

## Rare Diseases Contact Registry Form

Please sign Authorization at the end of this form. Questions marked with an asterisk (\*) are required.  
Please fax completed form along with signed Authorization Agreement to (813) 910-5997 or mail to  
RDCRN Attn: Contact Registry, 3650 Spectrum Blvd., Ste 100, Tampa, FL 33612

Patient Information (Person with disorder)		
<b>Disorder*</b> (choose only one): _____ Enter corresponding disease number from the next page		
<b>Date of Diagnosis</b> (if you don't know the entire date, please enter as much as possible)* ___/___/___ (DD/MMM/YYYY, e.g., 12/JAN/2002.)		
<b>Date of Birth</b> (if you don't know the entire date, please enter as much as possible)* ___/___/___ (DD/MMM/YYYY, e.g., 12/JAN/2002.)		
<b>Place of birth:</b> County: _____ State/Province: _____ Country: _____		
<b>Gender*:</b> <input type="radio"/> Male <input type="radio"/> Female		<b>Ethnicity:</b> <input type="radio"/> Hispanic or Latino <input type="radio"/> Not Hispanic or Latino
<b>Race</b> (check all that apply): <input type="checkbox"/> American Indian/Alaska Native <input type="checkbox"/> Black or African American <input type="checkbox"/> White <input type="checkbox"/> Asian <input type="checkbox"/> Native Hawaiian/Pacific Islander <input type="checkbox"/> Unknown		
Basis for Diagnosis (check all that apply)		
<input type="checkbox"/> Physician Diagnosis <input type="checkbox"/> Self-Diagnosis <input type="checkbox"/> Laboratory Testing		
Contact Information (Person to be contacted)		
First Name*: _____		
Last Name*: _____		
Mailing Address*: _____		
City*: _____		
State*: _____		
Country: _____		
Zip/Postal Code*: _____		
Primary Phone*: _____ - _____ - _____		Secondary Phone: _____ - _____ - _____
Email address: _____		Fax: _____ - _____ - _____
I am a*: <input type="radio"/> Patient <input type="radio"/> Parent/Guardian		
How do you prefer us to contact you? <input type="radio"/> Email <input type="radio"/> Phone <input type="radio"/> Mail <input type="radio"/> Fax <input type="radio"/> Withdraw		
What is the best time to contact you? <input type="radio"/> Morning <input type="radio"/> Afternoon <input type="radio"/> Evening <input type="radio"/> Any time of day <input type="radio"/> Never		
How did you find out about us? <input type="checkbox"/> Support group/Foundation <input type="checkbox"/> Medical Professional <input type="checkbox"/> Media <input type="checkbox"/> Publication <input type="checkbox"/> Internet <input type="checkbox"/> Other <input type="checkbox"/> Word of mouth		

Please use the table below to find the number assigned to your disease. In the space provided in the Disorder section at the top of the first page of this form, please write the number corresponding to your disease.

213	Alpha-Mannosidosis types I / II
203	Aspartylglucosaminuria
141	Batten disease
237	Batten disease, late infantile
214	Beta-Mannosidosis
150	Bone Disease in the MPS
205	Cystinosis
206	Danon disease
151	Fabry Disease
208	Farber disease
209	Fucosidosis
211	GM1-Gangliosidosis types I/II/III
212	GM2-Gangliosidosis
223	Galactosialidosis types I / II
210	Gaucher disease
146	Glycoproteinoses
218	Hunter syndrome
227	Hurler syndrome
228	I-cell disease
224	Krabbe disease
144	Late Infantile Neuronal Ceroid
145	Lipofuscinosis
231	Maroteaux-Lamy syndrome
215	Metachromatic leukodystrophy
230	Morquio syndrome
143	Mucopolipidosis Type IV
140	Mucopolysaccharidoses (MPS)
233	Mucopolysaccharidosis type IX
234	Multiple sulfatase deficiency
142	Niemann-Pick disease
238	Northern Epilepsy
149	Pompe Disease
229	pseudo-Hurler polydystrophy
239	Pycnodysostosis
225	Sandhoff disease
219	Sanfilippo syndrome A
220	Sanfilippo syndrome B
221	Sanfilippo syndrome C
222	Sanfilippo syndrome D
217	Scheie syndrome
240	Schindler disease
216	Sialidosis types I / II
241	Sialuria, Salla disease
232	Sly syndrome
235	Tay-Sachs disease
226	Vogt-Spielmeyer disease
148	Wolman Disease

## Authorization Agreement - Contact Registry

Please read the following carefully. The submission of information in the registry will be considered your consent to the following statements.

### Authorization Statement for Use and Disclosure of Protected Health Information

The University of South Florida and the Rare Diseases Clinical Research Network Data Management and Coordinating Center understand that information about you/(your minor child) and your/(your minor child's) health is personal, and we are committed to protecting the privacy of that information. You are granting your authorization before we use your/(your minor child's) protected health information (PHI) for the purpose of providing you notification of the availability of clinical studies or trials and updates on the results of clinical studies and trials performed within the Rare Diseases Clinical Research Network. You will also be given the option of sharing the information you enter into the contact registry directly with the study doctors. This form memorializes your authorization for us to use your PHI for this purpose and helps us make sure that you are properly informed of how this information will be used and/or disclosed.

By agreeing to this document you are permitting the Data Management and Coordinating Center (DMCC) to use PHI collected about you/(your minor child) so that they may contact you with information about availability of clinical studies or trials and provide updates on the results of clinical studies and trials performed by the Rare Diseases Clinical Research Network. Please carefully read and understand the information below before signing below.

1. Who will disclose, receive, and/or use the information? By signing below you authorize the following person(s), class(es) of persons, and/or organization(s) to be allowed to use and receive the protected health information for the purposes set forth in this form. The PHI will not be disclosed to any parties not named below without your authorization except as permitted by law.

- The Rare Diseases Data Management and Coordinating Center and the University of South Florida;
- Doctors and staff at clinical centers who are doing research in your/(your minor child's) disease/disorder. You will get to decide whether to share your information directly with the doctors/staff or not. If you decide to share your information directly with the doctors/staff then the Rare Diseases Data Management Coordinating Center and the University of South Florida will no longer have control over who has access to your protected health information.
- In unusual cases, the researchers may be required to release your/(your minor child's) identifiable medical information from the registry in response to an order from a court of law;
- Members of all review boards supervised by the USF Division of Research Compliance that oversee this research, including but not limited to the Institutional Review Boards (IRBs);
- The Members of the USF Privacy Board;
- The staff in the USF Office of Research, USF DRC and other offices that oversee this research.
- The successor or successors (if applicable) of the Rare Diseases Clinical Research Data Management and Coordinating Center.

The entities and persons listed above may employ or pay various consultants and companies to help them understand, analyze and conduct research. You are also authorizing use by and disclosure to such individuals.

2. What information will be used or disclosed? By signing below, you authorize the use of ALL of your/(your minor child's) protected health information that you choose to enter in the registry, such as your/(your minor child's) name, mailing address, birth date, place of birth, email address, telephone number, facsimile (fax) number, gender, ethnicity, race, name of disease, date of diagnosis of the disease, all of which will be deposited in a secure computerized database. Disclosure of you or your child's protected health information will be made to the above named USF research oversight offices/officials, the successor of the Rare Diseases Clinical Research Data Management and Coordinating Center, and as permitted by law.

3. Expiration date of Authorization: None

### SPECIFIC UNDERSTANDINGS

- By signing below, I authorize the list of person(s), class(es) of persons, and/or organization(s) listed above to be allowed to use and receive the information I enter into the registry for the purposes set forth in this form.
- I acknowledge that by signing below, the information disclosed pursuant to this authorization may be subject to redisclosure and may no longer be protected by federal privacy regulations or other privacy laws.
- I acknowledge that I have a right to refuse to agree to this authorization. I also acknowledge that refusing to sign below will not affect my/(my minor child's) health care, the payment for my/(my minor child's) health care, and my/(my minor child's) health care benefits, outside of this particular activity. However, I also understand that in order to register myself/(my minor child) to participate in the registry, I must agree to the terms of this authorization form and acknowledge my acceptance of this form by signing below once I have read and understood this authorization form.
- I acknowledge that if I agree to this authorization, I will have the right to revoke this authorization at any time by contacting the DMCC, except to the extent that the Rare Diseases Clinical Research Network Data Management and Coordinating Center or USF has already taken action in reliance on this authorization. I understand that this revocation will apply only to use of the data in registry after the date of Withdrawal.
- I acknowledge that by signing below, this authorization will never expire unless and until I choose to discontinue my/(my minor child's) enrollment by contacting the DMCC.
- Prior to signing below, if I have questions about this authorization form, then I will contact the Rare Diseases Clinical Research Network Data Management and Coordinating Center (at [RDRCNContactRegistry@epi.usf.edu](mailto:RDRCNContactRegistry@epi.usf.edu)) and have my questions answered. By signing below, I acknowledge that I have had the opportunity to ask questions about this authorization prior to accepting this authorization.

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By signing below, I acknowledge that I have read, understand, and agree to accept this authorization's terms.

I HEREBY GIVE permission to the Rare Diseases Clinical Research Network to use the information I provide to the online patient registry. I understand that if I enter my or my child's contact information, I agree to be contacted about future research studies. I understand that if I do provide my or my child's name or other contact information, neither will be identified by name or any traceable identification in any report published or distributed without my permission.

**By signing below you are agreeing to the terms and conditions of the statements above.**

If you consent to the statements above please sign below:

\_\_\_\_\_  
Signature

\_\_\_/\_\_\_/\_\_\_  
DD/MMM/YYYY