German Society for Neonatal Screening (DGNS)

National Screening Report 2022

Brockow I, Blankenstein O, Ceglarek U, Ensenauer R, Fingerhut R, Gramer G, Hörster F, Janzen N, Klein J, Lankes E, Lindner M, Murko S, Nauck M, Rödel M, Rönicke S, Röschinger W, Sommerburg O, Speckmann C, Nennstiel U for the DGNS

Introduction

Newborn blood screening (NBS) is a population-based medical preventive measure with the aim of early and complete detection and quality assured therapy for all newborns with treatable target diseases. Since October 2021, sickle cell disease (SCD) and spinal muscular atrophy (SMA) have been included in NBS as target diseases number 16 and 17. The regulations for the NBS program are specified in the Paediatrics Directive ("Kinder-Richtlinie") by the Federal Joint Committee (G-BA) [1]. Since 2004, reporting has been done regularly [2].

Methods

The report was 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 26.0, according to the Paediatrics Directive and quality criteria.

Results

The report provides a comprehensive statistical summary of disease-related screening numbers, recall rates (proportion of abnormal [positive] findings) and confirmed diagnoses for the year 2022 and provides data on process quality for all of Germany. The number of recorded first-time screenings (732,791) is slightly lower than the number of births (738,819). Cumulatively, 99.2 % of all newborns were screened, 716,861 (97.8 %) newborns had their initial screening after 32 weeks of gestational age and 36 hours of life. The recall rate was 0.6 % (n=4,372). Of the 20,635 requested subsequent cards 18,909 (91,6 %) were performed. The new target diseases SCD (1:5,432) and SMA (1:7,860) have a relatively high prevalence, and very low false positive screening results.

Conclusion

The DGNS reports show that NBS is successfully implemented in Germany [3]. It can be assumed that almost all newborns are screened. However, there is still room for improvement.

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1 Paediatrics Directive – "Kinder-Richtlinie", Federal Joint Committee on the Early Detection of Diseases in Children; https://www.g-ba.de/downloads/62-492-2675/Kinder-RL_2021-09-16_iK-2022-01-01.pdf. Zuletzt abgerufen am 27.05.2024

2 https://www.screening-dgns.de/reports.php. Last access 27.05.2024

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