

German Society for Neonatal Screening (DGNS) National Screening Report 2023

Brockow I, Blankenstein O, Ceglarek U, Ensenauer R, Fingerhut R, Gramer G, Hörster F, Holtkamp, U, Janzen N, Klein J, Lankes E, Lindner M, Maier E, Marzi C, Menzel A, Murko S, Nauck M, Odenwald B, Okun J, Rödel M, Röncke S, Röschinger W, Sommerburg O, Speckmann C, Winter T, Nennstiel U for the DGNS

Introduction

Newborn blood screening (NBS) is a population-based medical preventive measure aimed at the early and complete detection and quality-assured treatment of all newborns with one of currently 17 treatable target diseases, including cystic fibrosis. The regulations for the NBS program are specified in the Paediatrics Directive (“Kinder-Richtlinie”) formulated by the Federal Joint Committee (G-BA) [1]. Regular reporting has been consistently carried out since the year 2004 [2].

Methods

The reports are prepared by the DGNS e.V. in cooperation with the 11 German screening laboratories. The required data are collected annually in a standardized Access database, checked for plausibility, validated by experts and analyzed with SPSS® Statistics for Windows, Version 29.0, in accordance with the Paediatrics Directive and quality criteria.

Results

The report provides a comprehensive statistical summary of disease-related screening numbers, recall rates (i. e. the proportion of abnormal [positive] findings), and confirmed diagnoses for the year 2023. In addition, it provides data on process quality for the entirety of Germany. The number of recorded first-time screenings (687,424) was slightly lower than the number of births (692,989), resulting in a cumulative screening rate of 99.2 % of all newborns. A total of 674,458 (98.1 %) newborns had their first screening after 32 weeks of gestation and 36 hours of life. The recall rate was 0.6 % (n=3,841). Of the 17,448 follow-up cards requested, 15,486 (88.8%) were returned. Approximately 1 in every 730 children is diagnosed with one of the target diseases.

Conclusion

The DGNS reports show that, while the NBS is being successfully implemented in Germany, there is still room for improvement [3, 4].

1 Paediatrics Directive – “Kinder-Richtlinie”, Federal Joint Committee on the Early Detection of Diseases in Children; https://www.g-ba.de/downloads/62-492-3691/Kinder-RL_2024-03-21_iK-2024-07-13.pdf last access 26.03.2025

2 <https://www.screening-dgns.de/reports.php>. Last access 26.03.2025

3 Lüders A, Blankenstein O, Brockow I, Ensenauer R, Lindner M, Schulze A, Nennstiel U, on behalf of the screening laboratories in Germany: Neonatal screening for congenital metabolic and endocrine disorders—results from Germany for the years 2006–2018. Dtsch Arztebl Int 2021; 118: 101–8. DOI: 10.3238/arztebl.m2021.0009

4 Nennstiel U, Odenwald B, Throner V, Blankenstein O, Vieth A, Ratzel R, Coenen M, Brockow I. Neugeborenen-Screening aus Trockenblut (NBS) in Deutschland: Status quo und Vorstellung eines Konzeptes zur Weiterentwicklung. Bundesgesundheitsblatt 2023 Nov;66(11):1195-1204. doi: 10.1007/s00103-023-03771-8.