CISEPO: a contribution to a Canadian-led movement in global infant hearing health

Severe hearing loss has long been an unaddressed public-health issue worldwide through the 20th century. Since the mid-60s this matter has been recognized by opinion leaders in Canada, United States, Scandinavia, the UK and elsewhere through many ad hoc and titled scientific meetings that attempted to address the core of the problem which was to identify newborn and infant hearing loss, not just in high risk populations, but in the general population. It was clear this was a problem to be addressed through hearing screening methodologies beyond the accumulation of registers. And the consensus view over the next decades was to lower the target age at which an infant was identified as seriously hearing disabled. What became clear was that electro physiologic testing would become the key and that Dr Martyn Hyde in his quiet but persistent research would drive this issue successfully forward through his pioneering work and automated brainstem evoked potentials.

A series of consensus through the 80s and 90s conferences, driven by our American colleagues, raised awareness further with calls for the problem to be addressed through technical methodologies that would reduce the age at which an infant could be identified as having a significant hearing loss and the physicians and families in scientific and practice societies could be alerted and brought into some form of rehabilitative process. This is been well documented by Durieux-Smith, A and Stuart, A (2000), Newborn Hearing Screening: A Canadian Historical Perspective.

Professor Hyde had obtained his PhD in clinical neurophysiology and biostatistics from the University of Southampton, and was eminently qualified to begin a lifelong devotion to auditory evoked potentials and established himself and his research as setting the bar for the scientific understanding and the promotion of evoked potentials

Dr Martyn Hyde came to Mount Sinai Hospital in the Silverman hearing research laboratory in 1977 and began work on technical development and evaluation of ABR techniques as a tool for hearing measurement in babies. His work was supported by Canadian Medical Research Council funding for technical development and Health and Welfare Canada and Ontario Ministry of Health funding in matters of policy. The Silverman Hearing Research Laboratory was formally established in 1978 by funding from the Saul A Silverman Family Foundation at the direction of Dr Arnold Noyek for CISEPO and became the home for Martyn's research. Martyn works with OFU Director Krista Riko, the Otologic Function Unit and at the Silverman research laboratory (the laboratory is established with Dr Noyek's help). The high-risk neonatal intensive care unit in the second level nursery at Mount Sinai Hospital become the clinical and research 'laboratory' for the subject of their pioneering research investigations, searching to identify deaf babies at 48 hours after delivery.

Martyn and his scientific and clinical colleagues worked diligently and persistently on the challenge of developing a meaningful screening methodology and his mission was rewarded with the establishment of the Infant Hearing Program (IHP) as a pioneering milestone on the world scene through the establishment of provincial health policy for the province of Ontario in 2000. Martyn's 14 years of screening 200 newborn babies per year assisted the Ontario government budgeting and designing the IHP (a global first in its design) to which Martyn continues to play a role in program development, evaluation and quality improvement .

Now more than 1 million babies have been screened in Ontario since 2001 (and the program moves well beyond Ontario into British Columbia and onto the international scene) and now the public health community in pediatric societies have the capacity to advocate in promote the finding of newborns with a hearing loss at 48 hours after birth with electrophysiologic testing confidence but also the capacity to fix that hearing loss through hearing aids, auditory verbal therapy, cochlear implant surgery and educational programs reaching out into the medical and general communities as we move into the 21st century.

The Americans had remained active in pursuing a similar goal but it became globally recognized that Martyn's work strongly influenced the Joint Committee on Infant Hearing and Martyn has been recognized

by the Americans for his pioneering role in the Movement. Many individuals and projects contribute to the development of a movement but Martyn's quiet but determined seminal role with Silverman/CISEPO support at Mount Sinai Hospital is recognized for its Canadian and global leadership.

The CISEPO mission not only supported Dr Hyde's laboratory base of operations, it became an essential element in the implementation of similar IHP programs on a global scale with key influences in the United States, Britain and the Middle East among Israelis, Jordanians and Palestinians (with their high risk genetic populations for consanguineous hearing loss).

In 1984, Dr Arnold Noyek establishes CISEPO, the Canada International Scientific Exchange Program (<u>www.cisepo.ca</u>) as a Canadian registered charitable, volunteer health sector organization based at Mount Sinai Hospital. Additional elements in the collaboration were the Silverman Hearing Research Laboratory at Mount Sinai Hospital, and nowadays CISEPO is based at the University of Toronto and linked to York University with national outreach.

CISEPO's mission brings physicians, surgeons and public health specialists, alongside other health-care professionals, scientists, scholars and students from many disciplines together in Canada and the Middle East to better the lives of ordinary people.

At the same time, Dr Arnold Noyek becomes chief of Otolaryngology at Mount Sinai Hospital in 1989 and the hospital-based baby program continues under Professors Krista Riko and Martyn Hyde.

In 1995, His Majesty the late King Hussein of Jordan invites Professor Arnold Noyek to use health as a bridge to peace and bring Arabs and Israelis together following the peace treaty of 1994.

Through a series of CISEPO and University of Toronto sponsored continuing education events, Professor Arnold Noyek uncovers the high prevalence of genetic sensorineural hearing loss in the region due to consanguineous marriages as an unaddressed major public health issue.

Under his course direction over the next three years, and in a highly charged political environment, continuing education workshops and planning meetings were held in Amman (1996), Gaza (1997), Nablus (1997), Amman (1998), Petah Tikvah (1998) focused on the early detection of hearing loss.

In 1998, in an academic setting, under a Canadian umbrella, the Middle East Association for Managing Hearing Loss (MEHA) was brokered by Dr Noyek and CISEPO, with His Royal Highness Prince Firas Raad of Jordan as patron with deans of Israeli, Jordanian and Palestinian medical schools as steering committee participants with CISEPO regional directors for project selection. This was the first and only cross-border professional association among Arabs and Israelis

Dr Khalid Hadi, an emerging leader in otolaryngology from Qatar, comes to Mount Sinai and begins training in clinical audiology under Dr Martyn Hyde and Ms Krista Riko, studying universal newborn hearing screening, under the mentorship of Dr Arnold Noyek from 2000 – 2002.

Dr Arnold Noyek and the team continue CISEPO/MEHA and University of Toronto workshops in Amman (1999), Amman (1999), Jerusalem (1999), Abu Dis (1999), Tel Aviv (1999), Toronto (2000), Tel Aviv (2000), Bethlehem (2000), Toronto (2000), Tel Aviv (2001), Jerusalem (2001), Jerusalem (2001) working towards promoting the implementation of universal newborn hearing screening programming across the Arab and Israeli frontier.

In 2001, the Government of Ontario, following the demonstrable success of Dr Martyn Hyde's brainstem evoked potential research in baby screening, implements universal newborn hearing screening, habilitation and family support in Ontario through the Ministry of Health with partners at the Hospital for Sick Children, University of Western Ontario and other centers.

In 2001, Dr Arnold Noyek and the CISEPO/MEHA team, with the support of Government of Canada, granting through CIDA and utilizing the pioneering Ontario model, begin a successful cross-border study

in newborn hearing screening across the breadth of Israel, Jordan and the West Bank to determine necessary implementation protocols.

In 2001, CISEPO initiates through funding a pioneering and sustaining cross-border research project and scientific collaboration between Professor Moien Kanaan at Bethlehem University (now dean of life sciences) and Professor Karen Avraham (Vice Dean) at Tel Aviv University to explore the genetics of hearing loss in Palestinian newborns. These internationally acclaimed researchers in the field of genetics develop a 15 year relationship which remains ongoing across borders in cooperation and productivity fueled by NIH funding. The key to building this relationship, its long-term funding and its impacts is the CISEPO eight years of support funding of the first Masters and then PhD student in life sciences at Bethlehem University under their joint supervision. The relationship is highly productive at all levels achieving ground breaking genetic discoveries of new genes, through research carried out jointly by these Israeli and Palestinian scientists and their teams, which unlock the mystery of genetic links which cause some genetically transferred forms of hearing loss affecting Palestinian babies;

CISEPO, and University of Toronto promote universal newborn hearing screening as a movement through meetings and conferences in Nicosia (2002), Cernobbio (2002), Haifa (2003), Beer Sheva (2003), Ankara (2003), Aqaba (2003), Tel Aviv (2003), Tenerife (2003), Amman (2003), Brussels (2004), Cernobbio (2004), Petra (2004), Toronto (2004), Amman (2005), Jerusalem (2005), Ashkelon (2005), Havana (2005), Jerusalem (2005), Vienna (2006), Toronto (2006), Amman (2006), Toronto (2007), Tel Aviv (2007), Irbid (2007), Toronto (2007), Washington (2007), Amman (2008), Toronto (2008), Toronto (2009), Amman (2010), Jerusalem (2010), New Haven (2010).

In 2004, CISEPO and MEHA with the support of the Government of Canada begin universal newborn hearing screening, habilitation and family support in Jordan.

In 2006, the Ontario program (IHP) is placed under the Ministry of Children and Youth Services.

In 2007, the Ministry of Health in Jordan adopts universal newborn hearing screening, habilitation and family support as national health policy through legislation. To date: 800,000 babies have been screened (est).

In 2007, Qatar, as part of an ongoing Canadian-Qatari partnership, adopts universal newborn hearing screening, habilitation and family support as national health policy. To date: 165,000+ babies screened. Audiologist have been trained for the Gulf in a collaborative Canadian-Qatari initiative and universal newborn hearing screening and adopted in Oman

In 2010, based on CISEPO/MEHA protocols, Israel adopts universal newborn hearing screening as national health policy, screening 170,000 babies per year. The total number of babies now screened is now greater than 1 million

In 2010 Qatar develops an ongoing certification program for clinical audiologists, initially in partnership with the Peter A. Silverman Center for International Health and the International Continuing Health Education Collaborative at the University of Toronto (led by Abi Sriharan), with the support of Professors Noyek, Pat Gullane (Chair, Otolaryngology, University of Toronto), Hyde and Riko.

In 2010, Dr Arnold Noyek addresses (via telehealth) the US federal government and all state governments on the implementation of universal newborn hearing screening and habilitation through the Ontario and Middle East models at a major national conference in Chicago through the invitation of Professor Karl White and the US now begins to consolidate a similar Universal Newborn Hearing Screening (UNHS) undertaking.

In 2011, Ontario screens its one millionth baby as universal newborn hearing screening is also adopted in New Brunswick and British Columbia with Québec expected to join in shortly.

Professor Hyde continues to guide the Infant Hearing Programs (IHP) in Ontario and British Columbia for the provincial governments.

In 2011 a memorandum of understanding among The Royal Scientific Society of Jordan (RSS), CISEPO and American CISEPO enables the establishment of a global health model called Access Hear. It is a project in which deaf-mute, primarily on a genetic basis, now have the dignity of first time employment manufacturing affordable hearing aids for the use of deaf children in the region and for sale to government agencies and institutions. The project receives its initial funding from the Dr Arnold M Noyek OC legacy fund, a fund established in June 2011 to support projects and initiatives on the world scene in the health sector as directed by Dr Noyek the CISEPO team

As of today Canadian newborns, infants and children with severe hearing loss now have achieved the educational opportunities of their hearing peers and can attend mainstream schools. This now continues worldwide as CISEPO has played a key role in developing national health policies, creating 'new normals' for cooperation in the health sector and a needs-based movement on the global scene for children's hearing health and education in the context of medical education and health innovation has begun in support of maternal and child health globally.

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