Newsletter Issue #1

Welcome …

to the 1st issue of our **Screen4Care** newsletter! With this newsletter series, we will take you with us on our exciting journey to accelerate rare disease diagnosis through genetic newborn screening and digital technologies.

We will give you an update on our latest progress along with numerous links for more information about our project. **Have fun reading!**

Meetings

1st Screen4Care Consortium Meeting

On 6th and 7th March 2023, the **Screen4Care** consortium gathered for their 1st Consortium Meeting (hybrid) hosted by the University of Ferrara in Ferrara, Italy.

Besides discussing the project's progress and preparing for upcoming activities, the team could enjoy a delightful Italian-style dinner and immerse themselves in the Renaissance culture of Ferrara.

Summary of the 1st consortium meeting

In the Spotlight

Podcast Feature

The **Screen4Care EFPIA Lead, Dr. Nicolas Garnier**, joined the Dazzle4Rare Podcast hosted by Kimberly Thomas-Tague for an engaging discussion on newborn screening.
The episode sheds light on this programme's developments, ethical considerations, and potential, highlighting the pivotal role that **Screen4Care** plays in bringing hope to rare disease communities.

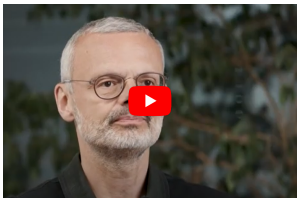
Dive into the podcast episode

Voices of Screen4Care

Screen4Care's consortium is composed of diverse set of academic and industry partners from **14 countries**. In the following series of videos, our partners introduce themselves, their organisation, and their role in **Screen4Care** in more detail.

Project Lead **Nicolas Garnier** from Pfizer explains Screen4Care's mission

Project Coordinator **Alessandra Ferlini** introduces herself and Screen4Care



Thomas Bols

Janbernd Kirschner

Ivo Gut

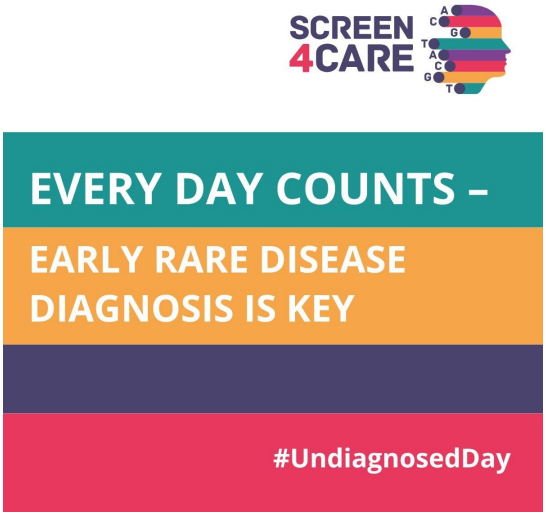
Discover the voices of Screen4Care

Screen4Care on Social Media

Newborn Screening Awareness Month 2023: #Screen4Reasons

International Day of Women and Girls in Science 2023: Women4Screen4Care

World Health Day 2023



Undiagnosed Day 2023

Rare Disease Day 2023

Events & Conferences

Duchenne Parent Project

On 16th - 18th February 2023, members of the **Screen4Care** consortium participated in the 20th edition of the **International Conference on Duchenne and Becker Muscular Dystrophy**, organised by Parent Project APS in Rome, Italy.
A notable moment: the poster presented by the **Screen4Care** consortium was selected among the top posters at the event!

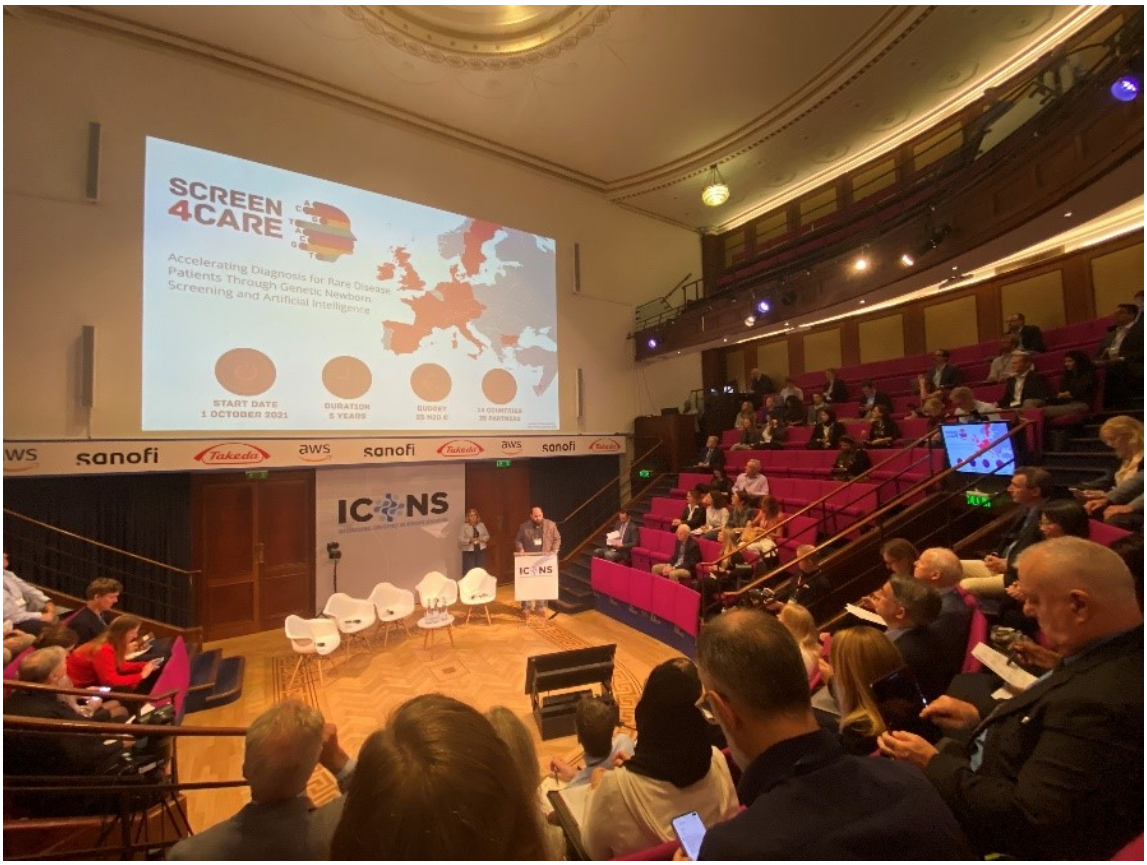
Frontiers in Pediatric Genomic Medicine 2023

On 19th - 20th April 2023, the **Screen4Care** consortium was represented by the Scientific Project Coordinator, **Prof. Alessandra Ferlini**, and the EFPIA Lead, **Dr. Nicolas Garnier**, in San Diego, California.

Click here for more information

ICoNS Conference 2023

On 5th - 6th October 2023, the Scientific Project Coordinator, **Prof. Alessandra Ferlini,** and the EFPIA lead, **Dr. Nicolas Garnier**, presented the Screen4Care project at the second Annual Conference of the ICoNS consortium at the Royal Institution in London, UK. The event offered an exceptional opportunity for fruitful discussions and networking among several internal initiatives focused on genetic newborn screening.



Click here for more information

Other Events & Conferences

16th International Congress of Paediatric Laboratory Medicine

Date: 20th May 2023, Venue: Rome, Italy

3rd International Conference on Rare Diseases: Greek Chapter

Date: 28th February 2023, Venue: Virtual

ERN-ITHACA Webinar #6 "Innovation in Newborn Screening across Europe"

Date: 21st March 2023, Venue: Virtual

XIV National Conference for Rare Diseases and Orphan Drugs

Date: 29th-30th September 2023, Venue: Plovdiv, Bulgaria

Publications

Rare diseases' genetic newborn screening as the gateway to future genomic medicine: the Screen4Care EU-IMI project

Challenges in mapping European rare disease databases, relevant for ML-based screening technologies in terms of organizational, FAIR and legal principles: Scoping review

Newborn Screening by Genomic Sequencing: Opportunities and Challenges

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Eurice - European Research and Project Office GmbH

Heinrich-Hertz-Allee 1, 66386, St.Ingbert