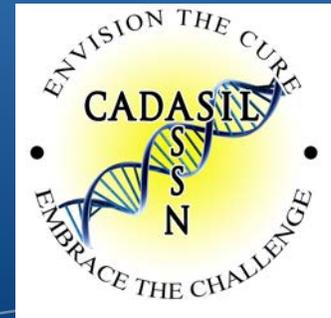


EMBRACE

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.



The ULF/United Leukodystrophy Foundation announced on June 10th that Fabrice Dabertrand, Ph.D., was awarded the \$25,000 CADASIL Research Grant. Many members of CADASIL Association contributed to the grant fund. We look forward to learning more. Read about Dr. Dabertrand here: <http://www.uvm.edu/medicine/pharmacology/?Page=profile.php&bioID=25684>

June 2014 - Issue 6

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Join us in the quest to
Cure CADASIL!



YES! Your donations **are** at work! Financial contributions to CADASIL Association have allowed us to award a graduate student a \$4000 grant to assist Dr. Joseph Arboleda in conducting vital research at Harvard this summer. See p. 9!
cadasilassociation.org/donate

Join CADASIL Association at: cadasilassociation.org/join-us

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/ch/45-5242623>

Welcome to
amazon smile

You shop. Amazon gives.

Want to tell your story? Have a question for the doctor? Planning an event? Upcoming newsletters 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



Kathy Phillips
Jacksonville, Florida
Daughter diagnosed at age 40

THE STORY OF MY CADASIL-ian DAUGHTER AS WRITTEN BY HER MOTHER By Kathy Phillips

My daughter Karla Smith was diagnosed with CADASIL around 10 years after she went through witnessing her father's decline for many years. It was later confirmed that her father Bill had CADASIL but did not know it. Karla has proved to me time and time again that she is a very strong person and is a very good and helpful person who interacts with everyone that is on the CADASIL and CADASIL-ians Facebook pages. Karla does whatever she can to support others who have CADASIL and helps them to smile and laugh if they are having a bad day.

Karla is often on the computer. Just knowing that she is not alone and that there are others out there who she can communicate with keeps her going and living. Karla is now 44 years old, and she is trying to keep a positive attitude. At times it is very hard, but then, you have to take one day at a time.

My daughter makes me very proud of her. Not only does she have a rare disease that threatens her life but she also lost her job, her medical insurance, and she is having a hard time making ends meet. Karla will still say things to make someone smile or laugh just to give them a little pick me up to make them feel better. Karla knows that the good Lord will watch out for her and will be there to guide her to the search for a cure, and to lift her and others up when they are at a low point and keep them going.

At first, Karla's condition was reported as having migraines, and then the doctor said possibly Multiple Sclerosis. Karla told the doctor that she wanted a second opinion. Before she could get that second opinion, she was taken one afternoon to the Ohio State University Hospital Emergency Room in Columbus, Ohio. While there waiting for 12 hours, she was finally taken to the ER room. While there she had a few silent seizure episodes. There just happened to be a team of Neurological Doctors in the ER. They observed her going through these seizures. They ran a sharp object across the bottom of her bare foot and there was no movement. Then they pounded on her chest and again, no reaction. Her friend and I tried to tell them that when she came out of the seizure she would talk to them. When she has the seizures, she can hear you but can't say anything to you. The hospital ended up keeping her a few days. They did an MRI, a skin biopsy, and a genetic blood test. We found out that the tests did confirm that she indeed had CADASIL.

Since the team of doctors was from the neurological field they were very interested and really wanted to listen to her and work with her. Karla's neurologist has been seeing her every few months and if something is wrong he wants her to call him.

We are very hopeful that one day there will be a breakthrough for all CADASIL patients and their families. Family and friends are very important to those that have a disease. Please help us spread the word about CADASIL. Read about it and share it. Godspeed and thank you for allowing me to write my story!

ASK DR. JOE ARBOLEDA



Read more about him at:

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

Joe is on CADASIL Association's Scientific Advisory Board:
cadasilassociation.org/scientific-advisory-board

Q: Can CADASIL be spread through blood donation?

A: CADASIL will not be transmitted from a patient to another person via blood donation or transfusion. It is transmitted only genetically from an affected parent to a child.

Q: Should CADASIL patients donate blood?

A: We don't have information indicating whether CADASIL patients should or should not donate blood. However, depending on the amount of blood donated, it can cause yet another stress for the cardiovascular system. After a consultation with their doctor(s), CADASIL patients can decide on blood donation or by helping out their community in other ways.

Q: Recently a CADASIL patient asked about taking L-Arginine after a heart attack. He knows of some research that shows you should not take it after a heart attack. Do you know more about that?

A: There is no research supporting the benefits of L-Arginine in CADASIL. If a patient with CADASIL has a heart attack while taking L-Arginine, it is advisable that the patients puts the neurologist in touch with the heart specialist so that between them they can coordinate an appropriate course of action.

Q: CADASIL patients are cautioned about having cerebral angiograms if we go to the hospital with stroke symptoms. Is there also a caution for coronary angiograms since the dye could pass through the brain?

A: It is essential that the patient inform the doctors about CADASIL. With this information in hand, the doctors will decide if a coronary angiogram is indicated.

Do you have questions for Dr. Joe? Send them to embrace@cadasilassociation.org and we will contact him. Chances are we will publish the question and answer in an upcoming newsletter.

RECENT NEWS



January 2014: Janet Mills submitted the video “CADASIL in Families” to the Neuro Film Festival. The video can be viewed at: cadasilassociation.org/video and also on YouTube.



The week of February 24th, 2014: (L-R) Karla Smith, Kathy Phillips, Barbara Hunt, Anne McGuinness, and Janice Ragazzo, represented the CADASIL Association at the 2014 RDIA Lobby Day and Rare Disease Day events in Washington, DC.

February 25, 2014: Janet Mills attended a online rare disease Twitter chat hosted by Dr. Richard Besser, ABC News Chief Health/Medical Editor.



February 2014: Amanda Radul spoke about the symptom of dementia in CADASIL at an Alzheimer’s event in Canada. View her video at: cadasilassociation.org/video

March 3, 2014: Jennifer Costner spoke about CADASIL at the Rare New Jersey State House Event “Rare Diseases and the Life Cycle.” Below is an excerpt of the press release prior to the event:

“Jennifer Costner from Bordentown, NJ is in the prime of her life. She has CADASIL (Cerebral Autosomal Dominant Arteriopathy with Sub-cortical Infarcts and Leukoencephalopathy). CADASIL is characterized by the potential onset of migraine headaches and multiple strokes progressing to dementia. Other symptoms can include cognitive deterioration, seizures, vision problems, and psychiatric problems. Jennifer knows first-hand how a life can change on a dime from this condition because her father, who also suffers from the condition, was a fully functioning adult one day, confined to home with multiple disabilities the next. Jennifer’s aunt also has the condition and it has left her completely paralyzed on one side of her body and bed-ridden.



While fine now, Jennifer is worried about the future. Jennifer’s story reminds us that rare diseases often affect whole families and of the enormous sense of the unknown and dread that comes with a diagnosis.”

Jennifer’s story is seen in the “Chasing New Jersey” video at: cadasilassociation.org/video

Full article: <http://www.businesswire.com/news/home/20140313005727/en/Rare-Jersey-BioNJ-NORD-Collaborate-Rare-Disease-.U0fU4axOVjo>

MORE RECENT NEWS

April 11, 2014: Anne McGuinness and Janice Ragazzo met with four neurologists with Capital Health in Pennington, NJ. Barbara Hunt and Michelle McGuinness participated via conference call. The doctors showed an interest in CADASIL and what the association is doing toward fulfilling our mission statement. We hope to involve them with a community outreach event for CADASIL Awareness Day in November and/or Rare Disease Day.

April 14, 2014: Barbara Hunt and Janice Ragazzo met with Assemblyman Lalor from New York. They discussed with him the need to educate doctors about CADASIL and other rare diseases. He is looking into ways to help with this project. Barbara Hunt, Janice Ragazzo, and Bobby Davis have created a petition to have doctors sign to support this campaign. Find it on our home page: curecadasil.org



April 21, 2014: The CADASIL Association Board of Trustees approved Mark Graham's application for the first CADASIL Association's Research Assistant Scholarship for \$4000. Mark is highly motivated to work on CADASIL since participating in the June 2013 CADASIL Family Conference hosted by the CADASIL Association in Boston. Dr. Joseph Arboleda-Velasquez at the Schepens Eye Research Institute/Harvard Medical School will be Mark's mentor during this summer internship. More of the story on p. 9!

April 24, 2014: The CADASIL Association held its Annual Membership and Public Meeting via conference call. We were pleased to meet several new people during the call. Minutes from the meeting will be emailed to all association members.

April 26, 2014: Barbara Hunt and Gail Hunt attended the Brain Health Fair in Philadelphia, PA. A reporter from the *Philadelphia Inquirer* did a short interview. Here is an excerpt:

In a sea of booths devoted to high-profile brain conditions such as multiple sclerosis -- seven Parkinson's groups alone -- to talk about brain diseases deemed rare by the National Institutes of Health, meaning each affects fewer than 200,000 Americans... Barbara Hunt at Booth 34 knows how that feels. "So many of our patients are misdiagnosed," she said about CADASIL, an inherited disease characterized by thickened blood vessels in the brain that block blood flow and cause strokes. "I've already spoken to no less than seven doctors (here) who have never heard of it." She's been attending events like this for more than two years as co-founder of the CADASIL Association and wife of a sufferer of the condition. "I feel every person that I can say the word CADASIL to, I've made a difference." People affected by rare diseases feel isolated, she says. "You feel lonely. You feel confused. When you have a (well-known) disease like MS, you have someplace to go. We just formed our organization two years ago..."

April 27, 2014: A northern Colorado CADASIL meet-up was organized by Janet Mills and held at Johnson's Corner. Four CADASIL patients and one family caregiver attended.

May 9-10, 2014: Anne McGuinness and Janice Ely attended the Columbia University Primary Care Conference and Expo in New York City.

May 23, 2014: Janet Mills organized a CADASIL meet-up in Spokane, Washington while visiting that city for her niece's wedding. Two patients and one untested adult child of a patient attended.

May 25, 2014: Another Washington state CADASIL meet-up was organized and held in Seattle in the home of a CADASIL patient. Five CADASIL patients attended.



→ Note: Meet-ups are encouraged and can be very beneficial!

Organize one near you!

EVENT SUMMARIES

Rare Disease Week in Washington, DC

by Barbara Hunt

From February 25 - February 28, 2014, Anne McGuinness and I attended RARE DISEASE WEEK in Washington, DC for the third consecutive year. Janice Ragazzo also joined us for the week, which was full of conferences and activities. Karla Smith, who was with us last year, joined us again for the Legislative Conference and Lobby Day on Capitol Hill. Karla was accompanied by her mother Kathy Philips, who has been a strong advocate in the CADASIL community.

The RDLA and the EveryLife Foundation did a great job, again, of gathering patient advocates, industry, government, and academia together to discuss the special issues that plague rare disease patients. Conferences and meetings were scheduled early each morning. The week was educational, exhausting and inspiring.

NORD held a day-long celebration at the NIH. The Office of Rare Diseases Research; the NIH Clinical Center, other NIH Institutes and Centers; the Food and Drug Administration's Office of Orphan Product Development; other Federal Government agencies; the National Organization for Rare Disorders; and the Genetic Alliance were present.

One of the messages I took away this year was that rare disease patients and caregivers must be proactive. They must take control. It is the responsibility of the rare disease patient and caregivers to educate the public and medical community about the disease. When you mention CADASIL to others and receive a response like, "I never heard of that," you must seize the opportunity to educate. Carry information about CADASIL with you. A brochure can be downloaded from cadasilassociation.org/raise-awareness. Each time you visit a doctor, regardless of the specialty, bring a brochure. Most doctors are eager to learn of diseases they are not familiar with.

Reach out and communicate with other patients or caregivers. Many of you are on FB and are members of the CADASIL Support group. On the top center of the page there are tabs: Members, Events, Photos, Files. Click on the Files tab. Find and click on the file WHERE WE LIVE. Click Edit at the top of the page and enter your info. Find someone who lives in your state or near you. Reach out to that person. You will find you are not alone. Join together with those nearby to form support groups. Together you can advocate for rare disease awareness and CADASIL research. If you have a doctor who is well informed about CADASIL, recommend that professional to others and send his contact information to: info@cadasilassociation.org for inclusion on our Doctor Directory webpage.



Have a fundraiser for CADASIL research or go to cadasilassociation.org/donate and make a contribution. Use GoodSearch.com and join Amazon Smile to easily donate to the CADASIL Association.

Special thanks to Catherine for organizing the Meet Up in San Francisco bay area for CADASIL support.

Be proactive. Take control by **COMMUNICATING, ADVOCATING, supporting RESEARCH, and EDUCATING,** while you ENVISION THE CURE, EMBRACE THE CHALLENGE.

Barbara Hunt and Janice Ragazzo at the NIH.

EVENT SUMMARIES

Rare Disease Week in Washington, DC

by Anne McGuinness

Rare Disease Legislative Advocates (RDLA) is a collaborative organization designed to support the advocacy of all rare disease groups. Their goal is to empower the individual to become an advocate. By growing the patient advocacy community and working collectively, the many voices of rare disease patients can be amplified and heard in the State and Federal Government.

I attended the RDLA Legislative Conference Day on Tuesday, February 26, 2014 with other members of the CADASIL Association: Barbara Hunt, Janice Ragazzo, Karla Smith, and Kathy Phillips. That evening, we attended the RDLA's 4th Annual Rare Disease Day Documentary Screening and Cocktail Reception featuring the new HBO Progeria documentary, "Life According to Sam" at the Carnegie Institution of Science. On Lobby Day, Wednesday, we advocated for CADASIL patients on Capitol Hill. We met with members of Congress and/or their staff to inform Congress about rare diseases and the many different needs of the patient community. We hope to build a lasting relationship with members of Congress and their staff to ensure that the needs of all rare disease patients are considered in future legislation and policy.

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

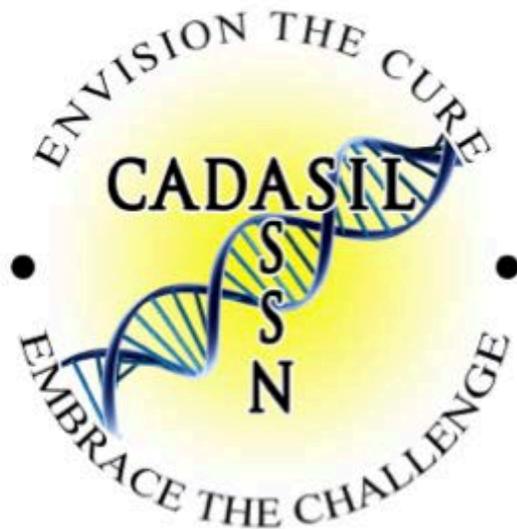
On February 28, 2014, the National Institutes of Health (NIH) celebrated the seventh annual Rare Disease Day with a day-long celebration and recognition of the various rare disease research activities supported by the NIH Office of Rare Diseases Research; the NIH Clinical Center, other NIH Institutes and Centers; the Food and Drug Administration's Office of Orphan Product Development; other Federal Government agencies; the National Organization for Rare Disorders; and the Genetic Alliance.

Rare Disease Day at the NIH was attended by CADASIL Association members Anne McGuinness, Barbara Hunt, and Janice Ragazzo. We had a poster board and exhibit table. We networked with other rare disease organizations and advocated for CADASIL patients. We wore our favorite pair of jeans to show our support for rare diseases.

Anne McGuinness (second from right) with U.S. Senator from New Jersey, Cory Booker, and other representatives for rare diseases on Capitol Hill in February.



UPCOMING EVENTS



5th Annual CADASIL Awareness Day November 16th

Raise awareness everyday by checking out our ideas at: cadasilassociation.org/raise-awareness

Have suggestions and ideas? We'd love to hear them! Please email us at: info@cadasilassociation.org

**Keep an eye on our website and
on Facebook for the news of a
possible USA CADASIL
Conference coming up in 2015!**

DONATIONS AT WORK

CADASIL Association's 1st Research Assistance Scholarship

When non-profit organizations request donations to help attain their mission and goals, sometimes the donors never know where their money went. The CADASIL Association strives to inform the public on how vital tax-exempt contributions are received and used. We do this via our Annual Reports on our website, through social media sites such as Facebook, and through our EMBRACE newsletter.

After just two years as a 501(c)(3) non-profit organization, the CADASIL Association Board of Trustees is excited to announce the awarding of a \$4000 Research Assistance Scholarship to one deserving college student. Mark Graham is highly motivated to work on CADASIL since participating in the June 2013 CADASIL Family Conference hosted by the CADASIL Association in Boston. Dr. Joseph Arboleda-Velasquez at the Schepens Eye Research Institute/Harvard Medical School will be Mark's mentor during his summer 2014 internship. Dr. Joe has also contributed funds to support Mark through the summer.



An excerpt from Mark Graham's scholarship application:

"My year under Dr. Joseph Arboleda introduced me to not only the research involved but the people with CADASIL as well. In June 2013 I attended the CADASIL Association conference in Boston, along with Dr. Arboleda and two other members of Team Notch. Here I learned about the clinical aspect of CADASIL and the patients' perspective, gaining a true insight into the effect of CADASIL on peoples' lives.

Having been fortunate enough to be inspired by Dr. Arboleda, Team Notch, and the attendees of the Boston CADASIL conference, I wish to continue research into Notch signaling and its implications."

Mark's research project is entitled "*Screening candidate biomarkers for the cerebrovascular disease CADASIL, the role of Notch signaling and its implications.*" He will report back about his research and progress at the end of his summer semester with Dr. Joe.

Mark comes highly recommended from both Dr. Joe Arboleda and Patricia D'Amore of Harvard Medical School. We look forward to hearing from him after his project is completed.

Vincent Primo, another college student who has worked with Dr. Joe at Harvard, and who attended the Boston conference, wrote an essay describing why he will now pursue a PhD in Biology. An excerpt:

"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."

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 now have a full-color tri-fold brochure printed and available for distribution. Other items are also available. Please request materials from: info@cadasilassociation.org

This summer of 2014, CADASIL Association is sponsoring a college graduate student for a research project, assisting Dr. Joe Arboleda at Harvard Medical School. This first award was given for \$4000. It takes \$16,000-\$20,000 to sponsor one undergraduate student for a year. Please see story on p. 9.

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.

CADASIL Association is a recognized charitable organization of iGive, where you can sign up to have a small amount of each item you purchase donated (at no extra cost to you) to your charity. iGive has a large variety of online shops that participate. You may already be using them! Please go to:



<http://www.igive.com/welcome/lptest/wr24.cfm?c=67724&p=19992&jltest=1>

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. Please go to: <http://smile.amazon.com/ch/45-5242623>



CADASIL Association is 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 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 attending 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.

MEMORIAL

The CADASIL community was hit hard in December by the news of Renee Milonas' death following a stroke. Renee was a member of the CADASIL Association. Many of us knew and loved her.



Josh Milonas

December 22, 2013

Facebook post 12/22/13

Today at 12:08 am just after winter solstice, my step Mom and friend Renee Pittsenbarger Larson Milonas passed away from a 13 year battle with C.A.D.A.S.I.L. She was a very special person that always loved me and treated me as her own. I already miss her and her gentle soul. May God Bless her soul. RIP.

Eulogy for Renée Milonas, written by Josh Milonas

When first given the opportunity of writing Renee's eulogy, I thought to myself: "How will I ever be able to capture such an influential person's life in just a couple pages?" As many of you already know, Renee wasn't just any ordinary person. I know everyone likes to think that about their own loved ones, but in this case it is more than accurate to say that Renee was an extraordinary person. The proof of that lies in all the lives she touched, all the people she helped, and all the women in Al-Anon she loved and cared for so much.

Growing up, I would come to visit my father every summer for a month or two. We would have a great time with just us two guys, going to meetings, watching movies and taking vacations. My father would always tell me: "I'm never getting married again." This made me, a precocious 14-year-old, feel very secure that no one would cut in on my action and start telling me what to do. Well, it didn't take long for another summer to come. Soon after I got off the plane, my father informed me he would be getting married again and that I would be staying with both of them that summer. My thoughts started racing as I imagined a monster for a stepmother, telling me what to do and making me do slave labor, much like Cruella de Vil.

Upon arriving I was greeted with a hug and acceptance. Renee was warm and welcoming to me. Within the first week of staying with them, she had started to win me over. You see, I was never allowed sugar at any time while visiting my dad, because if he doesn't eat sugar, than no one eats sugar! Renee, however, took quite a different approach and stocked the house with cookies, soda, and pie. She'd say: "We're eating all kinds of sugar here, BABY!" Needless to say, I soon had a partner in crime.

Not too long after that, it was time for the wedding. All the family was in town and everyone was in their places. I had never seen my father happier. During the reception, however, my grandmother informed Renee that I had been drinking a little too much hard alcohol from the open bar and she should know about it. She wasn't officially my stepmother for a whole hour and already was tasked with handling my drinking. But like a good Al-Anon she said nothing until years later.

After the wedding it was time for everyone to go their separate ways and for me to go home. I went outside and couldn't help but cry. I didn't want to leave my new family. Renee quickly followed me out and gave me a hug, telling me she loved me and everything would be ok. The stepmother I never wanted had become the person I loved.

Over the years Renee would be the counterweight in our family, always keeping us balanced with her secret Al-Anon voodoo. She also helped my father and me have a better relationship, and later taught Danny and me how to share meals on vacation, when my father got cheap.

The Monday before Renee ended up in the hospital I came home and saw her in her sitting room. I said hello, and in the Chicago accent she always used said: "Hi Josh!" Later after she was in the hospital I picked up the journal she was writing in and found these last journal entries. (Please see following page.)

MEMORIAL

Eulogy for Renée Milonas, written by Josh Milonas (continued)

Excerpts from Renée's journal:

December 16, 2013

"Monday, fun day spent with Madi and Danny. Tired. Tired and achy, Need rest."

(Note: Danny is Renee's son and Madi is her granddaughter)

"Hope - Life is for living. Today I will involve myself in the joy of living. We deeply desire to belong. Participation responds to our spiritual needs."

"Today is that someday to begin. Ask higher power for guidance in making dreams come true..."

"What you can do or think you can do, begin it. For boldness has magic, power and genius in it."
-Wolfgang von Goethe

"How I think has a lot to do with how I feel."

"I will be gentle with me, no one is to blame for our condition – Make a choice to be pleasant to those around me
– Take time for quiet time and have compassion for others."

As you can see, even in the end with as much pain as Renee was in, her spirit remained unbroken and she was still dreaming, still pushing, and still living. She loved life as much as any person could, although her story ended much like a great book you can't put down, wanting just one more chapter.

Renee left this world as beautifully as a person could, surrounded by countless friends and loved ones. She went home just like she lived: gracefully and dignified.



Renee Milonas, her own story

Note from Janet Mills: After my diagnosis of CADASIL in late 2009, I considered writing a book about this rare genetic condition. I wanted to include as many patient stories as I could to illustrate our struggles living with CADASIL. On Facebook and via email I requested story submissions. Renee Milonas sent me her story with permission to publish it. Someday the book may be finished. For now, I am very honored to share Renee's story here.

My Life with CADASIL

Written August 29, 2012 by Renee Milonas

I was diagnosed with CADASIL at the age of 45; I am 57 as I write this (August 2012). I was fortunate it only took two and one half years and 10 minutes for me to be diagnosed. The 10 minutes was the length of time it took for the doctor at Cleveland Clinic to diagnose me. He was the fourth or fifth neurologist to see me. At UCLA the doctor took over four hours with me, and I left there with the same diagnosis I had arrived with: atypical MS.

The doctor at Cleveland Clinic recognized the pattern for most patients with CADASIL. I was experiencing TIAs (transient ischemic attacks) or small strokes, migraines, and depression. The MRI of my brain was classic CADASIL, and my family history was strong with headaches and strokes.

I was a trained Nurse Practitioner with a Masters in Science with over two decades of experience, but I had never heard of CADASIL! I was to find out over the years that most medical professionals would have the same response: "What's it called? How do you spell CADASIL?"

In the beginning I saw many health professionals. I even participated in a study regarding CADASIL at Brown University in Providence, RI. My husband who has taken this ride along side me was the "control" for the study. I had watched my dad take care of my mom for years and never saw my husband in that same role with me. I have prided myself in my independence as a modern woman. However, CADASIL has humbled me -- not in a bad way, but my need for God has grown, and in this journey I have tried to stay very close to Him. Consequently my need for others and the act of asking for help has become a little easier.

My mother was creative, loving and hard working; however, she most likely had CADASIL. In my teens she became debilitated. Having multiple strokes, even as the youngest of five, she typically called for me. I was priming for a nursing career and didn't know it.

It was very difficult to watch my mom deteriorate. She eventually spent the last ten or more years of her life in a vegetative state in a nursing home. It felt cruel for me to visit her; I felt fear that I could be looking at my future. My four siblings had similar fears. I believe my oldest sister had the greatest fear. I look at pictures now and see how she responded differently to our mom in photos of all us gals. Recently she took her life. She had suffered a stroke that day, and years of depression lead to her death.

Years ago I visited a specialist in migraine headaches. His one helpful tip was for me to use ice on my head. It didn't really stop my headaches but it helped. I would love to find a helmet of ice to use for headaches, no joking!

The first couple of years when stroke symptoms occurred, I would rush to the ER at the local hospital. I had many different responses from the doctors. Some were curious, many had apathy, and some just ignored it!

I only go to the ER now if I am unconscious or have fallen. With development of smart phones there is no reason a physician or any healthcare worker can't quickly look up CADASIL and have a general idea of what they are dealing with.

(Continued on following page)

Renee Milonas, her own story (continued)

Almost five years ago I realized I could no longer work. I was teaching Nursing at a local college. I had a great boss and very kind supervisor; they both saw it coming. My energy level was so low it took everything out of me to get out of bed, get dressed, and drive to work. In the classroom I was forgetful and couldn't answer student questions quickly, sometimes not at all. I was very blessed with a woman who helped me with my state retirement -- actually she helped me with it all. I was approved by Social Security and my state retirement on full disability. I will always be grateful to her for her help.

For the last eight years I have lived with daily pain. My pain seems to move all over my body; however, my hips have the most so sleeping is difficult. I have had surgery on both hips to ease the pain; the doctor cut my IT band to release pressure on the bursa. I was diagnosed with chronic bursitis in 2004. Depression comes easier when in pain. Chronic illness comes with loneliness. Some days are worse than others. I make myself socialize. I have a great support system. I have made two quilts for my granddaughter by attending a quilting class. I am presently attending an art class. However, like most things in my life, it is hard to be consistent. There are days I simply can't attend class. I am in too much pain or too fatigued to go anywhere. I am afraid I am having more "bad" days than good.

In the past year I have felt a real progression of this disease. My fatigue is worse, pain is worse, and I don't know what to do most of the time. I wake up at 4:00am -- wide awake like an alarm went off. If I don't get enough sleep (10 hours) I suffer the next day. I use a cane off and on, depending on my balance. I am grateful to my husband who encourages me and helps me figure out what to try next. In my experience many medications eventually stop working.

I also have trigeminal neuralgia, called the "suicide disease." It gives me electrical pain in my jaw, in my teeth, and even in my ear. I have been on Tegretol for years for this. Lately I find it is not working as effectively as it once did. My mother also had this along with restless leg syndrome, as do I. So, does trigeminal neuralgia and restless leg syndrome occur because of CADASIL? Who knows? And what does it matter? I just want to be pain free.

I have had bouts of depression that seem to occur suddenly. Obviously, I grieve my sister. The last year has been the most difficult. The things I do that help the most: First and foremost, I pray. Living by spiritual principles helps me. I attend a family support group. I try to be of service to others, even if it is little things like calling others to see how they are, and I make donations of clothes or money. I try to exercise, but some days my muscles are so weak. I try to eat healthy, but I have "poor me" days and my husband brings me Dairy Queen.

I work hard on pacing myself. On my good days I tend to overdo it. On my not so good days I ask God to help me accept the things I cannot change. I *don't* believe having CADASIL is a punishment. And I don't have the answer why some people suffer more than others. I try to make a gratitude list each day, and enjoy my friends and family, including my CADASIL family. I take it one day at a time.

Thanks for allowing me to share my story.

Thank you, Renee. You are dearly missed. -JM





PARTICIPATE

Here's how!

Please join the CADASIL Association! Membership cards with information about CADASIL and the association will be mailed to new members. 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 may 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 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

WEB LINKS



These website links may be new, recently discovered, or information we wish to share with the CADASIL community again. If you find some as well, please let us know!

Please sign: A Petition for a Course in Rare Diseases

<http://www.ipetitions.com/petition/petition-for-a-course-in-rare-diseases>

The CADASIL Association, representing all rare diseases, invites you to join us in our campaign. We plan to present this petition to The Institutes of Medicine and The Association of American Medical Colleges to show that the public supports adding a college course in rare diseases to the medical school curriculum. Why? Because a course in rare diseases would provide new doctors with increased knowledge and awareness, ultimately shortening the time for a more accurate diagnosis and effective treatment.



Topic: Changing clinical patterns and increasing prevalence in CADASIL

http://scienceindex.com/stories/4168276/Changing_clinical_patterns_and_increasing_prevalence_in_CADASIL.html

Take action! Help ensure the Rare Disease Caucus Briefing is a success! We want to educate as many Congressional Staffers as possible about the issues affecting the rare disease community and continue the momentum for Rare Disease Legislation. Please take 5 minutes to contact Congress today! Follow the simple steps on this webpage to encourage your Congress Member to send a staffer to the Briefing.

<http://www.congressweb.com/kaki/29>



Fearing Punishment for Bad Genes: A New York Times article. CADASIL is mentioned.

http://www.nytimes.com/2014/04/08/science/fearing-punishment-for-bad-genes.html?smid=fb-share&_r=0



Rare Disease: A New Frontier

http://www.medscape.com/viewarticle/823704?src=wnl_edit_tpal&uac=163960EZ-1

What is vascular dementia? CADASIL is referenced.

<http://www.alzheimersweekly.com/2014/02/what-is-vascular-dementia.html>



Performer Charmaine Neville is a CADASIL patient and member of CADASIL Association

http://www.nola.com/entertainment/index.ssf/2014/05/charmaine_neville_performs_at.html

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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