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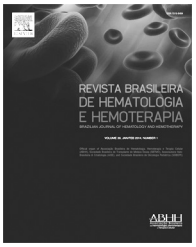

Scientific Comment

National neonatal screening program for hemoglobinopathies: how far have we advanced?☆

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Thanks to the efforts of Dr. Robert Guthrie at the beginning of the sixties, neonatal screening has become a true diagnostic tool for diseases that, if not detected early, can result in important complications to the health of the child.[1] Today, neonatal screening represents one of the main advances in the prevention of pediatric diseases, and is based on diagnosing pathologies that are relatively frequent and severe, that can be detected by methods that are simple, efficient and adaptable to large-scale application, and that can be treated to substantially modify the course of the disease.[2]

In Brazil, neonatal screening was first initiated by professor Benjamin Schmidt in 1976, but for a long time, there was no investment in or commitment to the treatment and follow-up of screened children.[3,4] After 2001, the Ministry of Health, through the Bill #822/GM, instituted the National Neonatal Screening Program (NNSP)[5] in the public healthcare system, incorporating the principles of neonatal screening: universal access to early diagnosis, and intervention in the disease with the use of therapies and interdisciplinary care, mandating a hierarchy of responsibilities and competencies at the federal, state and municipal levels. Sickle cell disease and other hemoglobinopathies were included in the NNSP,[5] allowing the adoption of prophylactic measures and complete treatment of children with these diseases before the development of clinical complications, thereby having an impact on morbidity and mortality.[6–12]

Screening should be considered a public health service with universal access and monitoring of screened individuals. The NNSP was essential to increase the screening coverage in Brazil,[3] but the higher number of screened children is only one of the indicators of the efficiency of such a program. Rules and regulations for all steps of screening are necessary, as is the production of informative material for patients and professionals, training of professionals, and especially, critical evaluation of the program, based on the results over the long term.[13]

Soares et al.[14] and other researchers,[15–17] on reporting their data, demonstrate the challenges faced by a neonatal screening program in a country of continental dimensions, especially in regions and populations with social and economic problems. Pechansky and Thomas in 1981[18] developed parameters for access to medical care, and some of these were later analyzed by Botler[3] in relation to neonatal screening programs. The data from Soares et al.[14] highlight one of these: accessibility, defined as the relationship between the location of the service and the location of the users, taking into account the resources necessary to permit the user to avail from the services.

The data reported by Soares et al., [14] together with those from previous studies,[19–21] as well as the indicators recorded in the NNSP management system, can help to define new care strategies for Brazilian children with hemoglobinopathies. The training and certification of pediatricians of government health clinics to treat these patients in their residential areas, greater integration of the Family Health Program with the NNSP, investment in infrastructure to allow greater

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☆ See paper by Soares et al. 250–5.

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local independence, and a greater involvement of professional societies[3] all need to be discussed. Some of the data presented by Soares et al.,[14] such as absence of family planning and indifference to early care for a second affected child, reinforce the importance of investment in information sources for families.

The foundation stone was put into place a half a century ago by Guthrie, now we need to identify and tear down the barriers that stand in the way of more effective results of the NNSP for the patient, the family, and society.

Conflicts of interest

The author declares no conflicts of interest.

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