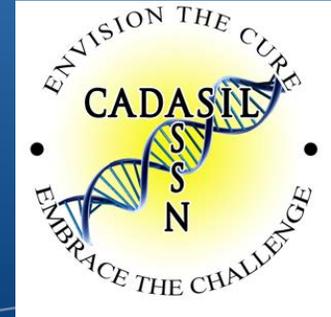


EMBRACE

A newsletter for anyone touched by the rare genetic disease CADASIL

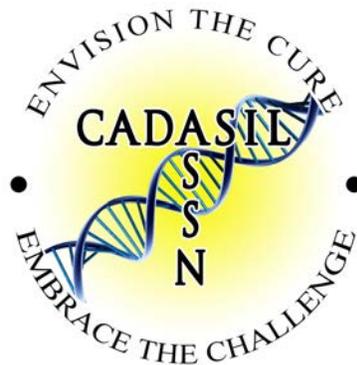
The mission of the CADASIL Association is to raise awareness of CADASIL, ensuring it will be universally recognized and understood by the medical community, enabling patients to be correctly diagnosed. We are dedicated to helping patients, families, caregivers, and other supporters touched by CADASIL. 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.



CADASIL Association organized and hosted our first Family Conference in Boston in June.



This issue of EMBRACE contains summaries from that event, starting on page 5!



A brighter look! The CADASIL Association is switching to a logo with a yellow center, keeping the blue DNA strand.

September 2013 - Issue 4

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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 STORIES



Barney Schroeder
DeKalb, Illinois
Age 59 at diagnosis of CADASIL

In 1998 my older brother was diagnosed with CADASIL after first being diagnosed with MS. As I learned more about the disease and how the D in the name stands for a dominant gene, I realized that I had heard about the symptoms of the disease as a child when my relatives talked about my grandfather, who died before I was born. Dad and his sisters would rarely talk about their father. Others spoke about him not being 'right'. Something had happened to him at some point in his life and that had an effect on his state of mind and his health. I was told that he had acquired measles as an adult. He had developed a high temperature then and perhaps that was why he just wasn't 'right'. My uncle told the story that when company was in the home, my grandfather would sit on the floor in the corner and not talk to anybody. It made me wonder.

My father died in 1981 at the age of 64. Although he undoubtedly carried the CADASIL gene, he was never diagnosed. He seemed quiet in the last couple of years before he suffered a stroke in 1977. The stroke left him paralyzed on one side, unable to talk.

I was probably in my early thirties when I began having episodes of vision problems. These occurrences would always be short, 15 minutes, and I probably had 3-4 per year. I wondered what caused them. After my brother, six years older, was diagnosed, his doctor, Dr. Elble at the SIU School of Medicine in Springfield, IL wanted the siblings to have neurological tests done. I agreed to the testing and the results showed some abnormalities. Dr. Elble believed that I could have CADASIL and recommended that I have additional tests in the future. At that time I wanted to forget what was probable for my future and chose to ignore.

At the age of 47 as I was teaching a class my vision became distorted, my speech unclear and thinking confused. I could not continue teaching and my wife insisted that I be taken to the emergency room. The result was that I had a CT scan, which again revealed abnormalities in my brain. I was told I'd had a migraine, though I never experienced a headache at the time. I began taking an aspirin and vitamins daily.

At the age of 56 I suffered an acute stroke resulting in aphasia, loss of memory and the ability to do some normal tasks such as typing and playing the guitar. I continued working even though I did have some depression and trouble staying focused. It was recommended that I see a neurologist and I asked for one that was nearby and had some experience with my brother's disease. At our initial appointment Dr. Richard Bernstein at Northwestern Hospital in Chicago asked me what he could do for me. I told him that I needed hope. I was afraid of being diagnosed with CADASIL. My older brother had had it, lost his job because of it, had become violent due to it, suffered from dementia the last years of his life, and died at the age of 55. I wanted something besides that to look forward to. Dr. Bernstein suggested that perhaps each case of CADASIL was different and that I could live into my eighties without further strokes.

I recovered from my stroke and a recent MRI indicates no significant increase in white matter in my brain. I also feel I have benefitted from brain training received through an NIU professor's research. I generally have a positive view of each day before me, have good relationships with my wife & children and am thankful for each day that God gives me to live. This is the day that the Lord has made. Let us rejoice and be glad!

ASK DR. JOE ARBOLEDA



Read more about him at:

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

The following questions were asked by attendees at the Boston Conference in June:

Q: What can we share with our doctors to send to other doctors?

A: There are good informative links about CADASIL. A good one to start with is the NIH page. Follow this link: <http://www.ninds.nih.gov/disorders/cadasil/CADASIL.htm>

Editor's note: The CADASIL Association website now has a page in progress for CADASIL Info at: <http://www.cadasilassociation.com/cadasil-information>

Q: How can you bring up the subject of CADASIL to distant family members?

A: It is difficult to bring up the troublesome news, but with knowledge comes responsibility. One way to do this is to share with them your situation and mention that because CADASIL is inherited they may be at risk. Putting them in touch with the association is important too.

Q: Is there a risk for stroke on an airplane flight?

A: There is no evidence indicating that airplane flights increase the risk of stroke in CADASIL patients.

Q: Is a completely natural birth – drug free – safe? Or is the laboring process too much pressure on the blood vessels?

A: There is no substantial evidence indicating that delivery affects pressure on the vessels of CADASIL patients. Consult with your doctor about medications that are available because the use of medications is also safe.

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

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 a college student 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 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) 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.

Inspiring Denim Headbands

\$1 from each sale goes to CADASIL Association to support our mission statement.



These reversible headbands are made from up-cycled denim and cotton fabric covered with encouraging words of strength and hope.

Cost: \$5 each plus shipping

Click on the Etsy shop link below to view and to purchase.

www.etsy.com/listing/150026476/reversible-denim-headband

Thank you for your support!



RECENT NEWS



In this issue, we are happy to share news from our first Family Conference in Boston, Massachusetts on June 27-29, 2013. It took some time following the conference to process what we learned. We hope you find the summaries on the following pages, written by attendees, helpful in describing the experience. Anyone else who wishes to add their thoughts about the conference can email us at: info@cadasilassociation.org for possible inclusion in a future issue of EMBRACE or on our website.

We hope to have the conference video available in DVD format soon. Several volunteers from the CADASIL community are working on the project.

100% of the evaluations turned in by attendees of our Saturday morning CADASIL Association Membership Meeting and Break-Out Sessions rated the conference Good to Excellent. Attendees found the amount of lecture time and Q&A time to be well balanced, and the majority felt the presentations were at an understandable level. Attendees who missed the Saturday morning sessions and wish to fill out an evaluation can request one by emailing us at: info@cadasilassociation.org.

We wish to thank all who were able to attend the conference. A special thanks goes out to our professional panelists for the valuable information in their presentations and discussions:

Dr. Joseph Arboleda-Velasquez, MD, PhD (Schepens Institute, Harvard) – Conference Scientific Director

Dr. Stephen Salloway, MD, MS (Neurology, Brown Research) – Keynote Speaker

Dr. Anand Viswanathan, MD, PhD (Neurology, Massachusetts General)

Dr. Sat Dev Batish, PhD (Director, Genetics, Athena Diagnostics)

Dr. Sigurros (Rosa) Davidsdottir, PhD (Neuropsychology, Massachusetts General)

Dr. Adrian J. Ivinson, PhD (Director, Harvard NeuroDiscovery Center)

Dr. Marcie Glicksman, PhD (Neuroscience, Harvard NeuroDiscovery Center)

Diane Lucente, MS (Genetics Counselor, Massachusetts General)

Peter Saltonstall (President and CEO of NORD)

In addition to Karla Smith, Event Planner, and four other CADASIL Association Trustees who assisted with the event (Anne McGuinness, Barbara Hunt, Christi Lushbaugh, and Janet Mills), we wish to acknowledge the following association members for their help and/or for donating items: Kathy Phillips, Marie Deets, Robin Spaur, Ona Cody, Ann Marie Pool, Joe Hunt, Tim Hunt, Tony and Janice Ragazzo.

We thank Trustees Nancy Maurer, Gail Hunt, and Pam Russell who could not attend but provided items, assistance prior to the conference, and advice.

Thank you to Ed Merritt, professional videographer, who recorded the conference at a very reasonable rate. Find him at: <http://vimeo.com/clearskiesmedia>



BOSTON CONFERENCE SUMMARY

What I learned in Boston by Christi Lushbaugh, Raleigh, NC

The trip to Boston was our third family meeting for CADASIL, having previously attended meetings in Ohio and Salt Lake City. Every meeting is different because there are different speakers, different topics, and because we are at a different place with our diagnosis. I find my openness to new people and new information varies based on how well things have been going at home. My husband has CADASIL. The road to the diagnosis was a journey as is every day since.



In Boston, as with the other meetings, the people make it so impactful to be there in person; the energy the researchers and family members bring, the impromptu questions, hugs, connections. You just never know where the next pearl will come from. We are all learning and sharing together.

Dr. Joe kicked off our theme of “What Do We Need to Do?” and gave us an historical perspective and a path forward with a goal of launching the first clinical trial for CADASIL with a disease-modifying drug by 2018. It is wonderful to work closely with a doctor who understands the urgency families feel!

There are two pathways that Dr. Joe discussed on how we can affect CADASIL: 1) Prevention protocol - This is testing that would be done on animals by injecting CADASIL animals at birth with antibodies to prevent the disease from developing. 2) Therapeutic intervention - Developing treatments that slow progression of the disease once symptoms have developed. This is where most of the patient work is done now. We are “building the bridge as we walk on it” and forging a new path.

Dr. Viswanathan helped me understand more about how CADASIL affects the brain and the patient. I am always on the lookout for stroke symptoms (as we should be) but there are many other ways to look at the progression or impact of CADASIL. First, I learned that depression and apathy is very common with a majority of the patients. I did not really know what apathy looked like but Dr. V explained it as a reduction in voluntary or goal-directed behaviors. Aggression and mood disturbances are also common. This can have a big impact in the family. Knowing this helps me plan better and respond appropriately when “things aren’t getting done.”

Dr. V. also gave me some good ways to look at disease progression clinically. The more often that lacunar strokes and micro-bleeds occur, the greater the increase in cognitive impairment. When we have testing done and we look at the MRI reports, it is natural to compare white matter changes. It is natural. However, a better marker might be to look at areas of stroke and definitely atrophy. There is a direct correlation between brain atrophy and cognitive impairments. The lecture by Dr. V. gave me new information to take to our local neurologist and a new way to evaluate the test results we get. I also got a new perspective on realistic expectations related to planning and follow through, and a better understanding of apathy.

Dr. Salloway shared a wonderful presentation on disease progression that was very enlightening to me, especially the patients’ videos he was able to share. He shared documentation of basic tests such as MOCA and SMMSE that showed the progression over time. Although some patients seemed able to converse and seemed “normal” when challenged with certain tasks, they were unable to perform them or at a very slow rate. This was very enlightening to me personally - although someone may seem “normal,” there can be significant deficiencies in certain abilities.

(Continued on next page)

(Continued: What I Learned in Boston)

Dr. Salloway also gave us a nice review of CADASIL sharing that most patients have MRI changes in their 20s; women seem to do better than men do with a better course of the disease and they can live longer. Smoking and heavy alcohol use does have a big effect on disease progression. Patients have slowness in their thinking that develops, decreased speech, inability to follow directions or wait their turn, sensitivity to unfamiliar stimuli and increased irritability. Along with the more commonly recognized memory loss and apathy.

Dr. Salloway suggested several real-world treatments that may help:

- 1) Develop an excellent, calm, predictable routine for the patient and the home. Write it down and stick to it. This helps the patient maintain participation and helps keep him/her focused. Even writing notes with what needs to be done – for example: “Fold laundry before lunchtime,” and “Walk dog at 3pm.” Provide meals at the same predictable time.
- 2) If apathy is an issue (and for 40% of patients it is) - treat it. Apathy is very hard on the family and can be underestimated. He suggested talking to your provider about using an antidepressant. (It may take some time to find the right one. The patient may not feel depressed, but it can help with apathy.) Dr. Salloway also recommended counseling for the family.
- 3) Adopt a healthy lifestyle related to diet, exercise, sleep, vitamins, treating high cholesterol, blood pressure or triglycerides, etc. Educate yourself about the stages of CADASIL and adjust responsibilities and activities to match the patient’s abilities. Supervise finances and driving safety, as these can be risky areas.
- 4) Adjust care and support for the patient and for the family members involved. At different times, we all need different support.

During the conference, we had several conversations about the development of a CADASIL registry, research opportunities, fundraising, testing, pregnancy effects on CADASIL, etc. We discussed as a group at length about what to do in an emergency situation. Each patient should have a plan. One thing to consider in a stroke situation is that generally in the U.S., if you go to the hospital during a stroke that is how you get into the system for rehabilitation services. There have been many discussions on if we should seek treatment or not and this was a new aspect to consider.

We also had wonderful presentations and panel discussion with Dr. Batish from Athena Diagnostics; Dr. Iverson, Director of the Harvard Neurodiscovery Center; Peter Saltonstall, President and CEO for NORD; Dr. Davidsdottir from Mass General; and Ms. Marcie Glicksman, PhD from LDDN. These were more technical and scientific in nature. They discussed many ideas on how to move research forward at the patient level and with the science.

There are many more items I took away from the conference but these are the pearls that have had impact on our daily lives since June. The overall mood was exciting and hopeful. Many more patients, family members, physicians, and institutions are learning about CADASIL.

We are building the bridge as we walk across it.

What are you doing to learn more, raise money, and support others?

BOSTON CONFERENCE EXPERIENCES

We are pleased to bring you several personal experience stories about the CADASIL Conference in Boston from the perspective of two CADASIL patients, two caregivers, and someone undiagnosed with CADASIL in her family. Anyone else who attended and wishes to share his/her story, please email us at: info@cadasilassociation.org for possible inclusion in an upcoming issue of EMBRACE.



My experience at the CADASIL Conference was wonderful, for the simple reason that I was able to meet others with the disease and discuss reasons for hope and not just the symptoms that we are all so frightened of. After so many years of focusing on the outcomes of CADASIL, I left the conference in Boston with a feeling that we were moving forward as a community in search of a cure and with a focus on raising awareness and promoting research. This inspired me to become more active in the CADASIL community and to volunteer more of my time and energy to help in any way that I can. I look forward to working with the association and to seeing everyone (doctors, patients, and caregivers alike) at our next conference!

~Robert Davis, Ashford, CT

As a caregiver my goal in attending the CADASIL Association Boston Conference 2013 was two-fold; information and support. I listened and learned from the medical professionals who were able to answer questions truthfully. If there was no factual answer it was stated so. I found the conference to be interactive with CADASIL patients sharing their firsthand experience and medical professionals intently listening.

It was supportive for my husband to share with others. As I looked on I could see this was what he needed...to share his symptoms, his story, and relating to others with CADASIL. Something I cannot do for him.

I was impressed by the medical professionals' willingness to do the footwork on the medical research side, along with the members of the Association's honest approach to the footwork that is required on our end to educate communities and professionals alike on CADASIL.

Saturday's breakout session for the caregiver was very valuable to me. I gained the much needed support from other caregivers in our group, along with exchanging contact information. We were able to speak our truth by sharing our experiences. Upon leaving the conference I was grateful I would no longer be alone on my journey caring for my husband with CADASIL.

~Grace M., Massachusetts

BOSTON CONFERENCE EXPERIENCES



I attended the conference in Boston in June. The conference helped bring about more discussion of CADASIL within my family. Two of my siblings attended with me. I had never really spoken about CADASIL with them. It was always something that was only spoken about with my parents. It was great to have this line of conversation open up. The conference brought me hope that if CADASIL has been passed on to my siblings or me, maybe our children will have a cure if they are affected.

I participated in the breakout group of those who are offspring of people with CADASIL. We have not yet been tested and therefore are not diagnosed. It was comforting to know that there are others with the same concerns and doubts as I do. We are the first generation to encounter these issues. Do we get tested? Do we want to know or are we better off living without knowing if we don't currently have symptoms? What if I have it and my siblings don't, will I be angry and jealous of them? What if they have it and I don't, I will feel so guilty if they have to suffer and I don't. Do we start a family and possibly pass the gene onto our children? Do we marry and then knowingly burden our spouse with having to take care of us? So many questions. In the end, many of us agreed that there is no right answer as to whether to get tested or not. Whatever choice is made is the right choice for that person. The best thing to do however is be informed about the disease that affects our families and that it would probably be in our best interest to visit with a genetic counselor before making the final decision to do so or not.

~A. Pool

I am extremely impressed with the CADASIL Association and with the thorough planning and high quality of the conference my husband and I attended in Boston in June. Dr. Joe is a huge gift for those of us who are connected in some way to this disease. The speakers and panelists he gathered included doctors, researchers, genetics counselors, the CEO of NORD, and the chief director of Athena Diagnostics. Each part of the schedule was intentionally planned and thoroughly appreciated! Time was planned for questions and answers. And the panelists let us know how valuable our participation was for them too!



The Association meeting on Saturday morning was not to be missed. It is amazing to realize all that is being accomplished by a small group of people. And it is inspiring to think what more could be accomplished if more of us would speak up for CADASIL and do some small part to assist in working toward a cure.

Afterwards we broke up into groups so that we could simply talk with others who are in situations similar to our own. My husband joined a group of people who have a diagnosis of CADASIL. A group of young people discussed their thoughts on whether or not they plan to be tested for the CADASIL gene. And I was able to join a group of caregivers to frankly talk about our concerns and needs. Our Facebook groups are a great support but it was a benefit to also meet people in person. The biggest challenge I came home with is the realization that we CAN make a difference and that if we expect money to go into CADASIL research, we are the voice that is responsible to make sure dollars go there.

~Carol Schroeder

BOSTON CONFERENCE EXPERIENCES

While my sister and I were in the lobby checking into the hotel on Thursday evening before the Meet & Greet, I heard the bell of the elevator door and turned to see a CADASIL friend I had only “met” before on Facebook. We both squealed in delight to finally meet in person and give one another a warm hug. There is something unique about coming together with other CADASIL patients that really is hard to put into words. For me, it is always an emotional experience.

The Boston Conference was the fourth CADASIL conference I attended since the first one in Illinois in 2010, and the third one I attended with my sister. In Boston, I reconnected with friends from that first conference, as well as friends made in Ohio in 2011 and Utah in 2012. Seeing someone from the CADASIL community again after the passing of a year or more is like a reunion with family. Meeting some CADASIL-ians for the first time, as I did in Boston, brings a smile to my face, and often tears to my eyes. We seem to forge an instant bond, since we understand what it is like to live with this serious condition. While it is a shame to have to meet because of our rare disease, I believe we all are thankful we are not on this journey alone.

This bond grew stronger during the full day of presentations and discussions on Friday, and continued on Saturday. After the CADASIL Association meeting that morning, we broke into smaller groups. It was good to be able to chat with other patients in a private setting, while other family members and friends could meet with their fellow caregivers in another location in the room, and the undiagnosed could discuss their situations in their own group.



In the patient group, we talked about our individual struggles and fears and gained some peace from knowing we share many of them. We named specific symptoms and raised our hands if we experience them. Over and over, we found that we have so much in common, regardless of how the disease is manifesting itself in each of us. We found strength in one another.

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.

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

September 10, 2013: Janet Mills will attend (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 will attend **Progress through Partnership: The 2013 NINDS Nonprofit Forum** at the NIH in Bethesda, MD. The forum will provide an opportunity to network with colleagues and the NINDS staff. This year's agenda will again feature plenary talks, breakout sessions, open discussion with NINDS program directors, and an independent session for Non-Profit Organizations only. Among the topics to be addressed is the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative, part of a new Presidential focus aimed at revolutionizing our understanding of the human brain. <https://meetings.ninds.nih.gov/?ID=5748>

September 12, 2013: Anne McGuinness will attend the **Rare Disease Congressional Congress briefing** in Washington, DC, and Barbara Hunt will attend the **NIH Advisory Council meeting** in Bethesda, MD.

September 20 & 21, 2013: Janet Mills will attend 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**
<http://globalgenes.org/2013-rare-patient-advocacy-summit/>

October 7-9, 2013: Anne McGuinness and Barbara Hunt will attend the **2013 NORD/DIA Conference on Rare Diseases and Orphan Products** in North Bethesda, MD.
<http://www.diahome.org/en-US/Flagship-Meetings/RareDiseases2013.aspx>

COMING SOON!

November 16, 2013: CADASIL Awareness Day! We will have press releases, flyers to post on bulletin boards in your community, and other materials and tips to help you help make this year's awareness day known. One association member is planning a fundraiser on this date. More details coming soon! If you have ideas for this day, please contact us. info@cadasilassociation.org

Please note: A number of CADASIL Association Trustees and members 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) 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.

OUR WRITINGS

Rare Disease and Summer Heat? Not a Good Combo! by Janet Mills

Posted on July 14, 2013 at: <http://globalgenes.org/rare-disease-and-summer-heat-not-a-good-combo-check-out-these-hot-tips/>

It's summertime and the living is...sometimes difficult. It can be so terribly hot. Not just the hot we expect during the warmer months in whichever part of the world we live, but bordering on, hitting, or exceeding our levels of tolerance. Throw in uncomfortable amounts of humidity and we can feel utterly or dangerously miserable.

Many of us with rare diseases have issues with temperature extremes. I personally prefer temperatures in the 60s and 70s (Fahrenheit), while 90s and above can literally make me sick if I am exposed to them too long without relief. Temporarily, drinking plenty of water helps me, but ultimately I need to seek refuge with an air conditioner or hug a fan until I can cool down.

As a patient with the rare genetic disease CADASIL, extremes in temperature can cause sick headaches. If my head gets too warm, I feel throbbing pain, pressure, nausea, dizziness, and a host of other symptoms. Likewise, in the winter months, prolonged exposure to frigid conditions tightens the skin around my skull and causes the same painful issues.

Heat also saps my energy, making me feel lethargic and emotional. I take a daily anti-depressant to even out my moods and help with anxiety, and guess what? Those meds can make heat intolerance worse.

I recently found a webpage where many prescription and over-the-counter medications are listed as possibly causing heat sensitivity: <http://www.netwellness.org/healthtopics/pharmacy/w18.cfm> (Remember that we should never start, change, or stop medications without our doctor's approval.)

I have elected to continue on my medication and supplement regimen even during the hottest days of the year. With these measures in place I've come up with a few general tips for staying cool:

- 1) Drink plenty of water and stay hydrated. Remember that even though a soda or sugary drink might seem tempting, it won't keep you hydrated.
- 2) Stay inside with an air conditioner or fan when possible. Remember that there are actually lots of places to beat the heat with air conditioning including libraries, the movies, and the mall.
- 3) Go for a swim or take a lukewarm shower—but remember to limit your outdoor time to morning or evening hours.
- 4) Stick to the shade. Umbrellas are great, and wide-brimmed hats will help keep you from sunburns!
- 5) Listen to your body's warning signs. Head inside if feeling overheated, dehydrated, begin getting a headache or notice your skin starting to flush.

Let's safely enjoy our summer! For more info on summer heat safety check out the CDC's guide to summer heat! <http://www.bt.cdc.gov/disasters/extremeheat/heattips.asp>

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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