

**Third Planning Meeting
of the Steering Committee of
the Middle East Association For Managing Hearing Loss (MEHA)**

January 3, 2002

FINAL REPORT

1. OPENING OF THE MEETING (Agenda item 1)

1.1 The Chairman of the meeting, His Royal Highness, Prince Firas bin Raad, Patron of the Association, welcomed the dignitaries, the Canadian, Israeli, Jordanian, and Palestinian Steering Committee and Operating Committee members, and the observers to the Third Planning Meeting of the Steering Committee, held at the Holiday Inn, Nicosia Center, Cyprus.

1.2 The list of participants is given in Appendix A.

1.3 HRH Prince Firas expressed his appreciation of MEHA participants' continuing commitment to MEHA and the importance of MEHA as one means of keeping hopes alive and demonstrating the existence of middle ground during difficult times.

1.4 The chairman acknowledged the assistance and support that MEHA has received from institutional, governmental, and corporate organizations and mentioned: The Isabel Silverman Canada International Scientific Exchange Program (CISEPO) based at Mount Sinai Hospital and the University of Toronto; The Canadian International Development Agency (CIDA), as part of its development assistance program; Unitron Inc, Canada; Yad Hanadiv, Israel; the Royal Medical Services of Jordan; the Schneider Children's Medical Center of Israel; Al Quds University; the Government of Cyprus, Ministry of Foreign Affairs and Ministry of Health; as well as other Canadian, Israeli, Jordanian, and Palestinian governmental and institutional organizations.

1.5 Dr. Chris Kaisis, the representative of the Minister of Health for Cyprus, the Honourable Frixos Savides, brought greeting from his Minister and delivered the Minister's expression of support for MEHA's goals of building of relationships among Israelis, Jordanians, and Palestinians and Republic of Cyprus government's satisfaction in hosting MEHA at this time and in the future.

1.6 HRH Prince Firas read a letter from the Minister of Health for Jordan, Dr. Falleh Al-Nasser, expressing his regret at not being able to participate in the MEHA Steering Committee meeting, and indicating his full awareness of MEHA's programs and activities and his keen support of them.

1.7 Ms Aliza Inbal, of the Ministry of Foreign Affairs of Israel (MASHAV), expressed the support of the Israeli government for MEHA's goals and programs and MASHAV's interest in extending its cooperation for MEHA's current and future projects particularly in the area of training.

1.8 Professor Arnold Noyek read into the record a message from the Canadian High Commission for Cyprus praising MEHA's program and projects and the commitment of MEHA's health professionals in Jordan, Israel and the Palestinian Authority despite the current difficult circumstances in the region.

1.9 Professor Arnold Noyek read into the record a message from Professor Harvey Skinner, Chair, Department of Public Health Sciences, Faculty of Medicine, University of Toronto, supporting MEHA's advances in its cooperative approach to the international public health issue of hearing loss and confirming the Department's continuing commitment to MEHA and CISEPO activities whenever possible.

1.10 Professor Ziad Abdeen indicated the strong support of Al Quds University, its President, Professor Sari Nusseibeh, and its Dean of Medicine, Professor Hani Abdeen for MEHA and for its programs and activities.

1.11 Professor, Dr. Nicolaos Marangos brought greetings from Professor, Dr. Wolf Mann, Chairman, Department of Otolaryngology, University of Mainz, Germany.

1.12 The Chairman read into the record a message of greeting from Professor Lawrence Spero, Director of Educational Computing, Faculty of Medicine, the University of Toronto, and CISEPO Webmaster.

1.13 The Chairman read into the record a letter from the Conrad N. Hilton Foundation in Los Angeles, California, which informed the meeting that CISEPO had been nominated for the 2002 Conrad N. Hilton Humanitarian Prize by the Honourable Art Eggleton, Minister of Defence, Canada.

2. ADOPTION OF AGENDA (Agenda item 2)

2.1 The meeting was invited to comment on the agenda.

2.2 The agenda was adopted as reproduced in Appendix B.

3. STEERING COMMITTEE MEMBERSHIP (Agenda item 3)

3.1 The Chairman called for a moment of silence in memory of the late Major General, Dr. Abdel Karim Abu Nowar, former Director of the Royal Medical Services, Directorate Royal Medical Services of Jordan and a former member of the Steering Committee.

3.2 The Chairman informed the meeting that Dr. Itamar Shalit would be stepping down as a member of the Steering Committee and acknowledged the contributions of Dr. Itamar Shalit as a founding Steering Committee member of MEHA and as an ongoing, strong supporter. He introduced and welcomed Dr. Shalit's replacement, Professor Menahem Fainaru, Dean of Medicine, University of Tel Aviv.

3.3 The Chairman introduced and welcomed as a new member of the Steering Committee, Major General, Dr. Manaf Hijazi, Director of the Royal Medical Services, Directorate Royal Medical Services of Jordan.

4. STEERING COMMITTEE MEMBERS' PRESENTATIONS (Agenda item 4)

4.1 The Chairman invited the members of the Steering Committee: Prof. Abdeen, Prof. Fainaru, Dr. Hijazi, Prof. Noyek, and Dr. Shalit (retiring) each to address the meeting.

4.2 The members of the Steering Committee indicated their satisfaction with the recent progress of MEHA Project 1, The Early Detection of Hearing Loss in Infants, and the particular need for regional cooperation as exemplified by the programs and activities of MEHA.

4.3 It was identified that MEHA provides a model for cooperation in promoting health and other scientific activities which could be expanded into other disciplines and would bring people together in the region. MEHA's program, it was noted, have developed a core of support which will contribute even more fully to the well being of the region once the political situation has settled.

5. OPERATING COMMITTEE AND MEHA REGIONAL CENTRE REPORTS (Agenda item 5)

5.1 The Chairman introduced the members of the Operating Committee: Dr. Mohammad Al Masri, Head, Department of Audiology, King Hussein Medical Centre, Jordan; Dr. Joseph Attias, Director, Institute for Clinical Neurophysiology and Audiology, Schneider Children's Medical Center of Israel (SCMCI); and Mrs. Rema Othman Jebara, Faculty, Al Quds University and Audiologist/Speech Therapist, Hadassah Medical Organization.

5.2 The individual Operating Committee reported on their activities. They placed particular emphasis in their presentations on MEHA Project 1, The Early Detection of Hearing Loss in Infants, describing the objectives and the experimental design of the project, and the results of the pilot studies conducted in Jordan and in Israel, and planned for the Palestinian Authority.

5.3 The pilot study in Jordan was divided into two parts: a neonatal hearing screening study for newborns before they were discharged from hospital at the age of 12-24 hours; and infants hearing screening at the age of 1-3 months.

5.4 Approximately 300 infants were tested. The initial results of the screenings revealed the prevalence of neonatal hearing loss was remarkably higher than the published data for developed countries and higher than the anticipated prevalence estimated during the planning of the MEHA project itself.

5.5 In Israel, the tests in the pilot project were conducted on 300 newborns. Only one of the 300 newborns was found to have severe, bilateral hearing loss. Considering the caution needed in interpreting the statistics for such a small sample, the results from the pilot study were not assessed as incompatible with the previously reported incidence of severe, bilateral hearing loss in the area.

5.6 It was also reported that approval of the Helsinki Committee for MEHA Project 1 has been obtained for SCMCI, and its extension will be sought for the 13 Hospitals in Israel that will be participating in the testing.

5.7 It was further reported that the testing of 500 infants in Al Makased Hospital as part of the pilot study for Project 1 is planned using the same equipment as has been used in Israel. Planning for the testing and the sharing of the equipment are in progress.

5.8 The Executive Director of the MEHA Regional Centre, Jordan, Dr. M. Al Omari, reported that the MEHA Regional Centre, Jordan is now fully developed as a facility with the infrastructure, equipment and staff necessary to carry out the activities of Project 1.

5.9 Funding for establishing the Centre was provided by CISEPO, from grants to CISEPO from the Canadian International Development Agency (CIDA), as part of its development assistance program, and from a Swiss based Foundation.

5.10 The Centre is functioning as envisioned with testing and habilitation of the Jordanian infant contingent for the pilot study having commenced. The MEHA Regional Centre team is demonstrating a cost effective operation, using as a basis for comparison the audiological services currently provided by the Royal Medical Services and the Ministry of Health.

5.11 The comments of the Steering Committee and other participants regarding the Operating Committee reports and the report on the MEHA Regional Centre focused on the following areas: Pilot Study Results, Genetic Hearing Loss Issues, Completing Project 1, Resourcing Project 1, and Habilitation.

5.12 Details of the comments are provided in Appendix C.

5.13 The meeting was informed of ongoing collaborative research, sponsored by CISEPO, as a MEHA project, on the genetics of hearing loss, carried out by Dr. Karen Avraham, University of Tel Aviv and Dr. Moien Kanaan, Bethlehem University. Further information is provided in Appendix D. The meeting was also informed of CISEPO's support for related public education for parents of children with hereditary deafness in the region through the production and distribution of matching brochures in Arabic and Hebrew.

5.14 The Steering Committee considered the reports and comments presented and provided the following guidance for the Operating Committee:

5.14.1 Operating Committee members are encouraged to continue the data collection for Project 1 ensuring that their experimental methods, instrumentation, and data analysis are compatible and scientifically rigorous. Making Project 1 fully successful is MEHA's top priority;

5.14.2 The habilitation which is to be included as a part of Project 1 needs to be defined, documented, and costed by the Operating Committee. If additional habilitation is to be considered beyond the minimum that is ethically required within Project 1, a separate project should be planned, costed, and recommended for Steering Committee consideration;

5.14.3 The genetics of hearing loss should be recognized as an important and a culturally sensitive issue beyond the scope of Project 1. MEHA's further involvement in this area will be considered by the Steering Committee;

5.14.5 The resources needed to complete Project 1 should be identified by the Operating Committee and will be sought by Steering Committee members and the Patron. Resources for activities beyond Project 1's current commitments will require discussions with governments.

5.15 The Chairman identified the need for studies associated with the economics of detection of hearing loss in early childhood and their impact on informed practice and health policy decision-making. A proposal to this end developed by CISEPO is provided in Appendix D. Members were requested to explore the commissioning of a joint project that would address the issue for the region.

5.16 The meeting was informed of the ongoing support to MEHA of Ms. Krista Riko and Professor Martyn Hyde of the Otologic Function Unit, Mount Sinai Hospital, as their experience in implementing a universal newborn hearing screening program for the Province of Ontario in Canada has relevance to MEHA project 1

5.17 The meeting was informed of discussions with Ms. Josee Levasseur, the Learning to Listen Foundation, North York General Hospital, Toronto, as a possible Canadian representative to the Operating Committee.

5.18 Professor Noyek indicated his intent, on behalf of the Steering Committee, to explore the needs of the Bedouins in the region with respect to the possible problem of hereditary hearing loss, and he asked for input from the attendees.

6. MEHA FINANCIAL REVIEW 2000-2001(Agenda item 6)

6.1 Financial support for MEHA has been based on CISEPO's commitment to fund and/or to find funding of CND\$150,000 a year for three years beginning in 1999/2000.

6.2 Between July 1999 and September 2001, MEHA received CDN\$419,478 (US\$ 278,143) from CISEPO. An additional transfer of CND\$200,000 by CISEPO for the remainder of this fiscal year is projected. Thus, CISEPO's funding commitment to MEHA will be fulfilled by July 2002.

6.3 CISEPO was successful in attracting funding for MEHA and its Project 1, The Early Detection of Hearing Loss in Infants, from Dr. Noyek's patient donors, from corporations, and from governments.

6.3.1 In March 2001, The Canadian International Development Agency (CIDA), as part of its development assistance program made a commitment to CISEPO of CDN\$240,000 over a three year period, for the funding of a development cooperation project that will strengthen co-operation among communities and health professionals in Jordan, the Palestinian Authority, and Israel (MEHA Project 1).

6.3.2 CISEPO also received a commitment of US\$70,000, over a two year period, from a Swiss Foundation to support MEHA Project 1.

6.4 It was identified that finding additional sources of funding for MEHA has become a critical issue. The ongoing well being of MEHA, the completion of Project 1, and the implementation of subsequent cooperative projects is dependent on finding additional resources.

7. RESOURCING FOR MEHA (Agenda item 7)

7.1 The Chairman thanked Dr. Noyek for his relentless enthusiasm, for his exceptional work, for his unremitting support of MEHA, and for his stimulation of patients, governments, and others as donors for MEHA's programs. He also thanked the entire CISEPO team for their extraordinary spirit of international commitment.

7.2 The Chairman indicated that he, as Patron of MEHA, would focus during the next nine months on identifying and securing other sources of funding from the North American scene.

7.3 The Chairman and Dr. Noyek will also explore strengthening academic links which can lead to support for MEHA and will arrange to jointly approach potential benefactors.

7.4 Steering Committee members were invited to identify additional avenues for securing funding for MEHA. A number of suggestions were made which will be pursued.

8. MEHA 2001-2002 PROGRAM AND PROJECT PROPOSALS (Agenda item 8)

8.1 The Operating Committee recommended the following activities for the next six months: Continuation of Project 1; Expansion of Project 1 to include the testing of 6,000 Palestinian infants; Training of Palestinian audiologists on the MEHA Project 1 equipment; Implementing an instrument training workshop for Operating Committee members at a site near the Israel/Jordan border; Development and presentation of a joint scientific paper on the findings from the Project 1 pilot study at the Milan, NHS conference.

8.2 The Steering Committee approved in principal the expansion of Project 1 to include the testing of 6,000 Palestinian infants. Before final approval can be given, a detailed, costed project plan must be developed and approved, and a source of funding must be identified.

8.3 The other recommendations from the Operating Committee in paragraph 9.1 were approved.

9. STEERING COMMITTEE PRIORITIES (Agenda item 11)

9.1 Members of the Steering Committee confirmed that the continuation and completion of MEHA Project 1, The Early Detection of Hearing Loss in Infants, was the Associations top priority.

9.2 Steering Committee members further identified as priorities:

9.2.1 The accomplishments of MEHA with respect to developing cooperative, cross-border relationships must be continued;

9.2.2 MEHA should not develop its activities as replacements for the services of governments;

9.2.3 Telemedicine and distance learning should be recognized as powerful tools which could assist MEHA in achieving its objectives;

9.2.4 Steering Committee and Operating Committee members should publicize MEHA's activities at national levels seeking community recognition of MEHA's accomplishments.

10. CLOSING OF THE MEETING (Agenda item 10)

10.1 The Steering Committee will meet in approximately nine months time (after the High Holy Days and before Ramadan).

10.2 The Chairman thanked all the participants for their commitment during difficult times and for moving the discussions ahead to productive conclusions. The Chairman particularly recognized and thanked on behalf of all present Phil Aber, Adviser and Secretary to the Steering Committee, and CISEPO Policy and Planning Adviser, and praised his efforts in comprehensively preparing the participants and the documentation for this further successful Steering Committee meeting.

10.3 The Steering Committee, on behalf of all present, expressed their collective deepest gratitude to His Royal Highness Prince Firas for his inspiration, his encouragement and his remarkable role as a truly hands-on Patron.

10.3 The meeting closed at 13:45, January 3, 2002.

APPROVED _____ DATE: _____

His Royal Highness
Prince Firas bin Raad
Chair of the Meeting
Patron of MEHA

Third Planning Meeting
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the Middle East Association for Managing Hearing Loss (MEHA)

January 3, 2002

MEETING PARTICIPANTS

Chair of the Meeting

His Royal Highness, Prince Firas bin Raad of Jordan, Private Secretary to His Majesty the King for Health Affairs and Patron of MEHA

Steering Committee

Professor Ziad Abdeen, Coordinator Health Sciences Faculties and Dean of Research, Al Quds University

Major General, Dr. Manaf Hijazi, Director, Royal Medical Services, Directorate Royal Medical Services of Jordan

Professor Arnold Noyek, Chairman, the Isabel Silverman Canada International Scientific Exchange Program (CISEPO), Otolaryngologist-in-Chief, Mount Sinai Hospital,

University of Toronto, and Director, Peter A Silverman Centre for International Health

Dr. Itamar Shalit, Schneider Children's Medical Center of Israel

Operating Committee

Dr. Mohammad Al Masri, Head, Department of Audiology, King Hussein Medical Centre, and Royal Medical Services of Jordan

Dr. Joseph Attias, Director, Institute for Clinical Neurophysiology and Audiology, Schneider Children's Medical Center of Israel

Mrs. Rema Othman Jebara, Faculty, Al Quds University; Audiologist/Speech Therapist, Hadassah Medical Organization

Executive Assistant to the Patron

Major General (Ret.) Dr. Mohammed Al-Omari, Otolaryngologist

Adviser and Secretary to the Steering Committee (By telephone link)

Mr. Phil Aber, CISEPO Policy and Planning Adviser

Observers

Dr. Qadr Alfawwaz, Office Director, the Office of HRH Prince Firas

Brigadier General, Dr. Asem Al-Omari, Head, Department of Otolaryngology, King Hussein Medical Centre, Royal Medical Services of Jordan

Mohamed El Hneti, the Office of HRH Prince Firas

Professor Menahem Fainaru, Dean, Sackler Faculty of Medicine, Tel Aviv University

Ms Aliza Inbal, Coordinator for Middle East Activities, Center for International Cooperation (MASHAV), Ministry of Foreign Affairs of Israel

Dr. Chris Kaisis, Medical Officer of Health, Ministry of Health, Cyprus

Prof. Dr. Nicolaos Marangos, ENT Department, University of Mainz, Germany and Chairman of ENT Department and Metropolitan Cochlear Implant Center, Metropolitan Hospital, North Faliro, Greece

Dr. Yehudah Roth, Vice Chairman, Department of Otolaryngology-Head and Neck Surgery, the Edith Wolfson Medical Centre; CISEPO Deputy Director, Israel

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the Middle East Association For Managing Hearing Loss (MEHA)**

January 3, 2002

PROVISIONAL AGENDA

1. OPENING OF THE MEETING
2. ADOPTION OF THE AGENDA
3. INTRODUCTION OF STEERING COMMITTEE MEMBERS
4. STEERING COMMITTEE MEMBERS' PRESENTATIONS
5. OPERATING COMMITTEE AND MEHA REGIONAL CENTRE REPORTS
6. MEHA FINANCIAL REVIEW 2000-2001
7. RESOURCES FOR MEHA
8. MEHA PROGRAM AND PROJECT PROPOSALS
9. STEERING COMMITTEE PRIORITIES
10. CLOSING OF THE MEETING

**COMMENTS ON MEHA PROJECT 1,
THE EARLY DETECTION OF HEARING LOSS IN INFANTS,
AND THE PILOT STUDIES IN ISRAEL AND JORDAN**

The comments of the Steering Committee and other participants regarding MEHA Project 1 and the pilot studies, focused on the following issues:

I. Project 1 Pilot Study Results

1. The incidence of hearing loss found in the pilot study in Jordan is astonishing;
2. The results of the Project 1 pilot study should be prepared for publication quickly;
3. The “astonishingly” high incidence found in the pilot project in Jordan may turn out to be real or even conservative once further testing is completed;

II. Genetic Hearing Loss Issues

1. Genetic study of hearing loss is essential in conjunction with, and in addition to, MEHA
2. Project 1 (see Appendix C for one example of work being done in cooperation with CISEPO and MEHA);
3. Other risks, in addition to genetics, could contribute to a high incidence of hearing loss;
4. Genetic counselling could be part of the educational component for reducing the incidence of hearing loss;

III. Completing Project 1

1. Completing Project 1 is a top priority for MEHA;
2. A “box” needs to be placed around Project 1 to ensure that it doesn’t continue to balloon and that it can be completed;
3. Expanding and validating the findings to create a more complete epidemiology is needed to assess incidence and to convince parents and politicians of the problem;
4. Experimental design issues need to be resolved, including use of TPOAE versus DPOAE systems, instrumental compatibility, and the best age for testing, i.e. neonatal versus 2-3 months;

IV. Resourcing Project 1

1. Finding the resources to complete Project 1 is a top priority;
2. Involving governments to address hearing loss will be easier once additional results from Project 1 are available;
3. The availability of published results from a larger sampling will be useful in approaching individual donors and international organizations for financial support;

V. Habilitation

1. Limits need to be set for habilitation within Project 1;
2. Finding the resources for extended habilitation will be a challenge;
3. Developing a separate MEHA project for extended/complete habilitation, and seeking funding for it, could be considered;
4. If habilitation for 4,000 children were required, it would require significant resources.

The Prevalence of Connexin 26 Mutations Within the Palestinian Deaf Population

H. Shahin^{1,2}, T. Sobe², T. Walsh³, K. Avraham^{2,4}, M. King³, M. Kanaan^{1,4}

In some Palestinian communities, the prevalence of inherited prelingual deafness is among the highest in the world. As an initial step towards understanding the genetic causes of hearing loss in the Palestinian population, 48 independently ascertained probands with bilateral non-syndromic hearing loss (NSHL) were evaluated for mutations in the connexin 26 gene. Connexin 26 encodes the gap junction protein *GJB2* and is the most common cause of recessively inherited NSHL worldwide. Of the 48 Palestinian probands, 11 (23%) were homozygous or compound heterozygous for mutations in *GJB2*. Multiple mutations were identified, both among and within extended families: -3170 G→A, 35delG, 167delT, 229T→C 235delC. We show that *GJB2* -3170 G→A disrupts splicing, yielding no detectable message. From genome sequence of chromosome 13, we determined distances between markers flanking connexin 26 on the BAC contigs. Distances between markers flanking connexin 26 are consistent with single origins in the Middle East for 35delG and for 167delT, with subsequent recombination between markers. Twenty-five deaf probands wild type at *GJB2* represent informative, extended families who may harbor mutations in as-yet-unknown genes for inherited hearing loss.

1 Department of life Sciences, Bethlehem University, Bethlehem, Palestine

2 Department of Human Genetics and Molecular Medicine, Tel Aviv University, Tel Aviv, Israel

3 Department of Medical Genetics, University of Washington, Seattle, WA, United States

4 Associate Scientific Staff, Mount Sinai Hospital, Toronto, ON, Canada

**[Supported in part by the Isabel Silverman Canada International
Scientific Exchange Program (CISEPO) as a MEHA project]**

Economic Evaluation of the Early Detection of Hearing Loss and Intervention Programs

Background

Undetected hearing loss in early childhood can significantly compromise the development of speech, language and literacy, all of which affect later academic performance and psychosocial skills.

Recent research has suggested that Early Detection of Hearing Loss and Intervention (EDHI) programs may lead to both improved functional status for children with a hearing impairment and savings in the provision of educational and remedial services once the child reaches school age.

Proposal

Evidence is necessary on the effectiveness and potential cost savings associated with EDHI programs to inform practice and health policy decision-making. Research would be carried out at the Masters, Doctoral, or post-Doctoral levels and would be completed in collaboration with the Middle East Association for Managing Hearing Loss (MEHA)'s Project 1. Project 1, The Early Detection of Hearing Loss in Infants, is a cooperative study among Jordanians, Israelis, and Palestinians. During the project, 12,000 infants in Israel, Jordan and the Palestinian Authority will be tested and treated for hearing loss. The results from these tests will be directed to develop new protocols for universal newborn hearing screening program, which will guide the decision makers in the region to achieve early identification of hearing loss.

The objective of this research project would be to develop a framework for the economic evaluation of EDHI programs in the Region, which would include costs associated with case finding and rehabilitation, and specific outcomes in the areas of communication, social development and academic placement. Evidence generated will help to assess the value of national EDHI programs.

CISEPO proposes a joint research program be developed involving researchers from Israeli, Jordanian, and Palestinian universities.