



Legal information

Patient Organization Name::

ID number:

Country:

Disease(s) included in our association:

Legal representative Name/Surname(s):ID:

Email of contact:

Telephone number:

<p><u>Person designated by the legal representative from your patient organization with access to Share4Rare</u></p> <p>Surname(s)..... First name.....</p> <p>ID number.....</p> <p>Position in the PO:</p> <p><input type="radio"/> President</p> <p><input type="radio"/> Vicepresident</p> <p><input type="radio"/> Secretary</p> <p><input type="radio"/> Treasurer</p> <p><input type="radio"/> Other: _____</p>

Consent

After having read the information made public by the S4R platform, I hereby **DO** / **DO NOT** give my consent to get included in the Share4Rare database and be contacted by Share4Rare users:

We have read and accept the [privacy policy](#)

We have read and accept the [terms of use](#)

Personal ID validation of the person designated to manage the POs user in S4R :

In order to validate the previous legal document, we will need to verify your ID (from the person that we will grant access to the platform). Please, **attach a valid ID document** (national card number or passport) to give you access to the platform. Please scan the front and back information on your ID card or the full first page of the passport where your image can be seen and include the image in the next page:

Signature of the president..... **Signature of the S4R representative**.....

City: _____ Country: _____ Date: _____

Responsible	<p>Fundació Privada per a la Recerca Sant Joan de Déu</p> <p>Calle Santa Rosa 39-56 – 08950 Esplugues de Llobregat (Spain)</p> <p>Data Protection Officer: dpd@sjdhospitalbarcelona.org</p>
Purpose	<p>The Foundation will keep the data for the duration of the relationship with the interested party and the interested party does not ask for the right to cancel. Inform that the Foundation will dispose of them in accordance with the corresponding regulatory norm, Law 21/2000, of December 29, on the rights of information concerning the health and autonomy of the patient, and the clinical documentation.</p>
Legal basis	<p>People that sign this document have the right to withdraw whenever they want.</p>
Address	<p>No data is transferred to third parties, except in the case of legal obligation.</p>
Rights	<p>Access, rectification and deletion of data, as well as other rights, as detailed in the Spanish Organic Law on the Protection of Personal Data (LOPD) and Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data (GDPR), has to be exercised through a written communication to Fundació Privada per a la Recerca Sant Joan de Déu (Santa Rosa 39-56 – 08950 Esplugues de Llobregat –Spain) or through an email to dpd@sjdhospitalbarcelona.org (Mr. Eduard Puig).</p> <p>If you consider that your rights have not been considered you can complain directly to the Spanish Data Protection Agency (Agencia Española de Protección de Datos).</p>