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NEWBORN SCREENING

An international training and support programme for the establishment of neonatal screening in developing countries

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Summary We report our experience in developing and implementing a training programme aimed at introducing neonatal screening to health care professionals in developing countries. It was originally envisioned as a 10-year programme but was later extended to 15. Our institute initially began offering the training course in neonatal screening on an annual basis in 1990, under the auspices of the Japan International Cooperation Agency (JICA). The aims of the programme were to enhance the participants' technical knowledge and skills, as well as deepen their understanding of the principles involved in neonatal screening. Over the 15 years that the programme ran, up to March 2005, a total of 130 participants originating from 36 countries completed the course, the participants comprising some 85 paediatricians, 4 obstetricians, 34 biochemists and 7 administrative officers or public health specialists, a number of whom have subsequently implemented neonatal screening programmes in their respective institutes, regions or countries. Having thus completed the initial 15-year phase of the training course, after a thorough evaluation we initiated the second phase of our international training and support programme for neonatal screening in 2006. With the objective of supporting the establishment of a neonatal screening system for congenital hypothyroidism, the new programme consists of not only specialist training in Japan but also financial and technical assistance for helping to establish neonatal screening in the participants' respective countries.

Abbreviations

CAH	congenital adrenal hyperplasia
CH	congenital hypothyroidism
JICA	Japan International Cooperation Agency
PKU	phenylketonuria
SCIPH	Sapporo City Institute of Public Health

Introduction

Many developing countries are typically faced with the problem of high infant and neonatal mortality. While the cause of death is largely infectious diseases, mental or developmental disabilities are largely the result of diseases of the central nervous system, perinatal hypoxia or various metabolic disorders. The magnitude of these problems is so great that they generally tend to overshadow the importance of inherited metabolic disorders in the causation of childhood mental and developmental disabilities. Clearly, to address these problems, the establishment of a neonatal screening programme in such developing countries is a major health priority. The implementation of such a programme, however, necessitates a training scheme to provide the necessary knowledge and skills to those involved with running the screening. Under the auspices of the Japan International Cooperation Agency (JICA), we at the Sapporo City Institute of Public Health (SCIPH) developed and implemented such a training scheme in 1991.

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JICA's technical training programme

JICA is responsible for the technical cooperation aspect of Japan's Official Development Assistance (ODA) programmes. Technical cooperation is aimed at a transfer of technology and knowledge that promote socioeconomic development in developing countries. JICA conducts various schemes to promote this end, including training programmes for overseas participants, an expert dispatch programme, an equipment provision programme and a development study programme. The technical training programme for overseas participants is one of JICA's main activities, involving technical cooperation for developing countries. Nationwide, there are more than 400 group training courses in which the curriculum is formulated according to the common needs of the developing countries. In addition, individual training courses are also offered, in which the curriculum is formulated on the basis of the needs of the individual country. Currently, JICA accepts about 10 000 participants from over 150 countries. The training course for neonatal screening is one of JICA's group technical training programmes.

Procedures for acceptance of participants

To ascertain what and help is needed and where, JICA and SCIPH annually conduct information programmes and surveys concerning health related needs in recipient and potential recipient countries. Information regarding admission to the training course is then sent to those countries that have expressed interest. This step is completed 6 months before the application deadline. Interested countries then submit the application form to JICA, and after consideration of the nominee, JICA and SCIPH make a decision whether to accept the applicant and inform the respective countries of the result. Successful applicants are then invited to come to Japan.

Outline and results of the training course for neonatal screening

The training course for neonatal screening was held once a year from its inception in 1991 at SCIPH. The duration was typically 12 weeks and the number of participants was limited to 8 persons. Diseases covered in the training course included congenital hypothyroidism (CH), phenylketonuria (PKU) and congenital adrenal hyperplasia (CAH). A series of lectures and related laboratory practice provided the necessary knowledge and technical skill base for trainees to both understand the importance of neonatal screening and gain the ability to perform the screening test itself. Lecture topics included the understanding of epidemiology, pathology, clinical symptoms, diagnosis, treatment and prognosis for relevant diseases. Laboratory practice for screening techniques included enzyme linked immunosorbent assay for CH and CAH, Guthrie testing, enzyme-fluorometric assay and high-performance liquid chromatography for PKU screening. In addition, DNA diagnosis techniques for CAH, chemical diagnosis for metabolic disorders using gas chromatography, and gas chromatography–mass spectrometry were sometimes included, depending on the participants' needs.

By the end of the first phase of the programme in March 2005, 130 participants from 36 countries had taken part in the training course. Of the total, 85 were paediatricians, 4 were obstetricians, 34 were biochemists,

Table 1 Participants' nationalities and total number and numbers of participants who are involved in newborn screening programmes

Asia		Latin America		Middle East		Africa		Eastern Europe	
China	1[a]/3[b]	Argentina	8/13	Egypt	3/9	Kenya	0/1	Bulgaria	1/1
India	1/1	Brazil	5/12	Jordan	2/4	Senegal	0/1	Latvia	1/1
Indonesia	2/4	Chile	0/2	Iran	1/4	Tanzania	0/3	Macedonia	0/1
Korea	0/1	Colombia	1/1	Iraq	1/1	Zambia	0/1	Poland	1/1
Laos	1/2	Costa Rica	2/2	Saudi Arabia	0/2				
Malaysia	2/5	Ecuador	0/1						
Nepal	0/1	El Salvador	0/2						
Pakistan	1/2	Mexico	7/13						
Philippines	2/6	Paraguay	0/1						
Papua New Guinea	0/2	Peru	6/11						
Thailand	6/13	Uruguay	2/3						

[a] Number of participants who are involved in newborn screening programmes.
[b] Total number of participants.

and 7 were administrative officers or public health specialists, a significant number of whom have subsequently implemented neonatal screening programmes in their respective institutes, regions or countries. Table 1 shows details of participant's nationalities and total number and numbers of participants who are involved in newborn screening programme in each country.

As a follow-up programme, SCIPH has been providing further information, consultation and expertise to participants on request. Some participants from Brazil, China, Egypt, India, Iran, Malaysia and Peru have sent dried blood and urine specimens to have screening results verified or checked. In particular, selective screenings have been carried out to check for aminoacidopathy, organic acidaemia, CH and CAH in high-risk infants. Samples have also been screened for DNA diagnosis of CAH and Wilson disease.

Review and evaluation of the first phase of the training programme and introduction of the second phase

Although initially planned for only 10 years, the first phase of the training programme was extended to 15 years, at which time a comprehensive review and evaluation was conducted. While this initial phase was successful, as borne out by both its longevity and the number of new screening start-ups, a need for improvement in a number of areas was recognized, leading to the recommendation of a revised second phase. Specifically, although the training course was helpful in establishing the neonatal screening programme, in order to improve the programme it was concluded that countries' needs, participants' qualifications, and subjects offered needed to be revised. Neonatal screening is only an effective system when the related organizations work in cooperation, from blood sampling to patient treatment stages. As such, the second phase aims to provide a forum wherein medical administration officers, laboratory technicians and paediatricians will learn together, enabling them to comprehensively and systematically establish a functioning neonatal screening system in their country.

This second phase, 'Support for the Establishment of a Neonatal Screening System for Congenital Hypothyroidism', was launched in collaboration with JICA in 2006. Addressing identified needs, the programme consists of not only technical training in Japan but also financial and technical assistance for starting congenital hypothyroidism screening in the participant's country. Target countries are those that have not yet (effectively) initiated any neonatal screening programme, and participants are drawn largely from medical administration officers, laboratory technicians and paediatricians from a common country. Course content focuses mainly on the development and implementation of a CH neonatal screening programme, chosen principally because of the disease's high incidence and cost-effectiveness of the screening. Programme objectives are fourfold and can be summarized thus:

1. Participants will understand the position of newborn screening in maternal and child health administration, the cost-benefit of neonatal screening, and the importance of education for parents and health professionals.
2. Participants will acquire a comprehensive knowledge base and learn sampling techniques, analytical methods and quality assurance.
3. Participants will be taught skills related to the diagnosis, treatment, long-term management and prognosis for CH.
4. Participants will be shown how to draft a plan to establish a neonatal screening system in their own respective countries, in addition to receiving instruction concerning how to prepare and submit a financial request to JICA.

The modified programme began in January 2006 and has been held twice since its inception. To date, a total of 11 participants from Panama and Paraguay have completed the programme, and JICA initiated a dedicated financial support programme in October 2006 to work in tandem with the training course. As a consequence, both countries were able to successfully implement CH neonatal screening.

Conclusion

A comprehensive training and support programme is vital for the establishment of a neonatal screening system in developing countries. Now in its second phase, we have developed and fine-tuned a programme designed to meet this end. We look forward to further refining the training programme by addressing specific country needs, and plan to initiate a systematic follow-up programme for participants.

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