



[Leuconnect.com](http://Leuconnect.com)

## Leuconnect

Leuconnect was created by ELA, the European Leukodystrophies Association, at the request of families, to accelerate research on leukodystrophies and allow the community to come together in a dedicated and secure environment.

### Register on LEUCONNECT!

Patient or parent, it is important to register on Leuconnect to be part of the Leuconnect e-cohort. **Your secured private account** allows you to communicate with Leuconnect community, store your personal information, and apply to clinical studies or be contacted by a healthcare professional to participate.

To register:

- Create your account
- Log in
- Join the cohort

- **Create your account with your email address and a password:** It must be at least 10 characters long, including one lower case, one upper case, one number and one special character.
- **Connect:** A two levels authentication protects your data in accordance with the regulations.

Email + Password + One-time password sent to your personal email and generated with each new connection

- **Sign the e-cohort form online:**  
Read the information notice, Read and accept the general conditions of use of the online signature system, Sign the form electronically  
**You are now a member of LEUCONNECT e-cohort!**  
For your child, minor or unable to register on its own, you will proceed in the same way but with **HIS** personal e-mail (existing or to be created). In the event that you are the legal guardian, as you will have registered on the account creation page, you will receive **parental authorization on YOUR e-mail** in order to authorize your child to open an account on LEUCONNECT. Once you have activated your child's account from YOUR e-mail,

you will be able to **register your child in the e-cohort from HIS LEUCONNECT account** previously created on the platform.

Watch [Leuconnect Registration video](#)

### Communicate with LEUCONNECT!

**Leuconnect offers you a secure messaging system to communicate with all members of Leuconnect community, anonymously** under conditions guaranteeing the security and confidentiality of your exchanges, in accordance with the legislative recommendations in force.

- **Create your community profile**  
Choose a nickname and write an introductory message. This is what will be seen by the other members of Leuconnect community. Once your profile is created, you must publish it to activate it.
- **Invite contacts**  
Create your list of contact using the character icon at the top right of your dashboard. **Search for new contacts** in the database of already existing profiles using the magnifying glass. Look at the profiles and send an invitation to the contacts with whom you would like to discuss. You will have to wait for them to accept, and then they will be part of your group. You may also receive contact requests.
- **Communicate using Leuconnect**  
You can exchange in real time and in complete confidentiality with your contacts by creating a discussion which can bring together 2 to 3 participants, or be invited to join a discussion thread already initiated.

Watch [Leuconnect Patient file video](#)

## Complete your "patient file" on Leuconnect

Select your situation:

- I do not have a leukodystrophy (I am a healthy volunteer). You then access your patient file in which you will be able to fill in your administrative profile.

- I have a leukodystrophy

Your "patient file" allows you to record information relating to your leukodystrophy, to update it and to keep it. It helps you retrace important episodes in your care pathway or that of your child.

Your file includes information on your leukodystrophy, the history of your disease, your family history, information on the healthcare professionals involved in your care path, and any factors that influence its course.

Your patient file gives you a place to keep your documents. This space is your personal library. You can enter your patient file wherever you want, correct it, complete it, update it. **With your "patient file", you have the keys to centralize your information and thus optimize disease monitoring.**

Watch [Leuconnect Community video](#)

## Let's accelerate research together: participate in clinical studies.

You are a member of Leuconnect e-cohort, you can easily access clinical studies and play a **key role in research**. You can apply for studies online or be contacted to participate. A study can be observational, it can take place completely online

on Leuconnect, or interventional, it requires a prior visit to your doctor in order to sign the consent form.

You will need to be aware of the elements of the study (the protocol, the objectives, the procedures) in order to sign the consent of the study with full knowledge of the facts. You must sign **Leuconnect agreement**. This agreement will constitute consent to the study if you are applying for an observational study. If this is an interventional study, the signing of the **study consent form** will be done during your visit to your study physician. Following this meeting, you will be invited to validate your agreement on Leuconnect

- **Sign Leuconnect agreement online:**

Read the information and consent document.

Accept the general conditions of use of the online signature system.

Sign the study consent. Once **Leuconnect agreement is signed**, the study will appear on your dashboard in "My clinical studies" box in order to include you in the study.

You will find your **agenda** on your dashboard. It will allow you to learn about the events corresponding to the study protocol: medical appointments you will need to make, and questionnaires or forms you will need to answer. This tool is only available when you are included in a study. It does not allow you to make your appointments but to record and follow them.

Finally, you will find the **questionnaires** to fill out on your dashboard. You can fill them in wherever you want, pause and resume, before submitting them to the investigators.

Watch [Leuconnect Clinical study video](#)

**LEUCONNECT was created for you. Open in five languages, indicate your country and meet families like you.**

