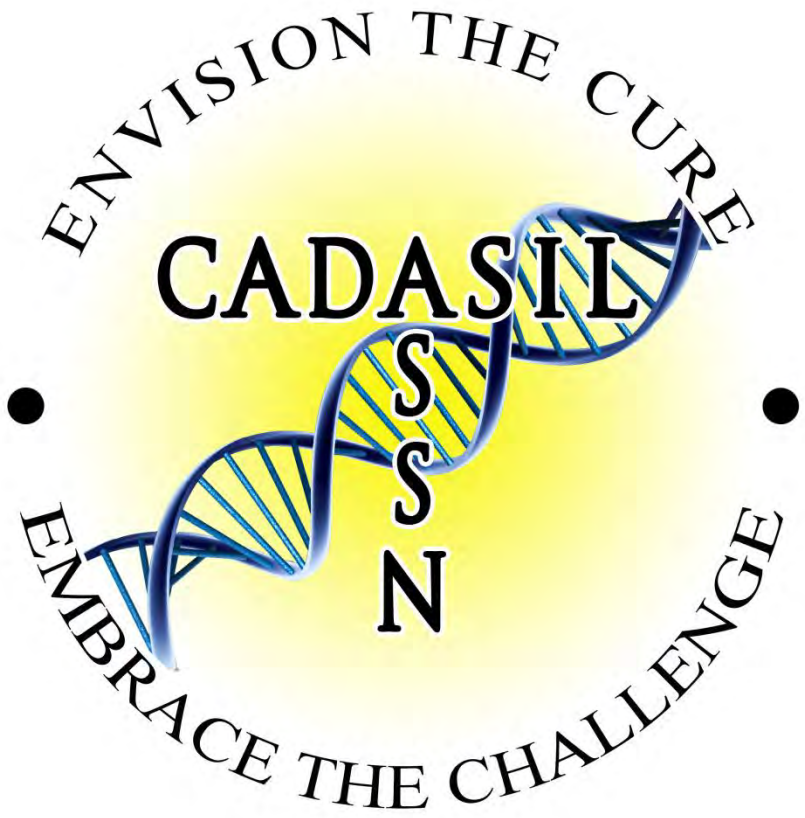
Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leukoencaphalopathy



CADASIL ASSOCIATION ANNUAL REPORT 2012

Dear Friends,

2012 marked the inaugural year of the CADASIL Association. I am pleased to present to you the CADASIL Association's Annual Report for 2012 (April 24, 2012 through December 31, 2012).

The CADASIL Association relies on a volunteer Board of Trustees to carry out the operations of the organization. In addition to our talented Board of Trustees, we have a group of extraordinary and dedicated volunteers that devote their valuable time to provide the resources necessary to accomplish our goals. It is our intention to continue building our volunteer network, and I would like to encourage you to contact us if you have an interest in volunteering.

Please visit our website at www.cadasilassociation.org to donate and to find the latest information about resources and upcoming events.

We look forward to the future, committed to working together to find a cure for CADASIL.

With hope and inspiration,

Anne McGuinness

President

CADASIL Association

My Family's Story by Alice Lindahl

I had been married for over 30 years to my high school sweetheart; a man who I knew loved me and was very devoted to our five children. I had everything my heart had desired for all of these years. Why then, would I be on the verge of divorce? What could be behind the change in my hard-working and loving husband? Why was this endlessly optimistic man now showing so much anger and frustration? Why was he not performing at work and jeopardizing everything we had worked for financially? I needed to know. I needed to know for myself, for my husband, our marriage and for the sake of our children. I knew the news was not good. My husband had CADASIL.

CADASIL (Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leukoencaphalopathy) is a rare, genetic, neurological disorder that affects the muscle walls in the small arteries that provide blood flow to the brain. The gene prohibits the body from making protein, causing the small blood vessels to be defective (Duncan-Smith, 2005). Symptoms of CADASIL include stroke (with paralysis, loss of sensation, unsteady gait, slurred speech…*),* migraine-like headaches, anxiety and depression, memory and thinking problems. The disease affects men and woman usually between early adulthood and mid-life. The incidence of CADASIL is unknown, however the number of affected families is only in the hundreds. (Salloway, 2005)

Wayne and I met in Jr. high school and began dating in high school. We attended the same church in St Paul, MN and were married there in 1957. With the help of my parents, we were able to purchase a home where our first son was born the following year. Over the next seven years Wayne worked for various cabinet-making shops and I stayed home raising our five children. Money was tight in those early years. Our lives were filled with church functions, PTA, scouting and all of the normal events of child-rearing. Aside from family activities, Wayne was also active with bowling leagues, softball teams, and hunting and fishing trips in Canada. His zest for life seemed limitless and our lives were *good!*

Being very skillful in his craft, Wayne decided to quit his job at the cabinet shop and give it a go on

his own. In 1965 he began building cabinets in our garage. Things went well for him and in 1970 we were able to purchase property that included an existing cabinet shop. We had our own business!

The '70s and early '80s were good years. Wayne worked hard and at one time or another, each of our children worked with their father at the shop. Our oldest son, talented like his father, eventually became a business partner. During these years Wayne's amiable personality led him into many activities. He became active in the local Lion's Club, holding several offices, including president. He joined the local Volunteer Fire Department where he served as an EMT, Captain, and District Chief. Wayne also began his interest in golf during this time, joined a couple of leagues and scored his first Hole in One in 1987.

There were many family activities during those years as well. We were able to take our family on several vacations: to Disneyland, Mount Rushmore, and camping trips. We spent one week each summer at a church sponsored family camp. In 1980, we purchased property on a golf course in a community in Wisconsin. Along with our sons, Wayne began to build a dome house. The plan was to spend weekends there, until retirement, and then move there permanently. Our family has many fond memories of times spent at "the dome".

One day, in 1982 while at work, Wayne developed numbness and slurred speech. He was 45 years old at the time. The doctors at first thought he was having a stroke, but tests could not confirm this. It was eventually determined that the symptoms were caused by an allergic reason to epoxy glue with which Wayne works. We accepted this explanation and thought very little about it until other episodes started happening. I remember one day when Wayne wanted to make a phone call. He stood with the receiver in his hand and didn't know how to dial the call. He knew what number he wanted to call, but couldn't dial it!

By the time he was 50, I knew there was something very wrong. Wayne's personality had changed. He became increasingly angry over many things and was very hard to get along with. There were other times when he would become quiet and withdrawn. Some days it seemed that he just wasn't thinking right. I will never forget one particular phone call I got from Wayne. He told me that he was out at an installation job, had all of his tools out, and didn't know what to do with them! My son went out to the job to finish it for him. My husband never discussed it with me again. He continually denied that anything was wrong. His work habits changed which in turn caused conflict within the family.

By late 1989, our son chose to no longer work with his dad. I later learned that my son had been covering for his father's mistakes at work for quite some time. The business closed in the first part of 1990. After being self-employed for 25 years, it was over. Now what?

Having been in the business for as long as he had, and with his good reputation as a cabinet-maker, Wayne was offered a job immediately. He was fired in the first two weeks. It turns out that he was incapable of doing the work! He was hired and fired from several jobs over the next couple of months. Wayne always seemed to have some sort of excuse for what was happening; he was not able to face the fact that something may be medically wrong with him. But I knew there was!

I finally made an appointment with our internal medicine doctor. Wayne was found to be in excellent health. The doctor referred us to a geriatric specialist to rule out the possibility of Alzheimer's disease, which was done. We were then sent to see a psychiatrist with the thought that Wayne was suffering with depression. After months of sessions with the psychiatrist, Wayne was released because no progress was being made. The doctor did prescribe anti-depressant medication, although no diagnosis was made. The medication did seem to make Wayne more alert and happier at times.

In 1991 and 1992 I worked two jobs while Wayne stayed home, looking for work and working on projects around the house. I was becoming emotionally and financially strained. I was angry at Wayne, yet I somehow knew it wasn't his fault. Things just seemed to be getting worse and worse. We had already sold our business property and in '92 we sold our dome home in Wisconsin. I knew there was no way Wayne would be able to finish the work up there. Then, maybe the worst thing for Wayne so far, he was asked to resign from the Fire Department---after 22 years of service! Although Wayne never shared with me that it was not his choice to leave the department, I was told by fellow firemen that he wasn't responding quickly and was in fact becoming a hazard at the fire calls.

At the end of 1992, Wayne had another of his stroke-like episodes. He had blurred vision, drooped mouth and lost his speech. I took him to the hospital. By the time we arrived there all of those symptoms had vanished! Nevertheless, I insisted that he be admitted. I needed answers. There had to be a reason for these continuous problems.

The hospital called in a neurologist, Dr. Kenneth Hoj, who ordered an MRI. The results were stunning. They showed Wayne's brain to be deteriorating in an extraordinary way. As a matter of fact, upon meeting Wayne in person. Dr. Hoj expressed shock at his abilities. Clinically speaking, he had expected someone that would not be nearly as functional as Wayne was. Although he could not give a reason for this, Dr. Hoj did say that the damage was irreversible and would likely continue to get worse. I was too shocked to cry. Wayne never made any response to the news at all. There was nothing to do now but go home and continue with our lives.

There were many good times when I almost thought this wasn't happening. Things would be so normal and then something would happen to remind me of the reality. And I had no name for the condition. In 1993 I decided to quit my job and move with Wayne to south Texas. Our daughter and her family lived in the Rio Grande Valley and after visiting her we decided to build a small house there in a golfing community where living expenses would be considerably less than in Minnesota. We left for our new life on Thanksgiving Day, 1993. Once settled, Wayne joined the men's golf league, together we joined a couple's league, and Wayne transferred his Lion's membership to the local Lion's Club.

We lived in Texas from 1993 to 1999. At first things seemed to be going very well for Wayne. He seemed very upbeat, and at times like his old self. But his deterioration began to be more noticeable. His thinking and his general coordination were affected. He suffered several more of the stroke-like spells, each time making him less and less capable of taking care of himself. I remember one day when Wayne sat for hours in the garage, beside his bicycle, trying to figure out how to change a flat tire. This was a man who could fix and build anything! Even his love for golf began to dwindle. Our neighbor, and Wayne's good friend, would take Wayne golfing, but would have to help set Wayne in the right direction for the shot. It was strange because Wayne could still hit a good ball—making his second Hole in One shot in 1994.

Our new neurologist in Texas was interested in Wayne's condition and ordered another MRI. After reading it he commented that after practicing for 25 years, he had never seen anything like this! He encouraged us to keep the MRI result and share it with Dr, Hoj on our next visit to Minnesota. I was, once again, struck with dread over the covertness of this condition.

In 1997 I received a letter from Dr. Hoi. With it he included an article, written by a French doctor, about CADASIL. The letter said that he believed this disease may be what Wayne was suffering from. Presently, the illness is mostly reported in Europe because the research started in European hospitals and laboratories. There still was no proven treatment for the disease. My only response at that time was—GENETIC? Our children? It can't be true. What was true was that Wayne's younger brother was showing many of the same symptoms at that time.

My husband gave up driving later that year after causing an accident. Thank goodness no one was seriously injured. In early 1999 another episode took place. This one was more profound. Wayne began leaning to one side while walking, while I had to hold him from the other side. He eyes became disoriented—one looking up and the other looking down, causing triple vision. He was hospitalized for one week. The doctors at that hospital had never heard of CADASIL so no treatment *was* offered.

During that week, I made contact with Dr. Hoj's office and with the Mayo Clinic in Rochester, MN. It was arranged that we would bring Wayne there for testing. We left the hospital in Texas and flew right to the Mayo Clinic. The doctors there agreed with the CADASIL diagnosis, although they couldn't clinically prove it through blood tests or skin biopsy.

We spent three weeks at the Mayo Clinic, mainly in their rehab unit. Due to Wayne's regressed thinking process, rehab was not very successful. By this time Wayne could not be left alone. After family conferences, we decided the best thing to do was to stay in Minnesota to be closer with the majority of the family. We sold the house in Texas and bought a small co-op apartment near St. Paul.

Wayne received several sessions of therapy, physical and occupational, which did no good. There were two more hospital stays due to the stroke-like seizures. At each visit I had to answer numerous questions about his disease. Doctors, nurses, therapists, no one had ever heard of CADASIL. It became so frustrating, I couldn't understand how nobody knows anything about this horrible disease that is clearly killing my husband! Then, in June 2000, after Wayne's falling and being unable to get back up he was hospitalized for twelve days and then spent four weeks in the Bethesda Rehabilitation Hospital. Wayne was not able to make any progress with his therapy and did not ever walk again. At this point I had to make the hardest decision yet. Wayne had to be put in a nursing home. He was 62 years old.

Wayne would live out the rest of his days receiving maximum care at Ramsey Nursing Home. Again, I had to inform the staff about his rare disease since nobody had ever heard of it. By this time, Wayne could no longer walk, needed to be fed, and became incontinent. With the wonderful love and care he received from the staff at the nursing home Wayne was safe and comfortable. He greeted me and all of his visitors with a big smile every day. He never once complained about anything. It broke my heart knowing how much this must be affecting him, yet he never let on to a soul that he was unhappy.

The genetic part of CADASIL hit home hard in October 2000 when our then 39 year old son was diagnosed with CADASIL and then again in 2002 when our oldest son, 43 years old, got the same horrid diagnosis. My entire world was crashing. I didn't think I could hold myself together. The nursing home staff and Dr. Hoj gave me great support during this time. And of course I couldn't have survived without my family.

Wayne passed away peacefully on August 5, 2004. His younger brother, also diagnosed with CADASIL and living in the same nursing home, passed away six months later.

Over the past several years I have made contact in writing and by phone to doctors all over the world in a quest for information and support for CADASIL patients. My hope has been to find someone who would be interested in my family and CADASIL—possibly for research. The common thread in the limited amount of research being done on CADASIL is always the funding due to the relatively small number of victims.

During my searching I made contact with two doctors very knowledgeable on CADASIL. Dr. Stephen Salloway and Dr. Stephen Correia with the Memory and Aging Program at Butler Hospital in Providence, Rhode Island (part of Brown Medical School). These doctors head a clinic that has become a leading center for CADASIL clinical care and research. I have been in contact with them since December 2003. Plans were made to have Wayne's brain sent to them after his death. They would perform an autopsy on it and then use it for research purposes. We also sent the brain of Wayne's brother. I desperately hope and pray that funding will become available so that active research can go on.

In the summer of 2005, a pharmaceutical company began a drug study on CADASIL patients. I received a call from Doctor Correia asking if our family would consider participating in it. This was the first ray of sunshine for a very long time! Over the next five months I made five trips out east with some of our family members. Two did not qualify for the study, one did. I was considered the study partner. This was all a very interesting learning experience for me. As it is still going on I do not have any information about the outcomes. (Study now completed. For info go to http://www.ncbi.nlm.nih.gov/pubmed/18296124) For me, the experience was very interesting and I learned more and more about CADASIL and CADASIL research as a result. During one of my visits, Dr. Salloway showed me pictures of diseased brains, which he had on his computer. He then told me that these were the brains of Wayne and his brother. I am so happy that receiving the brains has been useful to the research. I am hoping that these doctors may be part of the answer to my prayers.

I have made other contacts outside of the medical field as well. In particular I have been communicating with a couple that lives in Texas. The husband became disabled from CADASIL in his 40s. The woman has been extremely active in personal research of CADASIL and she works continually for funding of medical research. She has organized a foundation for those efforts. It is called CADASIL: Together We Have Hope! You can find them at www.cadasilfoundation.org or reach them at 1-877-519-HOPE. They send out newsletters with updated information to those who request it.

These contacts and glimmers of hope are indeed encouraging, but so far, all we really have is our hope. My life goes on, but I go to sleep each night and awaken each morning with those seven

letters in the front of my brain. I now worry about my other three children and all of my grandchildren. I believe that we have the largest number of family members affected by CADASIL. It has been traced back to my husband's grandfather, who died young of stroke-like symptoms. His father, who died at the age of 56 was diagnosed with MS, but that diagnosis has now become suspect. Wayne's uncle died of similar symptoms in his early 60's. Wayne's brother died of CADASIL at age 63.

Presently we have six living family members that have been clinically diagnosed with CADASIL.

These include my two oldest sons, Wayne's uncle, nephew, and two cousins. All of these people are between the ages of 42 and 70. You can see why this is of great concern and importance to me. By writing this article, I am hoping to bring awareness to CADASIL. I hope others will not have to go through the years of worry and frustration of waiting to find out what is causing their loved ones to deteriorate. I would be greatly appreciative if somehow our family would be contacted for research purposes relating to CADASIL. I will forever be thankful to Dr. Kenneth Hoj, Dr. Stephen Salloway and Dr. Stephen Correia for all they have done for my family already.

VISION

To have a cure for CADASIL

MISSION

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 ANNUAL REPORT 2012

WHO WE ARE

I am a CADASIL patient who has been told I have an incurable genetic disease with symptoms I endure everyday. . . I am a mother who wonders if my children have inherited this devastating disorder. . . I am a spouse who has watched the love of my life deteriorate physically and mentally as he withered away from me. . I am a mother who watches my child suffer identical symptoms as his father, who is now bedridden and incontinent . . . I am a mother who quivers at the thought of my young child watching her father's health decline, as she thinks, "is it possible this will happen to me"

We are the Board of Trustees of the CADASIL Association

On April 24,2012, the CADASIL Association was incorporated in the state of New Jersey by Anne McGuinness, President; Barbara Hunt, Treasurer and Gail Hunt, Secretary. The By Laws were drafted by the incorporators and approved in early May.
But the work had begun even before this time. In February 2012 during Rare Disease Week, CADASIL was represented in Washington DC. Anne McGuinness and Barbara Hunt were on Capital Hill, at the NIH and the FDA. A total of four self-financed trips were made to DC in 2012. Anne and Barbara met with Senators and Congressional Representatives, Doctors, government officials, and industry leaders throughout the year. Anyone willing to listen was educated about CADASIL. The response was always the same: "What is CADASIL? I have never heard of it." Anne and Barbara received a wealth of knowledge on all aspects of the plight of the rare disease community including the unique obstacles they encounter in bringing drugs to trail. They were introduced to the importance of having a good registry and the complicated process of implementing this.

In May 2012 Karl Stumpf created the CADASIL Association logo.

In June 2012 Janet Mills, Christi Lushbaugh, Frederica Schilling and Charmaine Neville accepted invitations to the Board of Trustees of CADASIL Association.

In September, 2012 the Talismen group held a CADASIL Motorcycle Rally in Columbus, Ohio in honor of CADASIL patient Karla Smith.

SUPPORT PATIENTS AND CAREGIVERS

CADASIL Association will serve the needs of patients and caregivers managing CADASIL in order to maintain well-being and quality of life. CADASIL Association is a link to a network of support, ensuring accessibility of information, education and counsel for each patient and caregiver touched by CADASIL. CADASIL Association will provide services including patient/caregiver educational resources, support groups, volunteer development, professional collaborations, online resources, webinars, social media, and national conferences. CADASIL Association focuses on symptom management to improve the daily living of people who struggle to maintain dignity, self-reliance and hope. CADASIL Association offers patient care resources about CADASIL to healthcare institutions, organizations, and facilities serving the CADASIL population.

On August 24, 2012 CADASIL Association applied for 501(c)(3) status. On September 24, 2012 non-profit determination was made by the IRS and is retroactive to April 24, 2012.

Most CADASIL Association board members attended the CADASIL Family Conference in Utah, which was well organized and hosted by the Russell family. http://www.cadasilforum.org The CADASIL Association was introduced to the CADASIL community.

On November 16, 2012 the CADASIL Association participated in the third CADASIL Awareness Day, together with the CADASIL community. A Press Release was issued and several local newspapers printed articles. NORD posted the Press Release on their website and Facebook page.

The first issue of the CADASIL Association newsletter EMBRACE was published by Janet Mills and Karla Smith in December.

LOOKING FORWARD TO 2013

OBJECTIVES

Explore grant writing options.

Sponsor Student for a research project.

Support planned fundraising efforts by Kathleen Montgomery and any other enthusiastic members who take on this task and continue to develop a strong volunteer team.

Continue with plans for an educational Family Conference in Boston.

Increase Board of Trustees by adding Associate Trustees to bring new and innovated inspiration.

Continue to seek qualified persons for our Scientific Advisory Board.

Explore funding for research fellowships for graduate students and post-doctoral fellows.

Develop educational materials for patients, caregivers, and healthcare professionals that are accurate, comprehensive and current.

Support patient and caregivers in the CADASIL community. Facilitate the development of local support groups composed of patients, family members, caregivers, and friends of persons with CADASIL

Collaborate with other organizations whose patients deal with similar symptoms and progression such as NMSS, American Stroke

PATIENT ADVOCACY AND PUBLIC AWARENESS

CADASIL Association will work together with patient advocacy groups with which we have established relationships, such as National Organization for Rare Diseases, Genetic Alliance, Global Genes, and RDLA. CADASIL Association will continue to maintain connections with important federal agencies, such as the National Institutes of Health/NINDS, FDA and the Social Security Administration, and be aware of their policies which have influence on research and services for its members. CADASIL Association will strive to advocate for patients, caregivers and others touched by CADASIL on public policy issues.

Association, ALS Association, Migraines.org, Association for Frontotemporal Degeneration, Alzheimer's organizations and support groups and Together We Have Hope.

Develop strong relationships and work in partnership with major governmental and patient advocacy groups including:

*Global Genes
*RDLA - Rare Disease Legislative Advocates
*Genetic Alliance
*NORD - National Organization for Rare

Work in coordination with federal agencies including:

*NIH-NINDS – National Institutes of Health and National Institutes of Neurological Diseases and Stroke
*NIH – National Institutes of Health, Office of Rare Diseases Research
*FDA – Food and Drug Administration, Office of Orphan Drug Development
*SSA – Social Security Administration, Office of Compassionate Allowances

Support the development of a patient registry for CADASIL that will be ready and appropriate when studies and drug trails begin.

Explore and implement the newest technologies, such as social media, to aid in expanding the reach of the organization's message.

Continue with design of website.

Expand and improve the quality of social media by developing media resources such as Facebook and Twitter.

Make use of other media — TV, newspapers, radio, etc. — to share information and to help educate the public about CADASIL including the fact CADASIL is often misdiagnosed as MS or other neurological disorders.

Continue to develop and refine printed materials to maximize impact and effectiveness.

Joseph Arboleda-Velasquez MD., PHD., an NIH funded investigator working at Schepens Eye Research Institute/Harvard Medical School, is currently testing in animal models new promising compounds that could be used to treat CADASIL.

Dr. Michael Wang at the University of Michigan and the Ann Arbor VA is an NIH- and VA-funded researcher who has identified proteins that may participate in the disease.

EDUCATE MEDICAL AND HEALTHCARE PROFESSIONALS

CADASIL Association will provide scientific and clinical information/resources regarding the specific nature of CADASIL—including their diagnoses, symptoms, and treatments to all medical and healthcare professionals, institutions, and similar organizations.

2012 CADASIL Association Board of Trustees

Anne McGuinness
Co-Founder, President

Barbara Hunt
Co-Founder, Vice President / Treasurer

Gail Hunt
Co-Founder, Secretary

Janet Mills
Trustee

Christi Lushbaugh
Trustee

Charmaine Neville
Trustee

Frederica Schilling
Trustee

2012 CADASIL Association Scientific Advisory Board

Dr. Joseph Arboleda-Velasquez, M.D., Ph.D
Investigator, Schepens Eye Research Institute, an affiliate of Harvard Medical School, Cambridge, Massachusetts
http://www.schepens.harvard.edu/arboleda

Dr. Angelo M. Santiago, M.D.
Neurologist & Owner at Central Wyoming Neurology, Casper, Wyoming

FUNDRAISING

CADASIL Association realizes that a vital aspect of any patient advocacy organization is fundraising. Fundraising enables the CADASIL Association to persevere in obtaining goals and objectives. CADASIL Association will continue to encourage all volunteers who wish to focus their support in this endeavor. CADASIL Association thanks everyone, who through their donations, have shown support for our vision and mission.

DONORS 2012

$1-$99

Mr. and Mrs. Dale Davis
Mr. and Mrs. Victor Talbird
Ms. Ruth Bellan
Ms. Karen Blackburn
Ms. Joy McFarland
Ms. Jaemy Parcero
Mr. and Mrs. Barney Schroeder
Ms. Anne Marie Massimine

$100-$499

Mr. and Mrs. James Alexander
Ms Ona Cody
Mr. and Mrs. John Heyder
Mr. and Mrs. Joseph Hunt
Mrs. Gail Hunt
Ms. Kathleen Keefe
Mrs. Jeanie Kovacs
Ms. Anne McGuinness
Ms. Michelle McGuinness
Mr. and Mrs. Andy Mills
Mrs. Eugene Mills
Mr. and Mrs. John Mulholland
Mr. and Mrs. Robert Taylor
Mr. and Mrs. Matthew Pool

$500-$999

Mr. and Mrs. Edward Maurer
Talismen Group

$1000-$4999

Mr. and Mrs. Devin Lushbaugh
Mr. and Mrs. Mark Spaur

$5000-$9999

Mrs. Eileen Peterson

$10,000-$20,000

VOLUNTEER

CADASIL Association is run completely by volunteers. CADASIL Association could not operate without its volunteers. CADASIL Association is thankful for all volunteer efforts big and small and will complement a volunteer's talents appropriately with the needs of the association. CADASIL Association will be more productive with more volunteers.

VOLUNTEERS

The CADASIL Association gratefully acknowledges and appreciates the effort of the following volunteers and organizations in 2012.

Courtney Colbert
Beth Fogg
Genetic Alliance
Kathryn Hunt
Alice Lindahl
Devin Lushbaugh
Nancy Mauer
Michelle McGuinness
Sarah Ruedebusch Moris
NORD
Sonia Prim
The Russell Family
Carol Schroeder
Billie Duncan- Smith
Karla Smith
Karl Stumpf
Dr. Michael Wang

RESEARCH

CADASIL Association will support research aimed at understanding the disease in a genuine effort to ultimately find a cure

C erebral

A utosomal

D ominant

A rteriopathy with

S ubcortical

I nfarcts and

L eukoencaphalopathy

HOW CAN I MAKE A DIFFERENCE?

Spread the word

Share CADASIL information with medical professionals, educators, and government representatives by contacting offices, providing brochures, and sharing online resources for CADASIL information.

Support those living with CADASIL

A supportive community helps improve the lives of patients, families, and caregivers of those affected by CADASIL.

Host an event

Events of any size are a wonderful way to raise awareness, build a community, and raise funds for the CADASIL Association. For information contact info@cadasilassociation.org

Donate to the cause

CADASIL Association is a 501(c)(3). Donations to the CADASIL Association are tax deductible.
Donations from individuals allow the CADASIL Association to help fund research, spread awareness, and provide support to those in need.
To find out more about current research or upcoming events go to: www.cadasilassociation.org

Consider brain donations

Brain donation is essential to the progress of CADASIL research and the search for treatments and for a cure. For more info go to http://www.butler.org/CADASILSite/support/brain.htm

CADASIL ASSOCIATION FINANCIAL STATEMENT

APRIL 24, 2012-December 31,2012

Income from Donations	$11,472.42
Expenses	
IRS Prep. fees	$200.00
Filing fees	$850.00
PO Box fee	$48.00
Bank fee	$5.00
Total Expenses	$1,103.00
Total Assets as of December 31,2012	$10,369.42

Barbara Hunt
Treasurer