

HISTORY OF THE INTERNATIONAL SOCIETY FOR NEONATAL SCREENING

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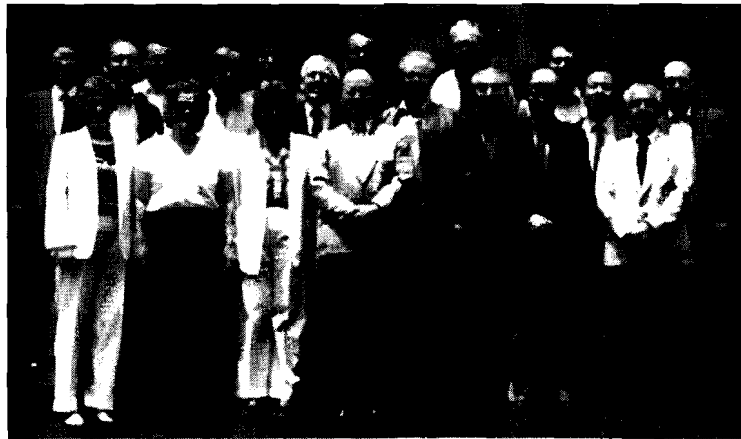
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HISTORY

Professor Naruse has outlined (see article in this issue) the events that were the forerunners to the formation of the International Society for Neonatal Screening (ISNS). The first three meetings on newborn screening in Dubrovnik, Tel-Aviv (Cohen *et al*, 1971) and Warsaw, were closed meetings for selected participants, and little information was generally available after the meetings. The next three were truly international meetings. After the meetings in Heidelberg (Bickel *et al*, 1980) and Tokyo (Naruse and Irie, 1983), the 6th International Newborn Screening meeting was held in Austin, Texas (November 16-19, 1986) (Therrell, 1987), and there were over 300 participants representing 27 countries. At the session on Quality Control, it was recommended that an international symposium dealing only with issues of quality assurance in newborn screening should

be held. The following year, May 23-26, 1987, Professor Naruse organized an international workshop on "Quality Control in Neonatal Screening" in Tokyo and Nikko, Japan (Lake Chuzenji). Approximately 20 persons attended this meeting [see photo (Fig 1)]. During an open discussion among participants on future activities in newborn screening, Dr Ian Lyon (New Zealand) proposed creating an international society. As explained in Professor Naruse's report (this issue), the discussion in Nikko was the culmination of much previous discussion among some of the leaders in the newborn screening field about creating an international organization. Professor Naruse agreed to serve as President with Dr Brad Therrell (USA) to serve as Secretary. It was also decided that Dr Robert Guthrie (USA) and Dr Horst Bickel (FRG) would be named as first Honorary Members (Patrons) of the Society. Details of organizing the Society fell to the two officers and dissemination of relevant



Front: Paige Mitchell (USA), Bohunka Blehova (Czechoslovakia), Judi Tuerck (USA), Hiroshi Naruse (Japan), Dietger Mathias (FRG), Antonio Velazquez (Mexico); **Second:** Brad Therrell (USA), Harry Hannon (USA), Ian Lyon (New Zealand), Benjamin Schmidt (Brazil), Toshiaki Oura (Japan), TS Chen (Taiwan), David Jinks (USA); **Third:** Masaru Matsumoto (Japan), Andrew Brown (Australia), Masaru Fukushi (Japan), Jean-Luis Dhondt (France), Ken Pass (USA), Harvey Levy (USA).

Fig 1. First official organizing discussants concerning the International Society for Neonatal Screening International Quality Assurance Meeting, Tokyo and Lake Chuzenji, Japan, May 23-26, 1987

information was to be distributed internationally through the newsletter *Infant Screening* (already being published with newborn screening information in the US by Dr Therrell).

During the following year (1987-88), under the direction of Professor Naruse and Dr Therrell, a simple constitution was prepared, a logo was designed and discussions began concerning goals of the organization and the frequency of its meetings. At the 7th International Newborn Screening Symposium in Sao Paolo, Brazil from November 6-9, 1988 (Schmidt *et al*, 1989), the first business meeting of the Society was held. Drs Naruse and Therrell were asked to continue their organizational efforts and to continue serving as ISNS officers. A standing Quality Assurance Committee was formed to work towards international standardization among newborn screening programs with particular emphasis on laboratory standardization. Initial efforts were to focus on laboratory nomenclature. Discussions also began concerning the possibility of regional meetings of the Society and the possible creation of a Society journal. The possibility of regional meetings focused on Shanghai, China in 1990 for the Asia Pacific Region and Havana, Cuba in 1992 for the Latin American Region. These regional meetings were

intended to address newborn screening issues specific to the region, and to provide a forum for regional information exchange. Eventually, the 1st Asia Pacific Regional Meeting was held in Sapporo, Japan in June 21-23, 1993 (Tagasugi and Naruse, 1994), and the 1st Latin American Regional Meeting was held in September 1997 in Havana, Cuba.

The 8th International Newborn Screening Symposium in Leura, New South Wales, Australia (November 12-15, 1991) (Wilcken and Webster, 1991), hosted by Dr Bridget Wilcken, was also the 1st meeting of the ISNS and the editorial committee of the newly proposed Society journal *Screening* [see photo (Fig 2)]. By that time, the ISNS had grown to over 250 members. Dr Naruse and Dr Therrell were then re-elected to serve their second terms of office. The creation of a journal in which Society members could more easily publish newborn screening articles was supported by the membership and Drs Hiroshi Naruse (Japan) and Harvey Levy (USA) were selected as Editors-in-Chief and Drs Brad Therrell (USA), Jean Dussault (Canada), Bridget Wilcken (Australia), Ichiro Matsuda (Japan), Jean-Louis Dhondt (France), and Dieter Schoenberg (FRG) served as co-editors. The first issue of *Screening* was published in 1992.



Seated: Brad Therrell (USA), Songya Pang (USA), Bob Guthrie (USA), Marie Bardsley (Elsevier), Horst Bickel (FRG), Hiroshi Naruse (Japan), Claude Dorche (France); **Front Row:** Bent Norgaard-Pedersen (Denmark), Marcello Giovannini (Italy), Kurt Widhalm (Austria), Antonio Velazquez (Mexico), Jean Dussault (Canada), Jean-Louis Dhondt (France), Harvey Levy (USA), Benjamin Schmidt (Brazil), Isamu Matsumoto (Japan), Bernard Lemieux (Canada); **Back Row:** Agne Larsson (Sweden), Ricardo Guell (Cuba), Ken Pass (USA), Robert Kennedy (Scotland), Neil Buist (USA), Edward McCabe (USA), Harry Hannon (USA), Dieter Schoenberg (FRG), Tadashi Sawada (Japan), Jean Frezal (France), Rui-guan Chen (PRC), Ichiro Matsuda (Japan)

Fig 2. Inaugural Meeting of ISNS Editorial Committee First Official ISNS Meeting, Leura, NSW, Australia, November 13, 1991

The 2nd Meeting of the ISNS occurred from September 13-17, 1993 in Lille, France (Farriax and Dhondt, 1994). At the ISNS Business Meeting at the conclusion of the Symposium, an amended constitution allowed for additional officers. Dr Brad Therrell was elected President, Dr Bridget Wilcken was elected Vice-President, Dr Jean-Louis Dhondt was elected Secretary and an Executive Council was elected that included Anne Greene, MSc (UK) and Drs Agne Larsson (Sweden), Ichiro Matsuda (Japan), and Dianne Webster (New Zealand). The Society continued to publish its journal, assist developing programs and support regional meetings. However, in 1995, the journal was officially discontinued for lack of sufficient high quality manuscripts. The Quality Assurance Committee published its nomenclature rules and began to focus on preparing international standardization materials on filter paper. The 3rd ISNS International Meeting was held in Boston on October 20-23, 1996 (Levy *et al*, 1997), and all officers were continued for another term while a new constitution was developed. Quality assurance efforts continued and a Constitutional Committee began to draft a new version of the constitution. The Society selected the *Journal of Medical Screening* to be its official journal. At the 4th ISNS International Meeting in Stockholm, Sweden, a new constitution was adopted and Dr Bridget Wilcken became President, Dr Jean-Louis Dhondt became Vice-President, Dr Gerard Loeber (Netherlands) became Secretary-Treasurer and 4 At-Large Members were elected to the Executive Council, Dr Harry Hannon (USA), Dr Stephen Lam (Hong Kong), Dr Alicia Aznarez (Uruguay), and Dr Toni Torresani (Switzerland).

Regional meetings of various groups have improved the local interest in the ISNS. Most notable have been the meetings in Latin America and the Asia Pacific. In Latin America, the Latin American Society for Inborn Errors of Metabolism and Neonatal Screening had its organizational meeting in Havana, Cuba, September 14-18, 1997, and followed this with meetings in Santiago, Chile, October 24-27, 1999, and Cartagena, Colombia, October 21-24, 2001. The Asia-Pacific Regional Meetings began in Sapporo, Japan in 1992 (Tagasugi and Naruse, 1993), with the second in Hong Kong in 1995 (Lam and Pang, 1996), the third in Chiang Mai, Thailand in 1998 (Wasant *et al*, 1999), and the fourth in Manila, Philippines

in October 2001 (this journal). Today there are approximately 250 ISNS members distributed internationally in Africa <1%, Asia 16%, Australasia 5%, Europe 42%, Latin America 16%, and North America, 21%. The future of newborn screening is bright, expansion is widespread, new programs are developing and the ISNS continues to take a leadership role in advancing science and knowledge.

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