



EU4Health Programme, Grant Agreement nr. 101085231

WEBINAR T&T - ERN ITHACA Webinar #6 2023

Webinars #6 on Tuesday 21st of March 5pm-6.30 pm French time “ERN ITHACA Innovation in Newborn Screening across Europe “

Chaired by Pr Laurence FAIVRE, Workgroup Teaching and Education

With this webinar about newborn screening (NBS), we will present two European pilot programs to extend NBS with a genomic approach, discussing on technical, clinical, and ethical aspects. We will also present an innovative research project to accelerate rare disease diagnosis, with a pillar focused on NBS, and the voice of patients. Finally, we will briefly present a research project aiming at studying the acceptability of the expending NBS in a European country.

Welcome and Introduction – (5.00-5.05 pm)

- Pr. Laurence Faivre, Centre de Génétique et Centre de Référence Anomalies du Développement et Syndromes Malformatifs, Dijon (France)

Topic 1 - Presentation of 2 European NGS pilot projects in Europe (5.05-5.35 pm)

- The UK 100.000 genome project in newborn screening
Dr. David Bick, Newborn Genomes Programs at Genomics England, London (England)
- The Netherland pilot NGS extended newborn screening
Dr. Marcel Nelen, Genome Diagnostics Center UMC, Utrecht (Netherlands)

Topic 2 - Presentation of the newborn screening axis of the Screen4Care project (5.35-5.50 pm)

- Pr. Alessandra Ferlini, Medical Genetics Unit, S.Anna University Hospital, Ferrara (Italy)

Topic 3 - The Eurordis position statement on extended newborn screening (5.50-6.05 pm)

- Gulcin Gumus, Research & Policy Project Manager, EURORDIS, Barcelone (France)

Topic 4 -The SeDeN project: a study of the acceptability of professionals and the population in France before setting up a pilot project (6.05-6.15 pm)

- Dr. Camille Level, Study engineer in health economics at Dijon Bourgogne University Hospital, Dijon (France)

Discussion time (6.15-6.30 pm)

Conclusion with speakers and moderator

Register

We would appreciate if you could fill out the Form if you plan to participate before March 17th.

<https://forms.office.com/e/zzkBPKbhnN>

Webinar Team Link to connect

https://teams.microsoft.com/l/meetup-join/19%3ameeting_Mzc5ZjEyM2YtODhmYi00NjdmLTlkNzgtYmYwMmZlYWQ2YjUy%40thread.v2/0?context=%7b%22Tid%22%3a%222461c129-d44f-406d-a778-d1a3c4c1527c%22%2c%22Oid%22%3a%223fe3bbab-4860-4b0b-bdc7-6ebc8a2f8f7b%22%7d