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Invited Review

A drop of blood: newborn heel blood screening programmes, innovations, and contrary voices in Türkiye and The World

Heel Blood Screening: Innovations and Oppositions

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Abstract

Congenital metabolic diseases are mostly autosomal recessive diseases that can be detected in the neonatal period and can lead to disability and even death if left untreated. Screening programmes for early diagnosis are organised worldwide to prevent such diseases. Heel Blood Screening (HBS), which is widely used in Türkiye and in the world, is an example of this. In our country in Türkiye, HBS is performed for phenylketonuria, biotidinase deficiency, cystic fibrosis, hypothyroidism, adrenal hyperplasia and spinal muscular atrophy. However, in recent years there has been opposition to heel prick screening among some people for different reasons. For families, navigating the abundance of available health information and making informed decisions is becoming increasingly complex. Today, when the influence of the media is stronger than ever, parents are exposed to so much information, opinions and messages about what they 'should' or 'should not' do about their children's health that it is difficult to distinguish right from wrong.

Keywords: Newborn, Heel Blood, Screening, Differences, Innovations, Oppositions

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INTRODUCTION

Congenital metabolic diseases are mostly autosomal recessive diseases that can be detected in the neonatal period and lead to disability and even death if left untreated (1). According to World Health Organization (WHO) data, 3 out of every 100 children born in the general population have congenital anomalies due to any cause. In addition, in a study conducted in 2018, it was found that the cause of death in newborns was consanguineous marriage in 25.4% of cases, and the most common cause of death in cases with consanguineous marriage was first-degree cousin marriage (46.2%). In Türkiye, 300.000 newborns die for this reason every year (2, 3).

Screening is a public health approach that aims to prevent disease development by detecting asymptomatic patients at an early stage of the disease. Some of the genetic and metabolic diseases that hinder mental and physical development can be detected and treated at an early stage with blood samples taken by heel blood screening (HBS) in the first forty-eight hours of newborns' lives. HBS, defined with the slogan 'One drop of heel blood, no more tears', is one of them. HBS in newborns is a health procedure for the diagnosis of metabolic, endocrinological or genetic disorders that may not have phenotypic and functional symptoms but require rapid intervention. Family education, appropriate treatment and follow-up are part of the disease management process. In Türkiye, capillary dry blood is analysed for phenylketonuria (PKU), biotidinase deficiency (BD), cystic fibrosis (CF), congenital hypothyroidism (CH), congenital adrenal hyperplasia (CAH) and spinal muscular atrophy (SMA) (4).

History of Heel Blood Screening in the World and in Türkiye

HBS, also known as the Gutherie test, was developed in the United States of America (USA) in 1961 by Dr Robert Gutherie at the Buffalo Children's Hospital to screen for PKU. The first official newborn PKU screening programme was initiated in Massachusetts in 1962. The program was implemented in thirty-two US states by 1965. Galactosemia was the second disease detected by the Gutherie test. In 1973 screening methods for CH were developed and in 1974 screening programme was initiated in the Canadian province of Quebec. These developments were followed by maple syrup urine disease, CAH and BD. Other countries followed this innovation initiated in the USA. For example, screening for PKU was introduced in the Canadian province of Alberta in 1967, in the UK in 1969 and in the Netherlands in 1974. In these countries, the test was included in secondary screening for CH. The subsequent development of tandem mass spectrometry enabled the identification, quantification and elucidation of the molecular structure of compounds in samples. In 1990, this measurement method was integrated into the newborn screening programme (NSP), enabling the identification and quantification of the acyl carnitine profile and the detection of organic aciduria. This facilitated the detection of amino acid disorders. With this method, more than thirty metabolic disorders were added to the NSP (5-9).

Newborn screening programmes in Türkiye started with PKU screening in 1983 and became a national programme in 1994. With the addition of CH to PKU screening in 2006, the name of the programme was changed to the National Newborn Screening Programme (NNSP). Later, BD was added in 2008, CF in 2015, CAH in 2017 and finally SMA in 2022. Currently, comprehensive screening programmes are offered free of charge by the Ministry of Health in family health centres (10).

With advances in technology and screening methods, the number of diseases screened has increased. The diseases included in screening vary from country to country. While 6 diseases are screened in Türkiye, different screening strategies are applied in other countries. For example, 51 diseases are screened with HBS in New York, USA, 40 in Italy, 32 in Australia, 26 in Norway, Ontario, Canada and the Netherlands, 19 in Germany and Denmark, 16 in Saudi Arabia, 12 in Israel and 9 in the UK. These diseases are mostly genetic, metabolic and immune

system diseases. The diseases screened by HBS in these countries are shown in Table 1 (11-23).

Objectives of the Expanded Newborn Screening Program in Türkiye

The report of the Turkish Grand National Assembly Research Commission published in March 2020 stated that in addition to screening for 6 diseases, 32 more diseases are targeted to be added to expand the scope of screening. These diseases include genetic and metabolic diseases. Metabolic Diseases Targeted to be Included in the HBS Programme in Türkiye are shown in Table 2 (24).

Table 1. Diseases Screened by Heel Blood in Different Countries

DENMARK	Medium-Chain Acyl-CoA Dehydrogenase Deficiency, Very Long-Chain Acyl-CoA Dehydrogenase Deficiency, Long-Chain 3-Hydroxyacyl-CoA Dehydrogenase Deficiency / Trifunctional Protein Deficiency, Carnitine Transporter Deficiency, Phenylketonuria, Hereditary Tyrosinemia Type 1, Argininosuccinate Lyase Deficiency, Maple Syrup Urine Disease, Methylmalonic Acidemia, Propionic Acidemia, Isovaleric Acidemia, Glutaric Acidemia Type 1, Holocarboxylase Synthetase Deficiency, Congenital Hypothyroidism, Congenital Adrenal Hyperplasia, Cystic Fibrosis, Severe Combined Immunodeficiency, Tetrahydrobiopterin Deficiency, Hyperphenylalaninemia, Multiple Acyl-CoA Dehydrogenase Deficiency, Spinal Muscular Atrophy, Galactose-1-Phosphate Uridyltransferase Deficiency, Homocystinuria, Mucopolysaccharidosis Type I-Hurler, Pompe Disease, Adrenoleukodystrophy.
UNITED KINGDOM	Cystic Fibrosis, Sickle Cell Disease, Congenital Hypothyroidism, Phenylketonuria, Medium-Chain Acyl-CoA Dehydrogenase Deficiency, Maple Syrup Urine Disease, Isovaleric Acidemia, Glutaric Acidemia Type 1, Homocystinuria.
ISRAEL	Phenylketonuria, Congenital Hypothyroidism, Congenital Adrenal Hyperplasia, Severe Combined Immunodeficiency, Maple Syrup Urine Disease, Homocystinuria, Tyrosinemia Type 1, Methylmalonic Acidemia, Propionic Acidemia, Glutaric Acidemia Type 1, Medium-Chain Acyl-CoA Dehydrogenase Deficiency, Very Long-Chain Acyl-CoA Dehydrogenase Deficiency, Galactose-1-Phosphate Uridyltransferase Deficiency.
ITALY	Phenylketonuria, Homocystinuria, Disorders of Biopterin Regeneration / Biosynthesis, Tyrosinemia Type 1, Tyrosinemia Type 2, Tyrosinemia Type 3, Maple Syrup Urine Disease, Cystathionine Beta-Synthase Deficiency, Methylenetetrahydrofolate Reductase Deficiency, Galactosemia, Isovaleric Acidemia, Beta-Ketothiolase Deficiency, HMG-CoA Lyase Deficiency, Propionic Acidemia, Methylmalonic Acidemia Mutase Type, Cobalamin C Deficiency, Cobalamin D Deficiency, 2-Methylbutyrylglutaconic Aciduria, Methylmalonyl-CoA Mutase Deficiency, 3-Methylcrotonyl-CoA Carboxylase Deficiency, Citrullinemia Type 1, Carnitine Transporter Deficiency Type 2, Argininosuccinate Synthetase Deficiency, Argininosuccinate Lyase Deficiency, Citrullinemia Type 2, Carnitine Palmitoyltransferase 1 Deficiency, Carnitine-Acylcarnitine Translocase Deficiency, Carnitine Palmitoyltransferase 2 Deficiency, Very Long-Chain Acyl-CoA Dehydrogenase Deficiency, Trifunctional Protein Deficiency, Long-Chain 3-Hydroxyacyl-CoA Dehydrogenase Deficiency, Medium-Chain Acyl-CoA Dehydrogenase Deficiency, Short-Chain 3-Hydroxyacyl-CoA Dehydrogenase Deficiency, Glutaric Acidemia Type 2 / Multiple Acyl-CoA Dehydrogenase Deficiency, Glycine N-Methyltransferase Deficiency, Methionine Adenosyltransferase Deficiency, S-Adenosylhomocysteine Hydrolase Deficiency, 3-Methylglutaconic Aciduria, 3-Methylcrotonyl-CoA Carboxylase Deficiency, Isobutyryl-CoA Dehydrogenase Deficiency, Short-Chain Acyl-CoA Dehydrogenase Deficiency.

Table 1. Diseases Screened by Heel Blood in Different Countries	
AUSTRALIA	Argininemia or Arginase Deficiency, Argininosuccinic Aciduria, Citrullinemia, Tyrosinemia Type 1, Homocystinuria, Maple Syrup Urine Disease, Phenylketonuria, Pterin Defects, Tyrosine Aminotransferase Deficiency, Beta-Ketothiolase Deficiency, Cobalamin C Defect, Glutaric Acidemia Type 1, Holocarboxylase Synthetase Deficiency, 3-Hydroxy-3-Methylglutaryl-CoA Lyase Deficiency, Isobutyryl-CoA Dehydrogenase Deficiency, Isovaleric Acidemia, Methylmalonic Acidemias, Propionic Acidemia, 2-Methylbutyryl-CoA Dehydrogenase Deficiency, 3-Methylglutaconyl-CoA Hydratase Deficiency, Carnitine-Acylcarnitine Translocase Deficiency, Carnitine Transporter Defect, Carnitine Palmitoyltransferase I Deficiency, Carnitine Palmitoyltransferase II Deficiency, Long-Chain 3-Hydroxyacyl-CoA Dehydrogenase Deficiency, Medium-Chain Acyl-CoA Dehydrogenase Deficiency, Multiple Acyl-CoA Dehydrogenase Deficiency, Short-Chain 3-Hydroxyacyl-CoA Dehydrogenase Deficiency, Trifunctional Protein Deficiency, Very Long-Chain Acyl-CoA Dehydrogenase Deficiency, Cystic Fibrosis, Congenital Hypothyroidism, Galactosemia.
NORWAY	Methylmalonic Acidemia/Propionic Acidemia, Propionic Acidemia, Carnitine Deficiency, Glutaric Acidemia Type 1 (Infant), Maple Syrup Urine Disease, Cystathionine Beta-Synthase Deficiency, Tyrosinemia Type 1, Hyperammonemia Syndrome, HMG-CoA Lyase Deficiency, Beta-Ketothiolase Deficiency, Biotinidase Deficiency, Carnitine Transporter Deficiency, Carnitine Palmitoyltransferase 1A Deficiency, Medium-Chain Acyl-CoA Dehydrogenase Deficiency, Carnitine Palmitoyltransferase 2/Carnitine-Acylcarnitine Translocase Deficiency, Very Long-Chain Acyl-CoA Dehydrogenase Deficiency, Long-Chain Acyl-CoA Dehydrogenase Deficiency, Trifunctional Protein Deficiency, Multiple Acyl-CoA Dehydrogenase Deficiency / Glutaric Acidemia Type 2.
UNITED STATES OF AMERICA (NEW YORK)	2-Methyl-3-Hydroxybutyryl-CoA Dehydrogenase Deficiency, 2-Methylbutyryl-CoA Dehydrogenase Deficiency, 2,4-Dienoyl-CoA Reductase Deficiency, 3-Hydroxy-3-Methylglutaryl-CoA Lyase Deficiency, 3-Methylcrotonyl-CoA Carboxylase Deficiency, 3-Methylglutaconic Acidemia, Type 1, Adrenoleukodystrophy, Argininemia, Argininosuccinic Acidemia Deficiency, Beta-Ketothiolase Deficiency, Biotinidase Deficiency, Carnitine Acylcarnitine Translocase Deficiency, Carnitine Palmitoyltransferase 2 Deficiency, Carnitine Palmitoyltransferase 1 Deficiency, Carnitine Uptake Defect, Citrullinemia, Cobalamin A,B Coenzyme Deficiency, Cobalamin C, D Coenzyme Deficiency, Congenital Adrenal Hyperplasia, Congenital Hypothyroidism, Cystic Fibrosis, Galactosemia, Glutaric Acidemia, Type I, Guanidinoacetate Methyltransferase Deficiency, Homocystinuria, Hypermethioninemia, Isobutyryl-CoA Dehydrogenase Deficiency, Isovaleric Acidemia, Krabbe Disease, Long-Chain 3-Hydroxyacyl-CoA Dehydrogenase Deficiency, Malonic Acidemia, Maple Syrup Urine Disease, Medium-Chain 3-Ketoacyl-CoA Thiolase Deficiency, Medium-Chain Acyl-CoA Dehydrogenase Deficiency, Medium / Short-Chain 3-Hydroxyacyl-CoA Dehydrogenase Deficiency, Methylmalonyl-CoA Mutase Deficiency, Mucopolysaccharidosis Type I, Multiple Acyl-CoA Dehydrogenase Deficiency, Multiple Carboxylase Deficiency, Phenylketonuria, Pompe Disease, Propionic Acidemia, Severe Combined Immunodeficiency, Short-Chain Acyl-CoA Dehydrogenase Deficiency, Sickle Cell Disease and Other Hemoglobinopathies, Spinal Muscular Atrophy, Trifunctional Protein Deficiency, Tyrosinemia Type I, Tyrosinemia Type II, Tyrosinemia Type III, Very Long-Chain Acyl-CoA Dehydrogenase Deficiency.
SAUDI ARABIA	Phenylketonuria, Argininosuccinate Lyase Deficiency, Maple Syrup Urine Disease, Citrullinemia, Propionic Acidemia, Methylmalonic Acidemia, Glutaric Acidemia Type I, Isovaleric Acidemia, 3-Methylcrotonyl-CoA Carboxylase Deficiency, Medium-Chain Acyl-CoA Dehydrogenase Deficiency, 3-Hydroxy-3-Methylglutaryl-CoA Lyase Deficiency, Beta-Ketothiolase Deficiency, Galactosemia, Congenital Hypothyroidism, Congenital Adrenal Hyperplasia, Biotinidase Deficiency.

Table 1. Diseases Screened by Heel Blood in Different Countries	
CANADA (ONTORIO)	Argininosuccinic Acidemia, Biotinidase Deficiency, Carnitine Uptake Defect, Citrullinemia, Cobalamin A and B Defects, Congenital Adrenal Hyperplasia, Cystic Fibrosis, Galactosemia, Glutaric Acidemia Type 1, Guanidinoacetate Methyltransferase Deficiency, Homocystinuria, Hurler Syndrome, Isovaleric Acidemia, Long-Chain 3-Hydroxyacyl-CoA Dehydrogenase Deficiency, Maple Syrup Urine Disease, Medium-Chain Acyl-CoA Dehydrogenase Deficiency, Methylmalonic Acidemia, Phenylketonuria, Propionic Acidemia, Severe Combined Immunodeficiency, Hemoglobin SC Disease, Sickle Cell Anemia, Sickle Cell Beta-Thalassemia, Tri-functional Protein Deficiency, Tyrosinemia Type 1, Very Long-Chain Acyl-CoA Dehydrogenase Deficiency.
GERMANY	Congenital Adrenal Hyperplasia, Carnitine-Acylcarnitine Translocase Deficiency, Cystic Fibrosis, Carnitine Palmitoyltransferase I Deficiency, Carnitine Palmitoyltransferase II Deficiency, Glutaric Acidemia Type I, Hyperphenylalaninemia, Immunoreactive Trypsinogen, Isovaleric Acidemia, Long-Chain 3-Hydroxyacyl-CoA Dehydrogenase Deficiency, Trifunctional Protein Deficiency, Medium-Chain Acyl-CoA Dehydrogenase Deficiency, Maple Syrup Urine Disease, Phenylketonuria, Severe Combined Immunodeficiency, Very Long-Chain Acyl-CoA Dehydrogenase Deficiency.
NETHERLANDS	Congenital Adrenal Hyperplasia, Cystic Fibrosis, Congenital Hypothyroidism, Severe Combined Immunodeficiency, Sickle Cell Anemia, Hemoglobin H Disease, Beta-Thalassemia Major, 3-Methylcrotonyl-CoA Carboxylase Deficiency, Biotinidase Deficiency, Galactosemia, Glutaric Acidemia Type 1, HMG-CoA Lyase Deficiency, Isovaleric Acidemia, Maple Syrup Urine Disease, Medium-Chain Acyl-CoA Dehydrogenase Deficiency, Methylmalonic Acidemia, Mucopolysaccharidosis Type 1, Multiple CoA Carboxylase Deficiency, Phenylketonuria, Propionic Acidemia, Trifunctional Protein Deficiency / Long-Chain Hydroxyacyl-CoA Dehydrogenase Deficiency, Tyrosinemia Type 1, Very Long-Chain Acyl-CoA Dehydrogenase Deficiency.

Table 2. Diseases Targeted for Inclusion in the Heel Blood Screening Program in Türkiye	
Fatty Acid Oxidation Disorders	Medium-Chain Acyl-CoA Dehydrogenase Deficiency, Long-Chain Acyl-CoA Dehydrogenase Deficiency, Short-Chain Acyl-CoA Dehydrogenase Deficiency, Multiple Acyl-CoA Dehydrogenase Deficiency (Glutaric Acidemia Type II), Long-Chain Hydroxyacyl-CoA Dehydrogenase Deficiency, Trifunctional Protein Deficiency.
Carnitin Cycle Disorders	Carnitine Transporter Deficiency, Carnitine Palmitoyltransferase I Deficiency, Carnitine Palmitoyltransferase II Deficiency, Carnitine / Acyl Carnitine Translocase Deficiency.
Organic Acidemias	Methylmalonic Acidemia, Beta-Ketothiolase Deficiency, 3-Hydroxy-3-Methylglutaryl-CoA Lyase Deficiency, 3-Methylcrotonyl-CoA Carboxylase Deficiency, Isovaleric Acidemia, 3-Methylglutaconyl-CoA Hydratase Deficiency, 2-Methylbutyryl-CoA Dehydrogenase Deficiency, Isobutyryl-CoA Dehydrogenase Deficiency, Propionic Acidemia, Glutaric Acidemia Type I, 3-Ketothiolase Deficiency, Holocarboxylase Deficiency.
Urea Cycle Disorders	Argininosuccinate Synthase Deficiency, Argininosuccinate Lyase Deficiency, Arginase Deficiency.
Amino Acid Metabolism Disorders	Tyrosinemia, Homocystinuria, Tetrahydrobiopterin Deficiencies, Maple Syrup Urine Disease, Cobalamin Disorders, Methylene Tetrahydrofolate Deficiency

Current Developments in Newborn Screening

Immune Deficiency Panel

Severe Combined Immunodeficiency (SCID) is a large group of inherited diseases in which the development and function of the T cells of the adaptive immune system are impaired, causing babies to be born without a functioning immune system. These disorders are also called primary immunodeficiency disorders. Humoral immunodeficiencies start to show signs from the 6th month of life on average due to the protection of antibodies passed from the mother, whereas in cellular or combined immunodeficiencies, the child usually becomes symptomatic within the first 3 months. Secondary immunodeficiencies can occur at any stage of life depending on the underlying factor (25). The immunodeficiency panel in heel prick screening is a screening test that allows early diagnosis of SCID detected by a drop of blood sample. The panel, which was first launched in the USA in 2008, was implemented in 50 states until 2018. According to the data of the Primary Immunodeficiency Treatment Consortium, 94% of babies who are transplanted before the age of 3.5 months survive, while the survival rate drops to 50% in babies with active infection and those who are transplanted later (26, 27).

Immunological parameters such as T cell receptor excision circle (TREC), CD3+ T cells, CD4+ T cell new thymic migrants (CD4RTE) and lymphocyte proliferation are measured in the immunodeficiency panel. With these parameters, naive T cells produced by the thymus, the proportion of immature T cells, the response of T cells to cytokines and absolute lymphocyte count (ALC) are evaluated. Haematopoietic stem cell transplantation, gene therapy or enzyme replacement are initiated in diagnosed infants and improve the survival of infants with SCID (27).

X-linked Adrenoleukodystrophy

X-linked adrenoleukodystrophy (ALD) is a congenital metabolic disorder caused by a mutation in the ABCD1 gene on the X chromosome. This disease develops due to a defect in ABCD1, a peroxisomal transmembrane protein that transports very long chain fatty acids. ALD is characterised by adrenal insufficiency and white matter lesions in the brain and spinal cord. In 2013, the US state of New York was the first region to add ALD to its newborn screening panel. Following this, in 2015, it was recommended that ALD be added to the newborn screening panel in the Netherlands and a pilot study was initiated. The screening strategy in the Netherlands was planned to cover only male infants. The reason for this is that ALD is fatal in males if left untreated, but in females it is usually symptomatic between 40 and 60 years of age. Detection of ALD in newborn screening is performed by quantitative analysis of C26:0-LPC in heel blood samples by high-performance liquid chromatography-tandem mass spectrometry (HPLC-MS/MS). Increased levels of C26:0-LPC indicate a defect in peroxisomal beta-oxidation; however, this finding is not specific for ALD. Therefore, exon sequencing analysis of the ABCD1 gene is required for definitive diagnosis. Between 2010 and 2018, a total of 32 different states in the USA were included in the screening programme. In addition, ALD was included in the national NSP in the Netherlands, Georgia and Thailand. In 2021, pilot studies were initiated in Italy and Japan (28-30).

Mucopolysaccharidosis

Mucopolysaccharidosis (MPS) is a rare inherited lysosomal storage disease that results from the inability to degrade glycosaminoglycans (GAGs) due to lysosomal enzyme deficiencies. It constitutes 30% of all lysosomal storage diseases. This accumulation leads to progressive damage in various organs and systems. MPS is classified into different types depending on the enzyme deficiency and the clinical features of each type may vary (31). The rarity and heterogeneous clinical course of MPS cause difficulties in the diagnosis and treatment of the disease. Therefore, newborn screening is important in the early diagnosis of MPS.

In recent years, some countries have started to include MPS types in newborn HBS programmes. For example, Taiwan initiated a national screening programme for MPS I (Hurler syndrome) in 2015 and measured α-L-iduronidase enzyme activity by tandem mass spectrometry (MS/MS) (32). In 2017, the US state of Illinois initiated newborn screening for five lysosomal storage diseases, including mucopolysaccharidosis type I (MPS I). In this programme, MPS I screening was performed by measuring α-L-iduronidase enzyme activity in dried blood drop samples by MS/MS. In the first 15 months, 219,973 newborns were screened and one case of MPS I was detected (33). A pilot NSP for various lysosomal storage diseases, including MPS I, was conducted in New York State between 2013 and 2017. In this programme, enzyme activities were measured using MS/MS and 65,605 newborns were screened. The results showed that such screening is effective in detecting late-onset diseases (34).

Arguments Against Heel Blood Screening

For families, navigating the abundance of health information available and making informed decisions is becoming increasingly complex. Today, when the influence of the media is stronger than ever, parents are exposed to a plethora of information, opinions and messages about what they 'should' or 'should not' do regarding their children's health, making it difficult to distinguish between right and wrong. In this confusion of information, it is also observed that some families develop opposing attitudes towards newborn screening. In January 2025, the "Grand National Assembly of Türkiye Commission for the Investigation of Violence and Abuse Against Children" stated that the refusal to HBS has increased approximately five times compared to previous years. The reasons for this opposition include people's belief that heel blood is smuggled abroad and used for genetic changes, the belief that the state sells blood samples abroad, the belief that it causes drug addiction, that the pain felt causes developmental retardation and that the procedure causes infertility (35).

There are also those who think that families do not want to see their children crying and that the pain caused by this practice is more harmful than beneficial. Based on this pain, a study was conducted in India in 2017 to compare the pain caused by two different methods (lancet and 26-gauge needle) used in heel blood collection, which is frequently applied in newborns and described as a painful procedure among the public, to determine which of the lancet and 26-gauge needle is less painful and more tolerable. In infants followed up in the neonatal intensive care unit (NICU), pain levels were evaluated using the Preterm Baby Pain Profile (PBPP) score and the effects of both methods were examined. Heel blood collection using lancet resulted in shorter duration of crying in newborns compared to needle ($p = 0.03$). However, no statistically significant difference was found between the two methods in terms of PBPP scores assessing pain level ($p = 0.052$). Both methods provided adequate sampling (36).

In Türkiye, different reasons are put forward for opposition in perception operations using the powerful influence of social media and these reasons are supported by the public. To cite an example that has been on the agenda on social media; a citizen raised a question: 'Why are the reproductive points on the feet of newborn babies pierced when there is no difference between blood taken from the heel and blood taken from the arm, hand or vein?' and submitted his complaint to the Ministry of Health. He tried to support his opinion by referring to the Reflexology table created by Eunice Ingham, an American physiotherapist in the 1930s. The Ministry of Health responded to the complaint by stating that reflexology is a method of practice and that it has not been approved to have any effect on the diagnosis and treatment of diseases. In addition, he emphasised the difficulty of blood sampling in newborns and stated that heel blood is a method that is selected considering the anatomy and physiology of the baby and is accepted and applied all over the world. The social media post shared by the citizen received five thousand likes and one thousand retweets (37, 38).

Another opposing view was shared on social media in 2023, criticising HBS in newborns. In the post in question, it was claimed that the pain felt by babies during screening was ignored, psychological pressure was applied to parents and there was a risk of infection. He also characterised this practice offered by modern medicine as 'Rockefeller Medicine'. To support his theory, he gave the example of the refusal of 'Amish people' to undergo screening. He argued that those who refused to be screened were healthier. This controversial post attracted attention on social media; it received a thousand likes and a thousand retweets, creating interaction (39). In addition to these public discourses, unfortunately there are also health professionals who support the opposition. They claim that HBS is unnecessary, that this is the reason why children walk on tiptoe, and that HBS can lead to phobias in the future (40).

Overview of Heel Blood Screening in Migrant Families Living in Türkiye and in the World

In 2022, forty-one migrant women registered at the Migrant Health Centre, a primary health care institution in Istanbul, were interviewed to learn migrant women's perspectives on HBS. Screening knowledge and attitudes were questioned during the interviews. It was observed that the participants had heard of the programme and understood its importance for early diagnosis. However, it was observed that almost all of the participants did not have information about the content of the programme and the diseases screened. While most participants felt that the benefits of the programme were high, some were more hesitant to accept the test. At the end of the interview, all participants agreed to have heel blood taken from their children (41).

The NSP is a non-compulsory practice in the Netherlands and is carried out with the consent of the families. A survey study was conducted in the Netherlands with parents who participated and did not participate in the screening programme between 2019-2021. In the study, parents' views on NSP, their experiences with the HBS process, and their suggestions for expanding the scope of NSP were evaluated. Socio-cultural characteristics of non-participating families were focussed on. The total number of parents who completed the questionnaire was 852, of whom 804 participated in the NSP and 48 did not participate. It was found that the participants who had the screening had higher levels of education compared to the general population than those who did not. Parents who did not participate in NSP were more likely to be 'fathers' (19% vs. 8%, p=0.3). These parents were found to have strong religious beliefs and were more prone to alternative medical practices. Parents who did not participate generally stated that they did not plan to vaccinate for infectious diseases. Factors such as life views and beliefs, the idea that it is a painful procedure for children, uncertainties about how the child and personal data are processed (conspiracy theories), and the coronavirus pandemic stood out among the reasons for not participating in the screening (42).

HBS, which is also practised in Ontario, Canada, is a process based on parental consent. Parents are informed in advance and their consent is obtained. In 2016, a study was conducted in Ontario with a total of 51 people using the interview method with parents and healthcare professionals. These included 32 parents and 19 health professionals. As a result of the study, it was determined that there were three parents who refused screening. One parent refused the test in the second child because of pain during the HBS of the first child, another parent refused the screening because of pain during the screening, and another parent refused consent because she found the blood collection disgusting (43).

Legal Processes and Court Decisions in Türkiye

In Türkiye, judicial processes related to HBS have led to a debate on the balance between individual rights and public health policies. In 2012, a family started a legal struggle after a heel blood sample was taken from their newborn baby without their consent. At the first stage, the court ruled that the screening was compulsory, citing public health. However, in

2014, the same family filed a new lawsuit claiming violation of the 'right to protection and development of material and moral existence' under Article 17 of the Constitution. This time, the court ruled in favour of the family and ruled that compulsory HBS constituted a violation of rights and the case proceeded to the next stage. The Constitutional Court stated that the discretionary power of public authorities in interventions against the bodily integrity of the individual is limited, but that the NSP did not exceed these limits. The Constitutional Court concluded the case in favour of the newborn HBS programme, stating that the HBS was carried out in a limited number for the diagnosis of certain diseases and that there were necessary regulations in terms of health. As a result, the Constitutional Court ruled that compulsory HBS does not violate the individual's right to the protection of his/her material and moral existence. This decision sets a precedent for cases to be filed on similar grounds (44).

A similar case was filed in Kars in 2024. The case of a family who refused HBS was taken to court by the Kars Provincial Health Directorate. However, the court stated that HBS was a hegemonic dictate imposed by the WHO and claimed that its positive results had not been proven. The court cited Aidin Salih, an alternative medicine expert, as saying that HBS is 'one of the greatest evils to be done to a child'. As a result, the Kars Provincial Health Directorate's court application was rejected. Numerous civil society organisations and associations opposed the decision and complained to the judge presiding over the process. The case was appealed to the Court of Appeal, which ruled that the Kars Family Court's decision, which threatened the best interests of the child and public health, should be annulled (45).

International Perspective: Heel Blood Data Controversy in the USA

Discussions on the storage and unauthorised use of biological data are not limited to Türkiye. Similar debates have also taken place in the USA, and especially the use of data collected without parental consent has turned into an important legal struggle.

In 2009, nine families in Minnesota and five families in Texas filed lawsuits against state health departments, stating that the storage and use of heel blood samples without parental consent was unlawful. As a result of the lawsuits, a new regulation was introduced in Texas and parental consent became mandatory for the storage of heel blood samples. However, the lawsuit filed in Minnesota resulted against the parents (46).

Conclusion

Heel blood screening, which started with PKU in the world to ensure a healthy life for newborns with genetic and metabolic disorders, has developed with technology and turned into a large-scale programme. Pilot studies continue to be carried out in order to move health programmes forward and benefit more people. Türkiye is also taking many steps in this direction. Developing technology has gained an important place not only in science but also in our social life and the circulation of ideas has increased. With the influence of social media, various perceptions, different opinions have started to form and oppositions have started to be seen. These views continue to increase because people do not have enough information. While Türkiye is trying to progress on the path of science as in developed countries, people's opposition to scanning by characterising it as privacy and individual rights has initiated legal processes. The fact that state institutions in Türkiye are pursuing this issue and our courts have ruled in favour of the HBS programme is an indication that the society is trying to protect children with the perspective of 'not the child of a family but the child of the whole country'.

In the future, clearer frameworks on the applicability and legal basis of compulsory health screenings will need to be determined. In this context, it is critical to develop balanced solutions that will protect both public health and individual rights.

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