



Dr. Florent Colin - colin@igbmc.fr
Pr. Jean-Louis Mandel - jlmandel@igbmc.fr

GenIDA

Genetics of Intellectual Disabilities and Autism Spectrum Disorders

An online study for patients, families and professionals

Create your account here: <https://genida.unistra.fr>

What is GenIDA ?

The GenIDA project has been initiated in 2014 by Pr. Jean-Louis Mandel at the Institut of Genetics and Molecular and Cellular Biology in Strasbourg, France, and aims at:

- Collecting medical longitudinal data on intellectual disabilities (ID) and autism spectrum disorders (ASD) **with a genetic origin.**
 - The website allows a direct participation of **families / relatives**
 - A semi-structured **questionnaire** understandable by lay persons and a limited number of questions with open answers about the most important manifestations that affect health and quality of life allow to collect the relevant data. *(Available in English, French, Dutch, German and Portuguese)*
- Allowing families / relatives concerned by the same given genetic cause of ID or ASD to exchange information through a secured platform.
- Allowing health professionals and patients' families to access to useful **medical anonymised informations** previously validated by reference professionals who are members of the project scientific and ethics committee.



Who can join *GenIDA*?

- **Parents and relatives**, you can register on the GenIDA website if:
 - One of your child, brothers, sisters or close relatives has manifestations of **intellectual disabilities** (ID) and / or **autism** spectrum disorders (ASD).
 - She/he has been diagnosed has **carrier of a genetic mutation** affecting a single gene or a small chromosomal segment and it has been concluded by a specialist that **this mutation is responsible** of the ID or ASD.
 - You are interested in providing and updating health information that will be kept anonymous and that will help gaining better knowledge on the genetic condition that affects you child, sister, brother or relative.
- You're a **clinician** and have in charge one or numerous patients affected by ID and/or ASD, or more generally you're a **professional** with a interest for this kind of pathology.
 - You can help the project by suggesting your patients to register.
 - You will have an access to anonymised medical data for the genetic cause of ID / ASD that you're interested in.

What will *GenIDA* provide?

- Generate, for specific genetic forms of ID/ASD, novel and medically significant knowledge that can be translated in **improved personalized care**.
- **Empower patients / families** by giving them the possibility to participate and to have a feedback on the health characteristics of their specific genes defects.
- Promote **interactions** between patients/families concerned by a given gene defect and between patients and professionals, at the international level.
- Be a **platform for professionals** who wish to submit specific questionnaires or recruit patients for clinical studies.

Such proposals will be screened by a international scientific and ethics committee (*that includes patients representatives*), that will control medical interest, feasibility and respect of ethical rules.

Follow and like us on Facebook  www.facebook.com/GenIDaproject/

This project is financially supported by the Institut d'Etudes Avancées de l'Université de Strasbourg (USIAS) and the Fondation de l'Université de Strasbourg (Fonds Roche)