SJD Sant Joan de Déu Institut de Recerca

eYPAGnet

Children and Young People's Rights in Health Research

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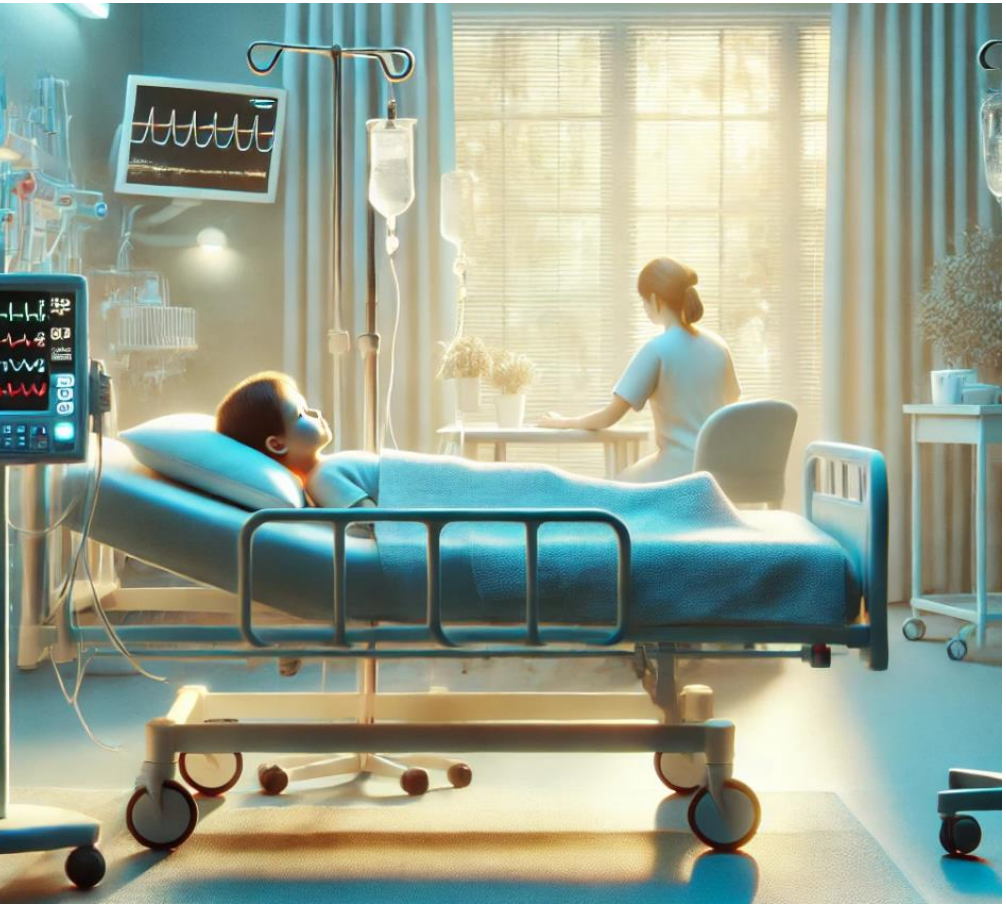
Brussels - 20th of November, 2024



Paediatric rare diseases

75 % affect children

1. Are life-threatening,
2. Chronically debilitating and,
3. Have a low prevalence.

01

DIAGNOSE

Average time: 4.7 years

02

TREATMENT AVAILABILITY

95% of these conditions have no treatment

03

TREATMENT ACCESS

What is your postcode?

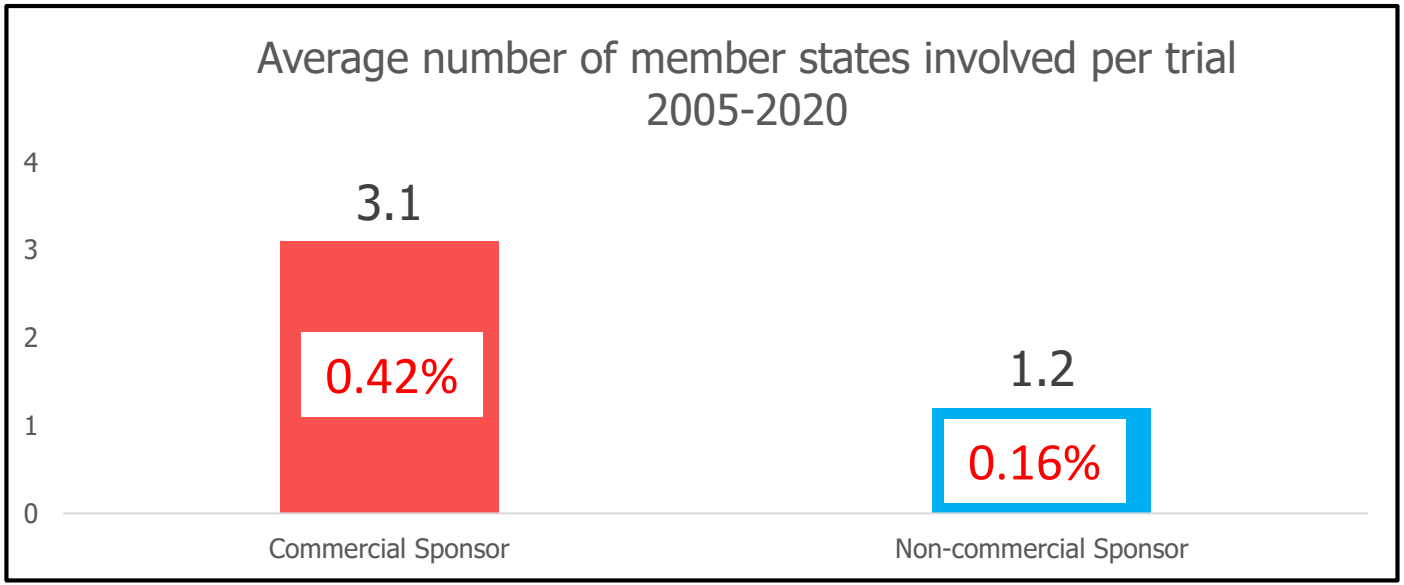
04

CLINICAL TRIALS

Only possible therapeutic opportunity

Challenges in paediatric clinical research

- **Scientific design of these projects**
- **Access to clinical trials.**



Source: Accelerating Clinical Trials in the EU (ACT EU)- Report


Young citizens represent
21%
of the world's population
Young citizens represent
100%
of the future of a healthy world

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eYPAGnet

Funder teams:
- Generation R
- Kids France
- ScotCRN
- Kids Barcelona

+ 30 YPAGs accross Europe

EnprEMA
European network of paediatric research at the European Medicines Agency

eYPAGnet

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European YPAG Network

eYPAGnet works in partnership with patients, children, families, industry and academic researchers to provide patient and public involvement advice and solutions to ensure paediatric clinical research is patient centred.

LEARN MORE

Join the Network

The European Young Person's Advisory Group Network (eYPAGnet) welcomes new members.

FIND OUT MORE

eYPAGnet initiatives:

1. Involving children and young people in the design of health research initiatives in a meaningful way.

EnprEMA
European network of paediatric research at the European Medicines Agency

eYPAGnet initiatives:

2. Ensuring children's rights in accessing clinical trials.

EnprEMA
European network of paediatric research at the European Medicines Agency

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Children should have a voice in health research in Europe!

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We all have rights!

Nothing about us, without us!

Thank you so much!

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