EMBRACE
A newsletter for anyone touched by the rare genetic disease CADASIL

The mission of CureCADASIL/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.

May 2016 - Issue 9

In this issue:

Honoring Anne McGuinness p. 2
Meet-Ups in May & June p. 3
Let us know if you can attend!
Photos & News pp. 4-12
Look what we’re up to!
Spotlight on CADASIL p. 13
Rare Disease Report
Creative Writing p. 14
A poem submitted by Donna Martin

Thank you!
A huge thank you goes out to Past President Anne McGuinness, who led this non-profit organization from the beginning: April 2012 to April 2016! Anne will continue to serve as Vice-President. We are fortunate to have Nancy Maurer as our new President. She has a wonderful vision for the future of cureCADASIL! Stay tuned!

cureCADASIL Meet-Ups and Registry Rallies

Four events are coming up in the USA:
May 15: Raleigh, NC
June 4: Dallas, TX
June 4: Johnstown, CO
June 11: Toms River, NJ
Made possible by a grant from Global Genes
See page 3 for more details!

Please join our cureCADASIL Family Registry!

Why should my family join the cureCADASIL Family Registry?
Because you can make a difference in finding a cure.

cadasilassociation.org/curecadasil-registry

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, memorials, and events. Please email them to: info@cadasilassociation.org
HONORING ANNE McGuINNESS

This nonprofit organization would not be where it is today without the years of dedication and tireless commitment to cureCADASIL/CADASIL Association that Anne McGuinness has given from the very beginning, before CADASIL Association was founded in April 2012, to her move to Past-President and Vice President in April 2016. We give Anne many thanks for everything she has done in the past, and for her continued work toward a cure for CADASIL!

Anne was given this trophy from members of the cureCADASIL Board of Trustees.

Members of the cureCADASIL Board of Trustees made donations to the organization for Anne to receive this quilt, made by member and patient Beth Fogg.
UPCOMING EVENTS

cureCADASIL Meet-Ups and Registry Rallies

Four events are coming up in the USA:

If you are not on Facebook to see these Event pages and are interested in attending, please email us at: info@cadasilassociation.org

May 15: Raleigh, NC
facebook.com/events/703180903156249/

June 4: Dallas/FW, TX

June 4: Johnstown, CO
facebook.com/events/1001532233273

June 12: Toms River, NJ

Come meet others from the CADASIL community in the regions listed above! These events will include: opportunities to share stories, learn about support and medical professionals in the area, gain knowledge of current CADASIL info and research, learn the importance of the CADASIL Family Registry, and find out what you can do to spread awareness and advocate for this rare genetic disease. We hope you will join us!

Trustee Sandra Talbird submitted a winning application, which enabled cureCADASIL to receive a Global Genes RARE Patient Impact Grant! The grant award funds are being used for our May & June events as listed above. From the Global Genes website: globalgenes.org/2016grantwinners

“The association will develop educational print materials for patients, caregivers and physicians to increase awareness of the cureCADASIL Family Registry though Grant support. The materials will describe the registry and its goals in detail and specify who can join, why it is important, and how to participate. These materials will be distributed at four Registry Rallies – in-person events across the country designed to inform the community. The Rallies will not only increase the number of patients participating in the registry, but will also facilitate local meet-ups between CADASIL patients and caregivers to create and foster support networks. The impact of this program will help speed research and potential therapy development for the CADASIL Community.”
PHOTOS & NEWS

Photos and news from conferences, meetings, and awareness events attended by cureCADASIL trustees and members from January 1 – April 30, 2016

Please share what you are doing so we can include you in EMBRACE! Email us at: info@cadasilassociation.org

On February 7th, CADASIL patient Vanessa Prontnicki was honored at a “Dine & Donate” fundraiser organized by parents from the school where she teaches. Over $1200 in proceeds raised at MaGerk’s Pub in Fort Washington, PA that night were donated to cureCADASIL. About 200 people came out for the event, and it was televised in the local area. MaGerk’s also donated 15% of their receipts.

You can see the video clip of Vanessa’s event and interview here: teacher-with-rare-disease

Above: Children play at MaGerk’s during the event; Vanessa is interviewed; a display promoting CADASIL awareness

Above: Vanessa is interviewed with her dad, also a CADASIL patient

Left: Vanessa and two of her young supporters
PHOTOS & NEWS

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On February 16, 2016, cureCADASIL was the Community Assist organization during the New Jersey Devils vs. Philadelphia Flyers Hockey Game. This was our second year to benefit from this opportunity.

At left: Trustees Janice Ragazzo and Anne McGuinness raising awareness for CADASIL at the game!

Have you seen our Fact Friday posts by Nancy Maurer on our Facebook and Twitter pages?

If not, please be sure to follow us at:

facebook.com/CADASIL.Association

and twitter.com/CADASIL_Assn

Vascular dementia is the second most common form of dementia. CADASIL is the most common inherited cause of stroke and vascular dementia in adults.
PHOTOS & NEWS

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Left: Trustee Sandra Talbird raising awareness during Rare Disease Week in North Carolina
Above: Trustee Christi Lushbaugh with Sandra in NC

Right: Trustee Nancy Maurer raising awareness during Rare Disease Week in Texas
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2016 Rare Disease Week Events & Efforts

Trustee Anne McGuinness speaks about CADASIL at the Rare New Jersey event sponsored by Janssen Pharmaceuticals

Dr. Swati Sathe speaks at the Rare New Jersey event.

Dr. Sathe is on the cureCADASIL Scientific Advisory Board
PHOTOS & NEWS

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2016 Rare Disease Week
Events & Efforts

Trustee Janice Ragazzo attended Rare Disease Day 2016 events in Washington, DC to spread awareness of CADASIL to our members of Congress. This year, Janice also delivered letters written by CADASIL patients to their state's representatives. Everywhere she goes, Janice displays the cureCADASIL logo in photos. Janice is working with NY Representative Maloney's office to get CADASIL added to the medical diagnosis ICD-10 code.

Left: Janice Ragazzo with Julia Jenkins of RDLA (Rare Disease Legislative Advocates)
PHOTOS & NEWS

In honor of Rare Disease Day in February, many patients in the global CADASIL community shared their photos for awareness. Some of these photos were featured in our Fact Friday posts online.
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The CADASIL community is AMAZING at spreading awareness!

www.cureCADASIL.org
PHOTOS & NEWS

Additional photos for Rare Disease Day in February of patients in the global CADASIL community

Thank You for your help in spreading awareness for CADASIL

cureCADASIL Association is a 501(c)(3) tax-exempt non-profit organization
Photos and news from conferences, meetings, and awareness events attended by cureCADASIL trustees and members from January 1 – April 30, 2016

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On March 29 & 30, Trustees Ronnie Bradbury and Anne McGuinness attended the Alzheimer’s Disease-Related Dementias Summit at the NIH in Bethesda, MD. CADASIL causes vascular dementia.

Above left: Trustee Ronnie Bradbury talked with Dr. Martin Dichgans, a CADASIL expert from Germany. Above right: Ronnie spoke to the medical professionals and other attendees at the conference, relaying a personal story about her family. When she finished, the audience applauded.
SPOTLIGHT ON cureCADASIL

Rare Disease Report is a website and weekly e-newsletter that offers an independent voice for the Rare Disease Community. It strives to bring together medical, scientific, investment, regulatory, and advocate professionals interested in rare diseases and orphan drugs.

Recently cureCADASIL was spotlighted by RDR.

Spotlight on CureCADASIL

Ruth J Hickman, MD
Published Online: Saturday, Apr 23, 2016

CureCADASIL (also known as CADASIL Association) is a nonprofit group dedicated to raising awareness of the rare disease cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy (CADASIL). Through the aims of communication, advocacy, research, and education, CureCADASIL is working to improve the lives of those affected by the disease.

This is just the introductory part of the article.

Please read the full article spotlighting cureCADASIL at this link:

raredr.com/news/spotlight-on-curecadasil
CREATIVE WRITINGS

The poem below was posted to a CADASIL group on Facebook by member and patient caregiver Donna Martin. The author's name is unknown.

Do not ask me to remember.
Don’t try to make me understand
Let me rest and know you’re with me.
Kiss my cheek and hold my hand.
I’m confused beyond your concept.
I am sad and sick and lost.
All I know is that I need you to be
With me at all cost.
Do not lose your patience with me.
Do not scold or curse or cry.
I can’t help the way I’m acting,
Can’t be different though I try.
Just remember that I need you,
That the best of me is gone.
Please don’t fail to stand beside me,
Love me ‘til my life is done.

-Author's Name Unknown
THANK YOU FOR READING OUR NEWSLETTER!

EMBRACE is created and edited by members of cureCADASIL 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: info@cadasilassociation.org

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