diseases) member organization, and is listed on NORD's database as a resource for patients and families.

<http://rarediseases.org/patient-orgs/current>

As part of our membership, the association supported the campaign asking for continued support for the Compassionate Allowances (CAL) program by signing the letter to the Acting Commissioner of the Social Security Administration. Hopefully, it will help CADASIL be recognized as a Compassionate Allowance in the future. <http://campaigns.rarediseases.us>



CADASIL Association became a RARE Foundation Alliance member of Global Genes in July.

From the Global Genes webpage <http://globalgenes.org/foundation-alliance>: “Foundation Alliance members are rare disease foundations which have committed to working with Global Genes | RARE Project and other nonprofit foundations to collaborate to create a stronger collective voice in the rare disease community.”



Trustee Janet Mills serves on the Global Genes Corporate Alliance Patient Advocacy Team, meeting once a month via webinar with other members of the Rare Disease Community including patient advocates with other rare conditions, leaders at Global Genes, and representatives from healthcare and pharmaceutical corporations such as Siren Interactive, Genzyme, Shire, Parabase Genomics, Alexion, Feinstein Kean Healthcare, Pfizer, GlaxoSmithKline, and Sigma Tau.



In August, CADASIL Association was approved as a bronze-level participant in the GuideStar Exchange. <http://www.guidestar.org>

UPCOMING EVENTS

Calling artists in the Rare Disease Community! The Rare Artist Contest is now open on Facebook:

https://www.facebook.com/pages/RareArtistorg/169101479780640?sk=app_451684954848385&app_data

Welcome to the EveryLife Art Contest 2014!

Open for submissions on Facebook on December 8, 2013.

Entry Deadline: Rare Disease Day, February 28, 2014 11:59 pm

Voting Deadline: March 15, 2014 *** Awards Announced: April 1, 2014



Cash prizes awarded!

Be heard on Capitol Hill!

The 2014 Rare Disease Legislative Conference and Lobby Day events are coming soon! Last year, four members of CADASIL Association attended the events in Washington, DC, sharing information about CADASIL and rare disease in general. If you are outside the DC area, you can apply for a travel stipend to offset your travel expenses.

See details at: <http://rareadvocates.org/lobby-day/#more-7>



Rare Disease Day 2014 is coming up on February 28, 2014



Get ideas on what you can do at: <http://www.rarediseaseday.org>

You can be heard at your state capitol on Rare Disease Day!

Locate your state government's website, then use their directory or "Contact Us" link to get information on the steps you need to take.

To find your state government's website, go to: <http://www.statelocalgov.net>

More great ideas for bringing awareness to rare genetic diseases in general, that you can adapt for CADASIL specifically, can be found at Global Genes: <http://globalgenes.org/world-rare-disease-day>



MY EXPERIENCE AS A CAREGIVER

By Kathy Phillips, mother of Karla Smith

Caregiving is a very important job. You have to have a very good attitude and be able to process many things that one may think to be an impossible task. You have to see the person/loved one as an illness and not necessarily the person as they used to be. It can be an emotional and a physical rollercoaster ride of your life. You can find it to be very demanding and time consuming.

In 1989 my late husband Bill was diagnosed with Dementia. He had been seeing a Neurologist at Ohio State University Clinic in Columbus, Ohio. I had seen Bill go through what I would call possibly different stages:

Stage 1 – thinking process, talking process, speech process

Stage 2 – mobility/getting around, stumbling and bumping into walls/door frames

Stage 3 – not sleeping at nighttime like a baby who might have their day and night turned around

Stage 4 – bathing, not knowing how to go about a shower, adjusting of the water and the use of soap and the rinsing off of the body

Stage 5 – common sense about everyday things

Stage 6 – bathroom problems, not making it to the bathroom in time or not getting up during the night

Stage 7 – temper, being mean and abusive both verbally and physically

Stage 8 – with being a smoker he would light more than one cigarette up at a time or take off and try to walk to the store in town with no money

With CADASIL it is scary because you don't know what to expect. You may encounter some of the stages listed above or just a few of them or maybe none at all.

Throughout the last five years of Bill's life I knew by watching him and seeing how fast he seemed to be declining. I was able to keep him at home up to the last four months of his life. I had a lady who came into the house to care for him during the day while I went to work at my full-time job. In the last six months he started getting mean and abusive to me. I just couldn't deal with working nine hours a day at my job and then come home and have three loads of clothes and bedding to hand wash in a bucket of water and flushing the dirty water down the toilet bucket after bucket. I also had to fix our meals. Then there was shower time. I think I was wetter than he was. I sometimes would get to bed about 11:00 p.m. and would get up at 4:00 a.m. to get ready for work and my day would start all over again.

Bill was placed in a nursing home in January 1999. On April 6th, Bill was taken to the hospital. His health was declining and he decided he was not going to eat. He was not himself. The doctor told us that his condition was serious and that he wasn't going to make it. We asked how long did he have, the doctor said 9-10 days and to work on final arrangements.

On April 15th, he was sent back to the nursing home. On April 16th, he passed away. I had made arrangements with his neurologists so that they could do a whole body autopsy to learn more about dementia.

Now my daughter Karla started having migraines and seizure like symptoms. As Karla was in the hospital with many tests being done, we told the neurologist about her dad and that we had allowed a full body autopsy to be done upon his death and the neurologist looked up his autopsy report and he came to the conclusion that Bill had CADASIL and that provoked the need to have the CADASIL genetic test to be done on Karla. Her tests came back positive for CADASIL. I will be there for her also!

OUR WRITINGS

Rare Disease During the Holidays: How Much Can You Handle? by Janet Mills

Posted on Dec. 17, 2013 at: <http://globalgenes.org/rare-disease-during-the-holidays-how-much-can-you-handle>



My first Christmas season knowing I had **CADASIL** (a rare genetic neurological disease with no treatment) was bittersweet. Christmas has always been my favorite holiday. I didn't want to feel cheated out of the joy and spirituality of the season, yet at first I was reluctant to embrace it, just in case it was my last before a disabling stroke.

I didn't start decorating the house right after Thanksgiving as I typically would. I didn't hurry to change my car's satellite radio channel over to seasonal tunes. I didn't blast my favorite Christmas CDs while I wrapped gifts in colorful paper and bags. Christmas cards? Maybe I would never send those out again.

The magic of the season prevailed, however, and after a delayed start, I delved into all the Christmas activities that brought me such happiness in the past. Wonder of wonders, they still did! My usual optimistic self kicked in, and I was soon dancing to "Jingle Bell Rock," stepping into Christmas with Elton John, and making a joke of Chet's nuts roasting on an open fire. I felt more grateful than ever for a savior born in a manger so many years ago.

All this fun does come at a higher price now, but I am willing to pay it during the holidays. Stress exacerbates my disease symptoms, so I make sure I get plenty of rest and let that perpetual small stuff go. I remind myself to stop and smell the pine boughs and scented candles, and enjoy all the unique sights, sounds, and flavors of Christmas.

If I'm having a rough day, my self-care kicks in. I say "no" if I cannot do something...and I give myself permission to let go of the guilt. (That one is still difficult for me!) Family and friends can help by not putting more on me than what I say I can handle (and then read my body and facial language to see if I'm being completely honest).

I encourage readers of this piece to consider strapping on a pair of angel wings and donating to a rare disease charity of your choice by the end of the year. This is where I insert a plug for **CADASIL Association**, which is striving to raise funds to finance research toward a cure for CADASIL. A donation of any size is appreciated more than you may imagine:
<http://www.cadasilassociation.org/donate>

May you too experience the blessings of the season!

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.

Cans for CADASIL: Does your state have deposits on containers? Have a Cans for CADASIL Drive! Ask your friends, family, schools, churches, social clubs, etc. to collect their cans and other recyclables and donate the money to CADASIL Association.

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: Clean out those closets and pick a date for a garage or yard sale! Enlist friends and neighbors who may want to help, and have fun together while supporting CADASIL Association.

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

Mailing address for donations or other written correspondence: P. O. Box 124, Helmetta, NJ 08828

THANK YOU FOR READING OUR NEWSLETTER!

EMBRACE is created and edited by members of 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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