

THE DEVELOPMENT OF INTERNATIONAL COOPERATION IN NEWBORN SCREENING AND THE EFFORTS OF BOB GUTHRIE AND HORST BICKEL

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After I started screening for phenylketonuria (PKU) in 1966, there were serious difficulties due to the lack of scientific information. There were no relevant international meetings useful for a beginner. In 1971, I was lucky to meet one of the major figures in our field, Horst Bickel. Due to his kindness, I was invited to an international symposium in Warsaw, Poland in 1972 where I met Robert Guthrie, Harvey Levy and many other pioneers in neonatal screening for metabolic disorders. Before the Warsaw meeting, there were international conferences on screening for PKU and related disorders in Yugoslavia (1966) and Israel (1969). These were supported by funding from the United States and were not open meetings. The proceedings of the meetings were not generally available worldwide.

The first open international symposium organized by scientists was the 1978 International Symposium in Heidelberg. Since this meeting was the initial step towards the formation of the International Society for Neonatal Screening, I would like to explain how it was organized. In September 1976, both Bob Guthrie and I attended a meeting for mental retardation in Washington DC. I told him that we organized the Japanese Society for Neonatal Screening in 1973 but were having difficulties getting updated information from other countries. Bob mentioned that he himself really wished to have better international communication. He emphasized that since screening for congenital hypothyroidism (CH) already started in Canada, the USA, Japan and Europe, there was a real need for an international meeting. Endocrinologists involved in CH screening had often not been exposed to mass screening and this was causing some problems.

Shortly after this discussion, in October 1976, Bob Guthrie started to correspond with Horst Bickel, urging him to organize an international scientific meeting in Heidelberg. Harvey Levy and I received copies of their correspondence. When the decision was made, funding was sought, and we in Japan also tried to raise contributions for the meeting.

Horst and Bob finally organized the Heidelberg meeting for neonatal screening in September 1978. It

was a very fruitful meeting and it turned out to be a turning point for many of us. The proceedings were published as a book by a German publishing company. This was a landmark publication for people who were just starting to establish their screening programs.

In 1977, Bob Guthrie organized the first international meeting on screening for CH with the cooperation of Delbert Fisher, an internationally known thyroid disease specialist. After this meeting, Dr Fisher organized an international committee for CH screening. The members were GN Burrow (Canada), JF Conelly (Australia), F Delange (Belgium), J Dussault (Canada), DA Fisher (USA), M Irie (Japan), G Morreale de Escobar (Spain), and H Naruse (Japan). Many of these people participated in the Heidelberg meeting. The committee then decided to have an international meeting on CH screening in Quebec in September 1979.

At the Quebec meeting, there was discussion whether cord blood should be used and whether endocrinologists should be responsible for CH screening. Fortunately, the conclusion of the Quebec meeting was that CH screening should be integrated with already established neonatal screening programs. At the end of the meeting, the Japanese group proposed having the next international symposium in Tokyo to encompass all kinds of neonatal screening. This proposal was accepted by the international committee for CH screening. However, in the case of screening for inborn errors of metabolism (IEM), there was no official committee with authority to decide the place and time of an international meeting, but all of the major figures in the field encouraged us to organize the meeting in Tokyo.

The international symposium in Tokyo, held in August 1982, had scientists from 35 countries. There were around 400 participants. After the meeting, the international committee for CH screening accepted the idea of integrating CH screening with general neonatal screening. Though this appears common sense now, it was one of the important steps for the future development of neonatal screening.

During the Tokyo meeting, we received a proposal to have the next international symposium in Latin America where many people were trying to start neonatal screening. It was unclear, though, whether this could be achieved. We asked both Horst Bickel and Bob Guthrie to organize an international committee to decide the meeting site, the time, the main program and so forth. They suggested a small temporary committee. Horst took on the role of chairman, and Bob was the vice chairman. They asked me to work as a second vice chairman. We initially explored the possibility of Dr Tony Velasquez organizing a meeting in Mexico and when this seemed impossible, Dr Benjamin Schmidt in Sao Paulo, Brazil, was proposed. However, he preferred to select a later year for hosting such a meeting. Finally it was decided that the meeting should be in the USA. Dr Brad Therrell accepted the task of running a meeting in Austin, Texas. Despite the short time available for organization, this meeting was very successful with over 300 people attending from 27 countries. At the end of the meeting, it was decided that Dr Schmidt should organize the next meeting in 1987-88 in Brazil.

During the preparatory period, we wrote to people in many countries, recognizing that there should be a real international committee to promote regular international meetings and to support the organizer of each meeting. In 1987, just before the meeting of the Society for Inborn Errors of Metabolism in Sendai, Japan, I organized a small meeting on quality control in neonatal screening in Nikko, Japan. The meeting had 25 participants and continued for three days. At the end of the meeting, Ian Lyon (New Zealand) proposed that we consider forming an international society for neonatal screening. Other speakers supported his suggestion.

As the organizer of the meeting, I accepted his proposal, but I was afraid that it might be too early to

organize such a society. If almost all countries had a national society for neonatal screening, we could have had an international society in the federation style. The situation in many countries, however, did not suggest this as the way forward. However, an international society would have many advantages, such as appropriate regional meetings, easy communication with outstanding people in other countries, quality assurance, and other related matters. Also, I thought that an official journal would be useful for many people. Harvey Levy and I both considered that either Bob Guthrie or Horst Bickel would be ideal as the first president, but neither agreed by reason of their age. Harvey Levy also declined. I then decided to accept the role of president, asking Brad Therrell to take the role of secretary. Bob Guthrie and Horst Bickel both accepted the roles of patrons of the new society. We invited thirteen well-known people in various countries and regions to serve on the committee and most accepted.

On November 6, 1988, the day before the official opening of the international screening meeting in Sao Paulo, Brazil, Dr Schmidt arranged for us to have time to discuss the International Society for Neonatal Screening. I remember that the number of people who joined in the discussion was beyond my expectation. After Brad and I explained the concept of the International Society for Neonatal Screening, many people spoke, most showing their enthusiasm for the Society and its proposed activities. The idea of having regional meetings was especially welcomed by people in Latin America. We decided that we should start the activity of ISNS by having the inaugural meeting in Sydney, Australia. This meeting in the evening of November 6th was very encouraging for us. I then realized that the efforts of Bob and Horst that began 1976 had come to a fruitful result.