



# What is Leuconnect ?

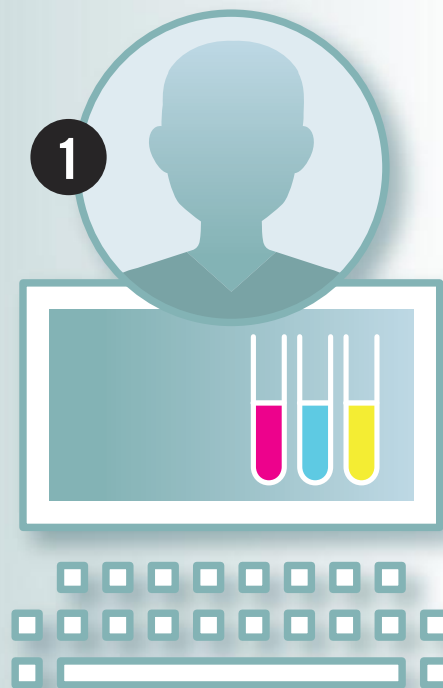
## Leuconnect.com : an innovative tool, accelerator of research

Clinical studies on leukodystrophies are facing a low number of patients that can be included in a given country. The result is a low statistical power and a low level of proof for the evaluation of treatment efficacy. To circumvent this deficit and accelerate research, ELA International developed Leuconnect: a platform to support online clinical studies on leukodystrophies. Patients, whatever their nationality, will be able to participate in a clinical study.

This platform revolutionizes access to clinical studies for voluntary and motivated patients and their families. With this new tool, the idea of a patient actively participating in research is making sense  
Be many to participate.

**Discover Leuconnect in 5 key steps.**

## 1 · I discover the public interface



- Information on leukodystrophies
- Useful links
- Information on studies
- Research updaters
- Publications

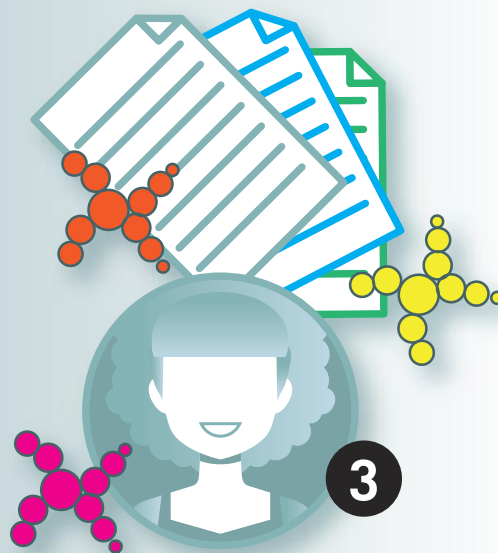
## 2 · I get involved

### I register in the e-cohort



- I create my account to join the e-cohort (creation with e-mail address and password).
- I receive my connection code.
- I log in.
- I complete my profile (personal information, administrative information, my medical data...).
- I find Information on open studies

## 3 · I participate in a study



- I apply to a study.
- I get invited to participate in a study.
- I receive the option for inclusion if criteria match.
- I sign regulatory documents (consent form...).
- I answer questionnaires.
- I receive personalized information.
- I consult results after closing of the study.
- I print my summary page.

## 4 · I register my child



- Each one with his OWN e-mail.
- Each one with his OWN account.

Patient's account is personal and nominative. To help your child register the cohort, you need HIS personal e-mail (existing or to be created).

- I create my child's account using HIS e-mail.
- I receive a parental authorization on MY e-mail.
- I authorize the creation of my child's account.
- I register my child in the e-cohort from HIS account.

## 5 · I communicate with Leuconnect



- I personalize my public profile.
- I access my secured message box.
- I choose to be in relation with other e-cohort members.
- I keep in touch with Leuconnect actors.

## Who is Leuconnect for?

### For patients and scientists actively participating in Research

Leuconnect is for patients with leukodystrophy and their relatives.

Leuconnect is also for the whole scientific community to conduct clinical studies from the platform.



## How does Leuconnect works?

### A secure tool easy to use

**You can access a public news page.**

The public page offers relevant information on the understanding of disease mechanisms, ongoing clinical studies and trials, and advances in leukodystrophy research. From this public page you can join the “e-cohort”. The e-cohort will be followed over time to gain knowledge on leukodystrophy progression.

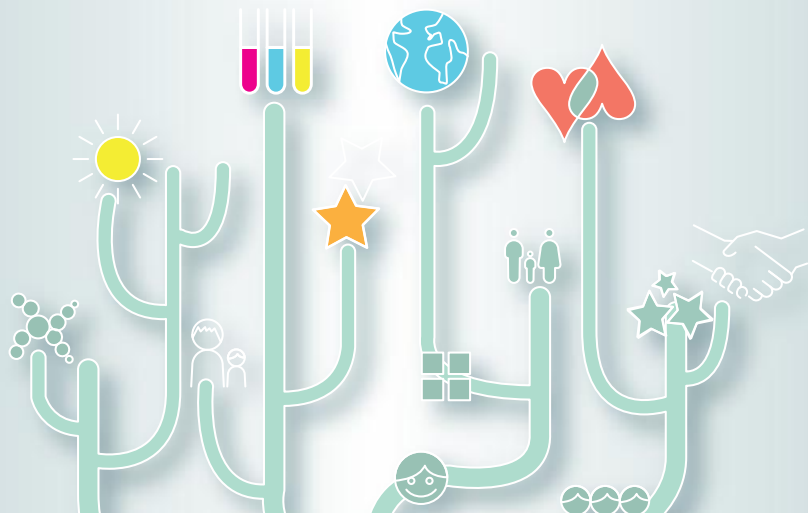
**You have access to a private interface.**

From your private account, you can apply for clinical studies listed on the site or be easily contacted by a health professional to participate. You can, on your account, complete your administrative and medical personal information, be informed of your inclusion in a study (if the criteria defined in the study protocol are met), sign regulatory documents online and complete study questionnaires.

## Communicate with Leuconnect

### A communication interface personalized

The private interface offers the option to access a secure messaging tool allowing them to be connected anonymously, and after accepting the option, to discuss common issues related to the disease.



## ELA International: guarantees

### Autonomy

Leuconnect offers you the option to be an actor of research. Data are anonymized. Access conditions and right to withdraw are assembled in the general conditions of use.

### Security

Access to the Leuconnect platform is highly secure. All your personal data is stored by a French Ministry of Health certified host (Almerys). Health professionals use a strong authentication mechanism. They access your personal data within the limits defined by the regulations in force.

### Responsibility. The proof of trust

ELA exists in France, Germany, Belgium, Spain, Italy, Japan, Luxembourg, the Indian Ocean and Switzerland. ELA International has the vocation to federate these different associations to act together against the disease.

# ELA engagement

*“ELA has always been concerned with putting patients at the center of all its concerns and decisions. Leuconnect goes in this direction. This project is perfectly in line with this desire to enable patients and their families to become involved in research and thus accelerate getting results.”*

*Guy Alba,  
President of Ela International*

With Leuconnect, ELA international reinforces its engagement in promotion of research on leukodystrophies. In addition to facilitate the conduct of clinical studies, with Leuconnect, ELA give you the means to become an active participant of research.



[www.leuconnect.com](http://www.leuconnect.com)