



### INFORMATION NOTE FOR PATIENTS PARTICIPATING IN THE EUROPEAN RESTLESS LEGS SYNDROME REGISTRY

Dear Sir or Madam,

We invite you to participate in the European registry on restless legs syndrome. This registry is coordinated by Professor Yves DAUVILLIERS of the Sleep Disorders Unit, Gui de Chauliac Hospital, CHRU of Montpellier (Promoter of the registry at the national level).

The objective of this research is to collect clinical data (medical information about your health history, symptoms, current health status and treatments) longitudinally (every 6 months and then every year), in order to better understand your disease. The main aim is to study the evolution of your impatience, your night-time sleep and other associated factors according to your management.

This research is not intended to change your management. There will be no additional consultations or examinations, or changes in the treatment prescribed by your doctor.

To be able to take part in this study you must be over 18 years old, have been diagnosed with restless legs syndrome, speak and understand French, be affiliated to a Social Security scheme or be a beneficiary of a scheme and agree to take part in the study.

You only need to complete the items on the dedicated platform which is secured with anonymised data. Your anonymised information will remain confidential and can only be consulted under the responsibility of Pr Dauvilliers. You can withdraw from this register at any time without justification and without any consequences. No immediate individual benefit is expected for participants in this register.

In the context of this research, your personal data will be processed by computer to enable the results of the research to be analysed in the light of the objective of the research presented to you. These data will be identified by codes.

This research complies with the French Data Protection Act and with the reference methodology MR-004 relating to the processing of personal data implemented in the context of research in the health field (Compliance with the General Data Protection Regulation).

In accordance with the provisions of the law relating to information technology, files and freedoms (Law No. 78-17 of 6 January 1978 relating to information technology, files and freedoms as amended by Law No. 2018-493 of 20 June 2018 relating to the protection of personal data) and the General Data Protection Regulation (EU Regulation 2016/679), you have the right to access, rectify, erase or limit the information collected about you in the context of this processing.

This research has obtained a favourable opinion from the Institute Review Board (IRB) of the CHU of Montpellier (IRB-MTP\_2021\_08\_202100904) dated 17/08/2021 and registered on the ClinicalTrials.gov website with the Identifier: NCT05044520.

20.11.2021, Yves DAUVILLIERS of the Sleep Disorders Unit, Hôpital Gui de Chauliac, CHRU de Montpellier, [ydauvilliers\(at\)rlsregistry.eu](mailto:ydauvilliers(at)rlsregistry.eu)

### CONSENT TO PARTICIPATE FORM

I freely and voluntarily agree to participate in the constitution of the European Registry on Restless Legs Syndrome whose coordinator is Pr Yves Dauvilliers (University Hospital of Montpellier).

As part of the creation of this database, I agree to answer a series of questionnaires.