




**European
Reference
Network**

for rare or low prevalence
complex diseases

 **Network**
Vascular Diseases
(VASCERN)

VASCERN DO'S AND DON'TS FACTSHEETS
FOR RARE VASCULAR DISEASE PATIENTS
FACING FREQUENT SITUATIONS

Cerebral Autosomal Dominant Arteriopathy with Sub-cortical Infarcts and Leukoencephalopathy (CADASIL)



VASCERN

VASCERN, the European Reference Network on Rare Multisystemic Vascular Diseases, is dedicated to gathering the best expertise in Europe in order to provide accessible crossborder healthcare to patients with rare vascular diseases (an estimated 1.3 million concerned). These include arterial diseases (affecting aorta to small arteries), arterio-venous anomalies, venous malformations, and lymphatic diseases.

VASCERN currently gathers 48 expert teams from 39 highly specialized multidisciplinary HCPs, plus 6 additional Affiliated Partner centers, coming from 19 EU Member States, as well as various European Patient Organisations, and is coordinated in Paris, France.

Through our 6 Rare Disease Working Groups (RDWGs) as well as several thematic WGs and the ePAG (European Patient Advocacy Group), we aim to improve care, promote best practices and guidelines, reinforce research, empower patients, provide training for healthcare professionals and realise the full potential of European cooperation for specialised healthcare by exploiting the latest innovations in medical science and health technologies.

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Introduction

These factsheets have been prepared by the patient representatives of the NEUROVASC Working Group, working with the Group's experts and intended for both patients and caregivers.

The NEUROVASC WG agrees with the recommendations, but would like to emphasize that these are recommendations made by consensus at the expert level. We recommend that you use these factsheets as a guide and consult with your physician about your specific situation.

Healthy Lifestyle



WHAT IS RECOMMENDED

- Stop smoking.
- Avoid excessive alcohol consumption and addiction to any toxic substances.
- Be aware of stroke risk factors:
 - Monitor your blood pressure.
 - Make sure that you do not have diabetes, high levels of cholesterol or too many lipids in your blood.
 - Avoid being overweight.
- Move as much as possible: walking, taking the stairs, etc.
- Stay active: keep doing what you like (i.e. shopping, cooking, etc.).
- Eat a healthy diet: low in animal fat, low in sugar, lots of vegetables, fruit, starchy foods, etc.

Social Life



WHAT IS RECOMMENDED

- Do not stay alone, without social contact.
- Talk about your illness with those around you.
- Talk about your illness with your general practitioner.
- Keep in touch with your relatives and friends.
- Stay involved in the community you live in.
- Get involved in projects.

Intellectual Wellness



WHAT IS RECOMMENDED

- Continue to engage in intellectually stimulating activities:
 - Keep reading.
 - Do crossword puzzles.
 - Play board games.
- Engage your memory in daily life by recalling recipes, appointments, and shopping lists from memory before referring to your notes.
- Go to the theater, cinema, concerts, etc. If possible, try to do these activities as much as possible outside of your home, rather than just in front of the screens at home.

Asking for Help



WHAT IS RECOMMENDED

- Ask for help from people with resources when you need it:
 - General practitioners
 - Neurologists
 - Psychologists, psychiatrists and neuropsychologists
 - Physiotherapists and psychomotor therapists
 - Speech and language therapists

Editorial Board/ Contributors

Editorial Board:

Elisabeth LISACK (Association CADASIL France, Paris, France).

Reviewed and validated by the VASCERN NEUROVASC WG:

Dr. Anna BERSANO (VASCERN NEUROVASC Reference Centre, Fondazione IRCCS Istituto Neurologico Carlo Besta di Milano, Italy).

Chantal NEAU (Association CADASIL France, Paris, France).

Dr. Dominique HERVE (VASCERN NEUROVASC European Reference Centre, AP-HP Nord, Hôpital Lariboisiere, Paris, France).

Dr. Francesco ACERBI (VASCERN NEUROVASC European Reference Centre, Fondazione IRCCS Istituto Neurologico Carlo Besta di Milano, Italy).

Prof. Hugues CHABRIAT (VASCERN NEUROVASC European Reference Centre, AP-HP Nord, Hôpital Lariboisiere, Paris, France).

Dr. Julie Rutten (VASCERN NEUROVASC European Reference Centre, Leiden University Medical Center, Leiden, Netherlands).

CADASIL

Dr. Saskia LESNIK OBERSTEIN (VASCERN NEUROVASC Reference Centre, Leiden University Medical Center, Leiden, Netherlands).

