

CALL TO ARSACS PATIENTS

Preparing Future ARSACS Treatment Trials:

Participate in an International Natural History and Biomarker Study

Study #1 PREPARE-ARSACS study

To prepare future treatment trials in ARSACS, robust information is necessary on the natural disease course of the disease. This is the prerequisite to plan future treatment trials and to perform sample size calculations for these trials. In addition, biomarkers identified in blood will strongly help to initiate treatment trials for ARSACS.

An international network of ARSACS centers has now started a multi-center study which is dedicated to collect these urgently required natural history data and biomaterials for biomarkers. We would welcome all persons affected by ARSACS to join this study and thus to support the preparation of future treatment trials.

All you need is an outpatient visit at one of the following centers:

(1) Center of Neurology & Hertie-Institute for Clinical Neurology, University of Tübingen, Germany;
contact person: Prof. Matthis Synofzik, matthis.synofzik@uni-tuebingen.de

(2) Radboud University Medical Center, Nijmegen, Netherlands
contact person: Prof. Bart van de Warrenburg, Bart.vandeWarrenburg@radboudumc.nl

(3) Institut du Cerveau et de la Moelle épinière, INSERM /Paris VI University
Hôpital Pitié- Salpêtrière, Paris, France
contact person: Prof. Alexandra Durr, alexandra.durr@icm-institute.org

(4) Département de Neurologie, Hôpitaux Universitaires de Strasbourg, Hôpital de Hautepierre,
Strasbourg, France.
contact person: Prof. Mathieu Anheim, mathieu.anheim@chru-strasbourg.fr

(5) IRCCS Fondazione Stella Maris, Calambrone/Pisa, Italy
contact person: Prof. Filippo Santorelli, filippo.santorelli@fsm.unipi.it

(6) Montreal Neurological Institute of McGill University, Depts of Neurology and Neurosurgery and
Human Genetics, Montreal, Canada
contact person: Prof. Bernard Brais, bernard.brais@mcgill.ca

(7) Centre de recherche Charles-Le Moyne-Saguenay -Lac-St-Jean sur les innovations en santé,
Sherbrooke University, Québec, Canada

contact person: Prof. Cynthia Gagnon, cynthia.gagnon4@usherbrooke.ca

(8) Molecular Biology and Genetics, School of Medicine, Koç University, Istanbul, Turkey

contact person: Prof. Nazli Basak, nbasak@ku.edu.tr

Only visits at one of these centers participating in this study, but not in other centers, will make a contribution to the study.

For further questions, please contact Selina Reich, Center of Neurology and Hertie-Institute for Clinical Brain Research, Tübingen Germany, selina.reich@uni-tuebingen.de.

If you live in Germany or in Quebec (Canada), please consider also participating in our advanced MRI biomarker study.

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