CADASIL Together We Have Hope
Non-Profit Organization

Presentation of
CADASIL REGISTRY DATA
MAY 2005 - JUNE 2012

CADASIL Together We Have Hope (CTWHH) has the most detailed CADASIL patient registry in the world.  www.cadasilfoundation.org

The following data in this presentation was compiled from patients who voluntarily signed the CADASIL Registry.  We respect the confidentiality of all personal information submitted by CADASIL patients/families.

CADASIL Together We Have Hope (CTWHH) was established on May 10, 2005, as a non-profit organization, which continues to work collegially with various CADASIL organizations, doctors, researchers, and groups to ensure the channels of communication are kept open among all stakeholders to find a treatment or cure for all CADASIL patients and their families.
WE ARE FORTUNATE TO BE AFFILATED WITH THE FOLLOWING ORGANIZATIONS, HOSPITALS AND UNIVERSITIES

- American Brain Coalition
- Brown Research, Rhode Island
- CADASIL France Association, Paris France
- CADASIL Research, London England
- CERVCO, Lariboisière Hospital, Paris, France
- Coalition for Genetic Fairness
- Coalition for Imaging & Bioengineering Research (CIBR)
- Genetic Alliance
- Loyola University Medical Center
- Ludwig-Maximilians-Universität München, Germany
- Memory and Aging Program, Butler General Hospital, Rhode Island
- New York Lagone Medical Center
- New York School of Medicine
- Newcastle University, Newcastle, England
- National Organization of Rare Disease (NORD)
- Perelman School of Medicine, University of Pennsylvania
- St. Georges Hospital, London England
- United Leukodystrophy Foundation
- University of Arkansas
- University of Calgary, Canada
- University of Glasgow, Scotland
- University of Michigan Medical School
CTWHH HAS OR IS ASSISTING IN THE FOLLOWING STUDIES:

• 2012 Canadian study by the Heart and Stroke Foundation Centre of Ontario entitled “Evaluating Compromised White Matter Cerebrovascular Reactivity in Individuals with CADASIL.”

• New York University 2011 - “Natural History of CADASIL: Migraine, Diagnosis and Misdiagnosis.”

• University of Rome 2011 - Crossover trial designed to compare one fixed dose of Dabigatran with open-label use of ASA in patients affected by CADASIL.

• British Columbia, Canada 2010 - Online CADASIL Survey/Study “How Diet Effects CADASIL.”

• University of Nevada 2008 - Effects of dental problems with CADASIL patients (Tiffany Simmons DMD)

• CADASIL Study – January – July 2006 - A randomized trial of Donepezil (Aricept, Eisai/Pfizer)

If you wish to recruit patients to participate in a CADASIL Study we work directly with the patient and post the study information on the website. Should any CADASIL patients desire more information or want to participate in a study, they will directly contact researchers directly.

CONTINUING STUDIES

• Brian tissue donations:
  Butler General Hospital (Dr. Stephen Salloway)
  Michigan University (Dr. Michael Wang)
WORLDWIDE PHYSICIAN LOCATOR

This locator lists physicians from all around the world who have seen one or more patients with CADASIL. CTWHH continually adds to this list.

If you are a patient and are pleased with the doctor who you have seen or are currently seeing for CADASIL, please share their contact information (name, address and telephone number) with us.

If you are a doctor and would like to be on this locator, please contact us at info@cadasilfoundation.org.

The following countries are represented on the locator:

- Argentina
- Australia
- Belgium
- Brazil
- Canada
- England
- Finland
- France
- Germany
- Greenland
- Italy
- Japan
- Lebanon
- Netherlands
- New Zealand
- Portugal
- Puerto Rico
- Saudi Arabia
- Scotland
- South Africa
- Spain
- Sweden
- Switzerland
- U.S.A.
- Wales

Disclaimer: CADASIL Together We Have Hope has made every effort to keep this list current. It is very important for patients and doctors alike to understand that every case of CADASIL is different and patients need to develop a good relationship with their doctors. The patient should have access to appropriate testing facilities, genetic counseling, and prevention medicines for symptoms.
AVERAGE VISITORS PER DAY TO CTWHH WEBSITE

Year 2010 - 28,250 Visitors

Year 2011 - 33,334 Visitors

Earthlink Urchin Tracking Program
CTWHH REGISTRY

The registry is a database (collection of information) to which people with this rare condition from around the world can contribute their information. All personal information provided to us is kept strictly confidential!

If you have a diagnosis confirming CADASIL, please complete the registry and if you have more than one family member diagnosed, complete each registry separately.

Name
E-mail
Address
City
State/Province
Postal Code
Country
Your Phone Number
Do you have CADASIL?
If not you, who has CADASIL?
What test was taken to confirm CADASIL?
Mutation
Year Diagnosed
Ethnicity/Race
Gender
Age at diagnosis
Present Age
Blood Type
Were you first diagnosed with M.S.?

Please check any symptoms you have or had:
No Symptoms
Strokes
TIA's/Small Strokes
Headaches
Migraines
Migraines with Aura
Memory
Depression
Mood Disturbances
Dementia
Fatigue/Tired
Weak
Balance/Gait
Seizures
Speech
Bladder Incontinence
Itching
Swallowing
Hearing Problems
Vision
Numbness

If your doctor knows about CADASIL, please provide doctor's contact information to help others.
Any other medical problems?

Other Symptoms
OVERVIEW OF CADASIL PATIENTS SIGNING REGISTRY
MAY 2005 – JUNE 2012
1,272 REPORTED ALL OVER THE WORLD
CADASIL PATIENTS GENDER
MAY 2005 – JUNE 2012

- 506 Males
- 682 Females
- 84 Not Reported

- 53% Females
- 41% Males
- 6% Not Reported
CADASIL PATIENTS ETHNICITY/RACE
MAY 2005 – JUNE 2012

Caucasian: 839 (66%)
Not Reported: 322 (26%)
Hispanic: 49 (4%)
Black: 25 (2%)
Asian: 22 (2%)
Indian: 9
Latino: 3
Hawaiian: 2
Filipino: 1
32% OF CADASIL PATIENTS WERE MISDIAGNOSED WITH MULTIPLE SCLEROSIS BETWEEN JULY 2010 – JUNE 2012
BREAKDOWN BY AGE, ETHNICITY, AND GENDER

- **Gender**:
  - 58% Females
  - 42% Males

- **Ethnicity**:
  - 74% Caucasian
  - 3% Asian
  - 6% Black
  - 7% Hispanic
  - 10% Not Reported

- **Age Distribution**:
  - 3% 11 - 19 years old
  - 0% 20 - 29 years old
  - 17% 30 - 39 years old
  - 32% 40 - 49 years old
  - 35% 50 - 59 years old
  - 12% 60 - 69 years old
  - 1% 70 - 79 years old
  - 0% 80 - 89 years old

- **Countries**
  - 76% USA
  - 1% Scotland
  - 1% Turkey
  - 9% England
  - 1% New Zealand
  - 1% Canada
  - 1% Chile
  - 1% Ireland
  - 1% Netherlands

CADASIL TWHH - www.cadasilfoundation.org
CADASIL PATIENTS BLOOD TYPE
SEPTEMBER 2010 TO JUNE 2010
78 PATIENTS REPORTED THEIR BLOOD TYPE

B- 1%
B+ 4%
AB- 5%
A- 13%
O- 18%
A+ 20%
O+ 26%

33%
26%
14
10
4
3
1

REPORTED CADASIL SYMPTOMS BY NUMBER COUNT
MAY 2005 – JUNE 2012

Itching (New Symptom) - 6
Bladder Incontinence - 22
Swallowing - 59
Dementia - 92
Mood - 105
Weakness - 118
Depression - 121
Numbness - 128
Migraines with Aura - 147
Speech - 166
Vision - 181
Fatigue - 190
Gait/balance - 201
Headaches - 246
Asymptomatic - 268
Memory - 296
TIA - 340
Strokes - 394
Migraines - 428
REPORTED CADASIL SYMPTOMS BY PERCENTAGES
MAY 2005 – JUNE 2012

- Speech: 13%
- Migraines with Aura: 12%
- Swallowing: 5%
- Dementia: 7%
- Mood: 8%
- Weakness: 9%
- Depression: 10%
- Numbness: 10%
- Migraines: 34%
- Strokes: 31%
- TIA: 27%
- Asymptomatic: 21%
- Memory: 23%
- Headaches: 19%
- Gait/balance: 16%
- Fatigue: 15%
- Vision: 14%
- Speech: 13%
- Numbness: 10%
TOP FIVE CADASIL SYMPTOMS
MAY 2005 – JUNE 2012

- Migraines: 428
- Strokes: 394
- TIA: 340
- Memory: 296
- Asymptomatic: 268
MIGRAINE SYMPTOMS
428 CADASIL PATIENTS REPORTED
MAY 2005 – JUNE 2012

6 Not Reported

150 Males
272 Females

COUNTRIES
Argentina 2
Australia 17
Austria 1
Brazil 6
Canada 24
Chile 1
Cyprus 1
Denmark 1
England 29
France 2
Germany 4
India 1
Ireland 13
Italy 3
Mexico 1
Netherlands 1
New Zealand 4
Not Reported 3
Philippines 1
Puerto Rico 2
Scotland 5
South Africa 1
Spain 1
Turkey 1
USA 299
Virgin Islands 2
Wales 1
West Indies 1

AGE DIAGNOSED
3 Patients 11 - 19 years
27 Patients 20 - 29 years
98 Patients 30 - 39 years
142 Patients 40 - 49 years
113 Patients 50 - 59 years
31 Patients 60 - 69 years
7 Patients 70 - 79 years
7 Patients Not Reported

312 Caucasian
15 Black
19 Hispanic
8 Asian
4 Indian
1 Latino
69 Not Reported
### STROKE SYMPTOMS
394 CADASIL PATIENTS REPORTED
MAY 2005 – JUNE 2012

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### AGE DIAGNOSED

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*CADASIL TWHH - [www.cadasilfoundation.org](http://www.cadasilfoundation.org)*
TIA SYMPTOMS
340 CADASIL PATIENTS REPORTED
MAY 2005 – JUNE 2012

3 Not Reported
8 Black
8 Asian
65 Not Reported
6 Indian
14 Hispanic
239 Caucasian

COUNTRIES

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AGE DIAGNOSED

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MEMORY SYMPTOMS
296 CADASIL PATIENTS REPORTED
MAY 2005 – JUNE 2012

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AGE DIAGNOSED

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ASYMPTOMATIC
268 CADASIL PATIENTS REPORTED
MAY 2005 – JUNE 2012

78 Males
135 Females
55 Not Reported

COUNTRIES

Australia 8
Belgium 2
Brazil 5
Canada 17
England 15
Germany 9
Greenland 2
Hungary 1
India 1
Ireland 3
Italy 3
Netherlands 3
New Zealand 7
Not Reported 2
Puerto Rico 1
Scotland 1
South Africa 1
Sweden 3
Switzerland 1
Turkey 1
USA 181

AGE DIAGNOSED

1 Patient under - 9 years
4 Patients 10 - 19 years
10 Patients 20 - 29 years
31 Patients 30 - 39 years
67 Patients 40 - 49 years
27 Patients 50 - 59 years
50 Patients 60 - 69 years
8 Patients 70 - 79 years
2 Patients 80 - 89 years
68 Patients Not Reported

1 Filipino
7 Asian
141 Caucasian
8 Hispanic
CADASIL TWHH - www.cadasilfoundation.org
WHAT’S ON OUR WEBSITE
www.cadasilfoundation.org

Current News
Registry
For Medical Professional

What is CADASIL
CADASIL is ..
Questions/Answers
Medicines to Avoid
CADASIL Map
Should I get Tested?
Tests and Locations
History of CADASIL
Misdiagnosis
CARASIL

Coping with CADASIL
Family Experiences
Family Forum
Caregiver Forum
Caregivers Guide
Filing Social Security
Genetic Non-Discrimination Act
Disability Information Acts
Vocational Agency

Educational Materials
Brochure
Emergency Plan
Definitions
Podcasts by Doctors
Videos
Your Genes
Understanding Strokes

Physicians Locator
USA Letters A thru L
USA Letters M thru Z
Australia/New Zealand
Canada
United Kingdom
Other Countries

CADASIL Awareness
Donate
Wristbands
Ways to Help
News Articles
2010 Conference
2012 Symposium

CADASIL Studies
2012 Canadian Study
2011 Dabigatran
2011 NYU
2010 Diet.htm
2008 Dental
2006 Aricept

CADASIL Research
Donate Directly to Research
Mouse Model
Brain Donation
Mouse Model
CADASIL Together We Have Hope Non-Profit Organization
3605 Monument Drive
Round Rock, Texas 78681
www.cadasilfoundation.org

Phones:
512-255-0209
1-877-519-HOPE

e-mail: info@cadasilfoundation.org

Data complied by: Billie Duncan-Smith, CTWHH Director
June 30, 2012