

Information may be provided in writing, upon oral or written request.

Approved Rare Disease Centre – Processing of your Personal Data

As part of your care in a Rare Disease Centre approved by the Ministry of Health, the healthcare facility uses a specific software application called “BaMaRa”. This application allows a better understanding of care and improves the census of rare diseases in France by monitoring the medical follow-ups and by analysing the activity of the centre. In order to do this, statutory reports are sent regularly to the Ministry of Health’s Directorate of Health Care (DGOS).

The Personal Data (sex, date and place of birth, place of residence, healthcare, medical family history, health status, vital status, clinical research participation) is processed under the responsibility of your healthcare facility for a period of 20 years. Data will be collected either directly during your care or by the transfer of your data [via the Parisian Health Authority (AP-HP)] which was collected during the French National Commission on Information Technology and Liberties (CNIL) authorised rare disease project “CEMARA”.

The data collected is stored on the Parisian university hospital (AP-HP) servers which have been approved by the Ministry of Health in application of article L1111-8 of the French Public Health Code relating to personal data hosting.

The hosting company doctor and guarantor of the confidentiality of Personal Health Data is the Dr. Daniel Reizine - AP-HP - DSI PATIENT (Patient IT System Department) - Hôpital Rothschild - 33, Bd de Picpus, 75571 Paris Cedex 12. Opposition to the outsourcing of data can be done by contacting the doctor by letter at the above mentioned address or by email: medecin.hebergeur@aphp.fr

You have the right to access, verify, rectify, complete, update or oppose the use of your Personal Data, or request that the information be deleted. You may exercise this right by contacting the physician in charge of your care or by sending an email to: xxxx@xxxx.fr (physician / person responsible for user relations at the hospital/ hospital director).

Furthermore, the data is likely to be reused for research purposes, principally by the National Rare Disease Data Bank (BNDMR) managed by the Parisian Health Authority (AP-HP). To find out more about the research projects, the intended partnerships and information on how to exercise your rights, you may consult the National Rare Disease Data Bank’s information Portal: <http://www.bndmr.fr>

If you have any questions about the protection of your Personal Data or if you are encountering difficulties in the exercise of your rights, you can contact the Data Protection Officer xxxx@xxxx.fr