



CLINICAL TRAILS AND ETHICS

Virtual SYMPOSIUM ELA International

Saturday November 27th - 3:00 PM - 6:00 PM (CET)

Hosted by Pr. **Grégoire Moutel**, Expert in Ethical issues, University Hospital of Caen, France

Introduction: **Guy Alba**, President of ELA International, Luxembourg

3:05 PM – 4:30 PM SESSION 1

Better patient involvement in research program, particularly in the preparation of clinical trials

Overview through two examples: gene therapy trial for metachromatic leukodystrophy, and drug trial in adrenomyeloneuropathy

3:05 PM Presentations and testimonials

Valeria Calbi, Investigator, St Raphaël Milan Hospital, Italy

Emmanuel Binet, family, France

Céline & Jean Hooge, family, France

Florian Eichler, Investigator, MassGeneral Hospital for Children, USA

Jean-François Platarotti, family, France

Sébastien Mariotti, family, France

3:45 PM Panel DISCUSSION

4:10 PM QUESTIONS / ANSWERS Open to all participants

4:30 PM BREAK

4:45 PM – 5:50 PM SESSION 2

Ethics of partnerships and benefits to the patient community

Towards equitable sharing of patents, of their exploitation, of data, of results exploitation, and re-investment in research

4:45 PM Presentations and testimonials

Guy Alba, ELA International, Luxembourg

Frédéric Sedel, Medday, France

Nathalie Cartier, ICM, France

Marjo van der Knaap, University of Amsterdam VUmc, The Netherlands

Bruno Flesselles, Expert in intellectual property, France

5:30 PM Panel DISCUSSION with **Gaël de Miomandre**, President of ELA Belgique

5:40 PM QUESTIONS / ANSWERS Open to all participants

5:50 PM CONCLUSION

Summary of key points and perspectives: **Grégoire Moutel & Guy Alba**