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# REPORT ON THE THIRTEENTH ANNUAL MEETING OF THE PARTNERSHIP COMMITTEE OF NONGOVERNMENTAL ORGANIZATIONS COLLABORATING WITH THE WHO PROGRAMME FOR THE PREVENTION OF BLINDNESS

GENEVA, 7-8 FEBRUARY 1995


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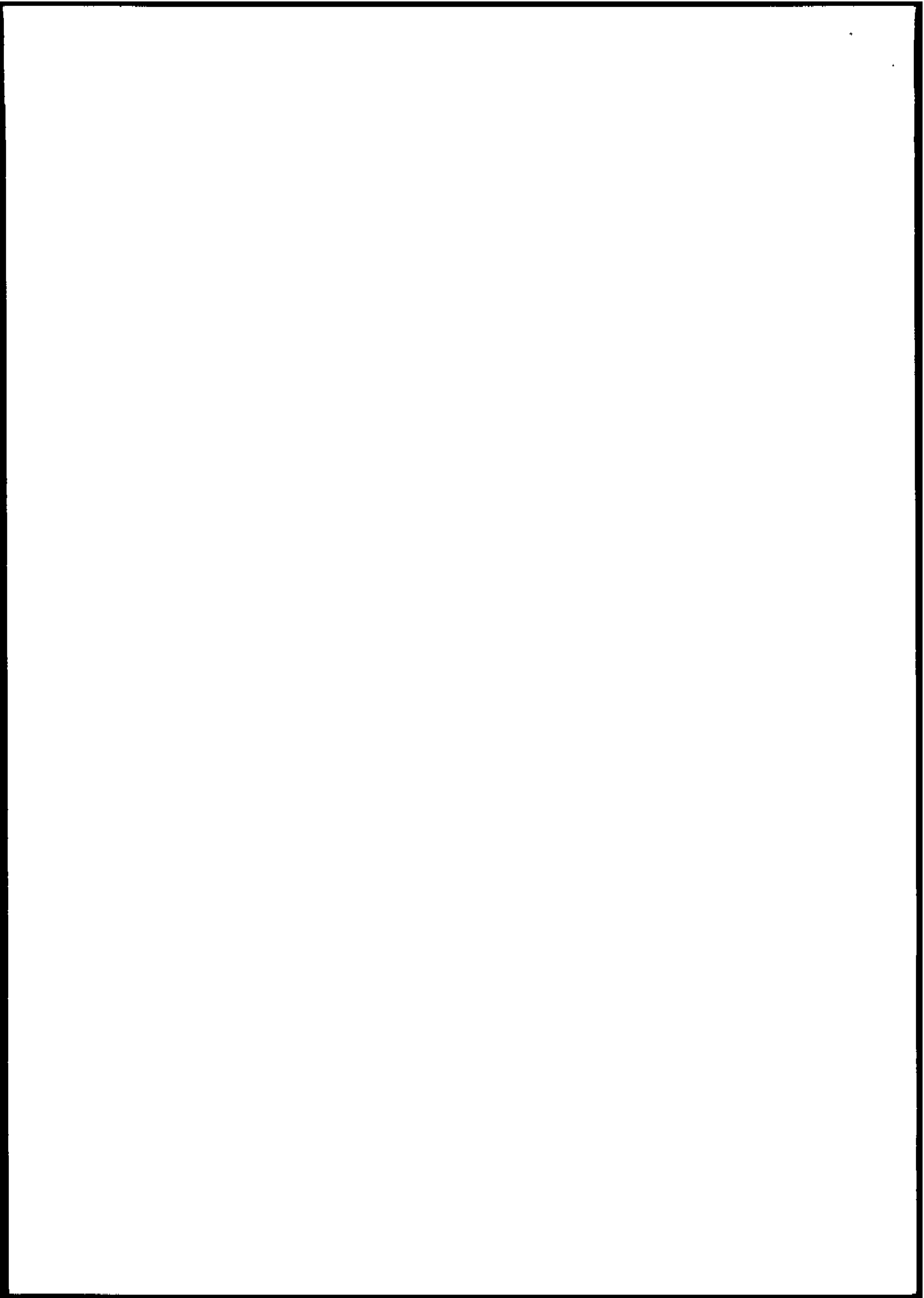
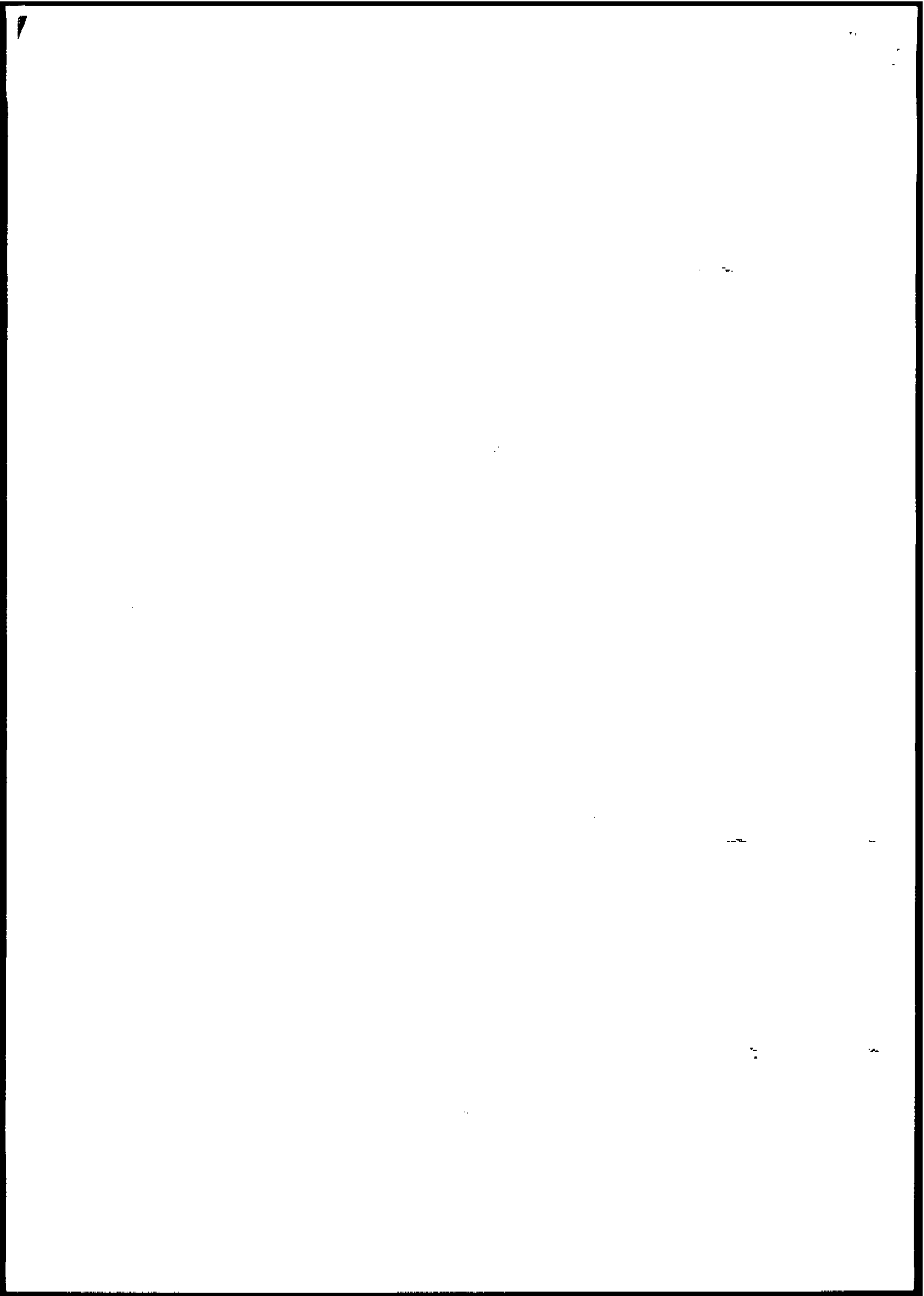


The meeting was chaired by Ms Victoria M. Sheffield, Executive Director of the International Eye Foundation. Tuesday, 7 February was agreed to be for "Prevention of Blindness" and Wednesday, 8 February for "Education and Rehabilitation of the Visually Handicapped".

Ms C. Cross, of Sight Savers International, and Mr M. Pajonk, of Lions Clubs International Foundation, agreed to serve as Rapporteurs. The preliminary agenda was adopted with no modification (Annex 1). The list of participants is attached as Annex 2.



## SECTION A

# BLINDNESS PREVENTION

## 1. INTRODUCTION

Ms Sheffield welcomed everyone to the meeting and gave a note of thanks to the many participants for their attendance.

This report reflected both the work in prevention of blindness as well as the education and rehabilitation (E&R) of the blind, as many member NGOs were involved with both areas. However, prevention and E&R programmes interacted, as some blind and partially sighted persons could be helped with clinical and surgical management, while at the same time the medical side had to refer those who could not be helped for social services of E&R. The Partnership Committee was seeking to strengthen this interaction, especially in the area of low vision care.

Dr B. Thylefors also welcomed everyone to Geneva on behalf of the WHO Programme for the Prevention of Blindness. He expressed recognition that the Partnership Committee and its work were of great importance to the WHO Programme. The support and collaboration received over the last 15 years had been much appreciated. The present meeting was of particular importance in view of the status of the Consultative Group and new activities of the Task Force of the Partnership Committee. It was noticeable that several of the collaborating nongovernmental organizations had activities both for the prevention of blindness and for the education and rehabilitation of the blind; hence the formula for two meetings within the Partnership Committee context.

The minutes of the previous meeting, held in Montevideo, Uruguay, on 24 February 1994, were approved.

## 2. OVERVIEW OF NGO ACTIVITIES FOR THE PREVENTION OF BLINDNESS

All NGO members and observers provided brief overviews of their activities. Agencies represented were 12 full members, 4 associate members, 6 candidates and 7 observers. The Partnership Committee members provided programming in either prevention of blindness or education and rehabilitation of the blind, or both.

The agencies with blindness prevention activities (see list of participants) presented an update for the last year. Programmes focused on the following:

- Clinical and surgical service delivery
- Training of medical personnel
- Technology transfer
- Institutional development
- Development of services in underserved areas
- Research on prevalence of ocular morbidity

- Development of high-quality, low-cost, high-technology resources (IOLs, microscopes, etc.)
- Capital development
- Provision of pharmaceuticals and supplies

The six candidate agency representatives were given additional time to make their presentations; it was noted that three of the six agencies focused their work on education and rehabilitation of the blind and on low vision services.

## 3. OVERVIEW OF WHO ACTIVITIES - PROGRAMME FOR THE PREVENTION OF BLINDNESS (PBL)

Reflecting the general concern about dwindling resources within the global community, the difficulties currently faced by the WHO/PBL Programme were explained. WHO now had 189 Member States, 19 of which had joined in just the last three years. Furthermore, WHO had seen a decade of zero budgetary growth and many of the new Member States had not been able to pay, while many had accumulated arrears. WHO had therefore been functioning on only 80% of its budget for the past few years.

At the recent WHO Executive Board meeting, Dr H. Nakajima, Director-General, noted three exemplary programmes - the Global Programme on AIDS, Human Reproduction, and Prevention of Blindness. PBL was highly regarded, especially for its history of strong collaboration with the international NGO network. The Director-General's comments were as follows:

> "My third example is the WHO Programme for the Prevention of Blindness, which faces a different sort of challenge. Worldwide, some 150 million people are blind or have disabling visual loss. Ninety per cent. of them live in developing countries. The successful Onchocerciasis Programme in West Africa has documented the heavy economic cost of blindness to the community in terms of vulnerability, need for social support and, ultimately, increased mortality.
>
> Through intense networking, WHO's programme for the prevention of blindness has been particularly successful in mobilizing and coordinating funds and support from nongovernmental organizations to match the needs of developing countries. This must be a continuing effort as long as primary health care infrastructure in developing countries remains weak. The general aging of the population would also rapidly increase the number of people with serious visual disability, with a considerable human and economic impact on all societies in both developed and developing countries. Through its technical and managerial leadership, with seed money and a small core of staff only, this WHO programme plays a key catalytic role in enhancing the partnership of NGOs with Member States."

PBL was now part of the Division of Communicable Diseases, which was a priority within WHO; however, Prevention of Blindness was struggling to maintain its position. The Partnership Committee's new Task Force would be critical in PBL's ability to carry forward its agenda in the near future and the NGOs would have to continue to impress upon their counterparts in Member States the importance of prevention of blindness programmes within overall health planning.

Many new ***documents*** were available from the PBL Programme, some of which had been produced in collaboration with WHO collaborating centres and NGOs. Full details were available

in the list of documentation for the WHO Programme. It was noted that the Programme's Global Data Bank on Blindness had been updated and computerized. Two documents had recently been issued: Global Data on Blindness - An Update (WHO/PBL/94.40) and Available Data on Blindness (WHO/PBL/94.38). Mention was also made of the collaboration with The Edna McConnell Clark Foundation in the development of a series of technical and training manuals, slide sets and videos pertaining to trachoma.

*New areas* being considered, in consultation with the WHO Programme Advisory Group on the Prevention of Blindness, included low vision care, especially for the elderly, diabetic retinopathy and macular degeneration.

Particular mention was made of the ***Nongovernmental Development Organizations (NGDO) Coordination Group for Ivermectin Distribution***. This Coordination Group, made up of interested NGDOs who were implementing ivermectin distribution programmes, met twice a year with the WHO/PBL Programme staff to discuss planning, technical programmes and funding issues. The Coordination Group was currently mobilizing resources for ivermectin distribution in the non-OCP (Onchocerciasis Control Programme) countries of Africa at both country and regional levels.

The various meetings which had been held over the past year were reviewed. It was noted that the number of planned WHO/PBL meetings had been reduced and that efforts had been made to schedule meetings "back to back" in order to save travel funds.

With regard to ***regional developments***, the following was noted:

- In the ***African Region***, Dr Ebrahim Samba, former Director of the Onchocerciasis Control Programme, had recently been elected Regional Director. Dr Samba, although extremely busy, had always been supportive of prevention of blindness as a priority in health programmes.

- In the ***Region of the Americas***, Sir George Alleyne had recently been elected Director of the Pan American Health Organization (PAHO). The PBL Programme Manager updated the group on the status of the optic neuropathy epidemic in Cuba. Out of 52 000 cases affected, 50% had had optic nerve involvement. The PBL Programme and WHO/PAHO were providing support for low vision services which were much needed for patients with irreversible visual loss, at present estimated at approximately 1000 cases.

- In the ***Eastern Mediterranean Region***, it was noted that an update on blindness prevention work was being undertaken, with a plan of action to be proposed to the forthcoming Regional Committee in October 1995 for adoption by the Member States of the Region. It was hoped that this would give further impetus to PBL in those countries.

- In the ***European Region***, there had been little response from countries, especially those of the former eastern bloc, to offers of collaboration. The International Eye Foundation (IEF) is working in Bulgaria and Albania and ORBIS in Romania.

- In the ***South-East Asia Region***, the recent World Bank loan of US$ 120 million to the Indian National Programme for the Prevention and Control of Blindness, for seven states over a five-year period, was highlighted. That was an important development and the

recognition by the Bank of the tremendous cost-benefit of prevention of blindness programmes was very significant.

- In the ***Western Pacific Region***, the PBL Programme had participated in a national workshop in China and in a subregional workshop in Japan on training of mid-level personnel for eye care.

***Collaboration with nongovernmental organizations*** was reviewed and it was noted that there was a growing number of joint activities, which varied both in geographical and subject focus (see further points 4&5).

With regard to ***research***, the activities of the PBL Programme and the collaborating centres were reviewed. It was noted that there now needed to be an emphasis on evaluation of country programmes, in order to demonstrate the effectiveness of blindness prevention interventions. That was going to become a particularly crucial issue over the next few years of the WHO Programme's work.

The group noted that the ***WHO Programme for the Prevention of Deafness and Hearing Impairment*** was created in 1986 and placed under PBL in 1990. Funding had so far been difficult. However, in spite of limited resources, there were some new developments which might, hopefully, bring about an expansion of programme work in 1995 and 1996.

## 4&5. OVERVIEW OF CONSULTATIVE GROUP ACTIVITIES AND REPORT OF THE TASK FORCE

It was noted that the Partnership Committee started small and now is just over 10 years old. There had been a great deal of evolution; this included the development of the Consultative Group in 1986, which had also become Group E of the International Agency for the Prevention of Blindness (IAPB), interacting directly with the WHO/PBL Programme. It was felt that evolution and change should continue in the best interest of collaboration between the NGDOs and the WHO/PBL Programme. Over the last year, a Task Force had been functioning within the Partnership Committee which had made funds available, and had been able to act quickly to plan and fund activities jointly with WHO/PBL. All members of the Partnership Committee had the opportunity to work with the Task Force, as appropriate for each agency.

A brief history of the ***Partnership Committee***, the ***Consultative Group*** and the ***Task Force*** was presented, as follows:

**1975.** Group E of IAPB consisted of the six major NGOs working in blindness prevention worldwide.

**1982.** European and North American NGOs joined to form the Partnership Committee, which still functioned today as an informal body and included agencies dedicated to the education and rehabilitation of the blind.

**1986.** Group E of IAPB expanded to include 10 NGO members dedicated to blindness prevention. Those 10 members were elected every four years by and from the Partnership Committee. Group E's 10 NGO members then became the Consultative Group to the WHO/PBL Programme. The Consultative Group did not have official relations with WHO, as four of the members now did, but had a relationship with the PBL Programme. As

funding was becoming limited for the WHO/PBL Programme, the Consultative Group members undertook the joint planning and funding of collaborative activities with the PBL Programme. The Consultative Group members were invited as observers to the WHO/PBL Programme Advisory Group meetings held every two years, and the Consultative Group held its own meetings in alternate years.

**1990**. The IAPB IVth General Assembly approved a revision of the Constitution to give formal recognition to the Partnership Committee as the body to elect 10 of its members to the Board's Group E category.

In the perspective of the ***World Health Organization***:

**1978**. The Trachoma unit within WHO became the Programme for the Prevention of Blindness. At that time, only three blindness-related organizations were in official relations with WHO: IAPB, the International Federation of Ophthalmological Societies, and the World Council for the Welfare of the Blind.

**Early 1980s**. PBL began to work closely with individual NGOs, as PBL collaboration with NGOs through IAPB was felt to be too restricting. Beginning in 1985, four NGOs applied for and were accepted into official relations with WHO - International Eye Foundation, Helen Keller International, Christoffel Blindenmission and the Royal Commonwealth Society for the Blind (now Sight Savers International).

**1986**. Those four, along with the other six members of IAPB's Group E, had a common commitment to blindness prevention programme development and recognized its joint activities and need to meet and discuss strategies. Thus, the Consultative Group was formed and began to collaborate directly with the PBL Programme. Seed funds became available through the Consultative Group for joint activities such as ophthalmic manpower development workshops in Africa and the WHO/NGDO Coordination Group for Ivermectin Distribution.

**Early 1990s**. WHO's overall budget began to be reduced and that also affected the PBL Programme's budget. At the same time, fundraising for the NGOs became difficult within the global economic climate. The Consultative Group was not as easily able to fund joint activities with PBL and it was recognized at the Partnership Committee meeting in 1994, in Montevideo, that there was no longer any difference between the activities of the Partnership Committee and of the Consultative Group. It was recognized that a new working formula needed to be found. Over the past year, a small Task Force of the Partnership Committee had been developed and functioned in the way the Consultative Group was meant to do.

It was noted that the Consultative Group had been an excellent body for discussion and joint programming, especially before the limitations on funding. However, it met only every two years and *ad hoc* with the WHO/PBL meetings held every two years. That was not often enough to implement joint programmes and give immediate response to needs.

An *ad hoc* meeting of the Consultative Group in May 1994, during the IAPB Vth General Assembly in Berlin, agreed that a Task Force of the Partnership Committee would meet to plan and fund joint programmes with the PBL Programme. The Task Force had met four times and had an agenda of activities and a budget.

It was explained that members of the Task Force, currently Christoffel Blindenmission (CBM) and Sight Savers International, agreed to provide an annual contribution of US$ 25 000 for joint NGDO/PBL programming. Any other member of the Partnership Committee could contribute to any of the activities on the agenda with a contribution of 10% or a minimum of US$ 1000 for each activity which interested them. The Task Force met approximately four times per year with the PBL Programme Manager to plan and implement joint activities. NGDOs "buying in" to any of the individual activities would be invited to those meetings discussing that activity. NGDOs could also suggest activities for the agenda.

The current activities on the Task Force's agenda included activities which amounted to US$ 73 000, creating a shortfall of US$ 23 000 over the US$ 50 000 contributed by the Task Force. The Al-Noor Foundation stated that it would provide the US$ 10 000 needed for the EMRO adviser. Regarding the proposed blindness prevalence survey in Jamaica, it was felt that the Barbados Eye Study could be used as prevalence data for the entire Caribbean; however, it was recognized that it might be too age- and disease-specific and that a community-based survey was still required for that reason.

**Action:**
**The member NGDOs were asked to consider which activities of the Task Force they would like to support, and to inform its Chairman.**

In the general discussion, it was noted that the new Task Force had greater flexibility and had already been able to initiate joint activities. It was also an advantage that all members of the Partnership Committee had the opportunity to participate in the planning and funding of joint activities without bearing the entire burden.

The Partnership Committee felt that annual meetings were necessary for the purposes of information exchange, Task Force interaction and collaboration with the PBL Programme.

**The Committee members unanimously felt that the Consultative Group should be phased out and replaced by the Task Force.**

- **The Partnership Committee would continue to function and have direct collaboration with the WHO/PBL Programme. The PBL Programme Manager would attend each annual meeting of the Partnership Committee.**
- **The Consultative Group would no longer exist.**
- **The Task Force of the Partnership Committee shall function within the Partnership Committee and meet approximately five times a year in collaboration with the PBL Programme, to plan and budget joint activities.**
- **The Executive Director of CBM would continue as Chairman of the Task Force until the next IAPB General Assembly.**
- **The Partnership Committee shall continue to elect 10 members involved in blindness prevention to Group E of IAPB.**

**It was noted that, if any members wished to suggest activities for the new Task Force, they could write directly to the Executive Director of CBM.**

## 6. DUES STRUCTURE FOR MEMBERS OF GROUP E OF IAPB

A clarification was requested on the breakdown of subscription requirements for members of Group E of IAPB and on how often the structure was reviewed. It was noted that the dues structure was agreed upon at the meeting of the IAPB Executive Board in Baltimore, in 1989. It was reviewed and noted in the minutes of the *ad hoc* meeting of the Consultative Group held in Banjul, in 1991.

**NGOs were finding it difficult to meet their subscriptions due to limitation on funding; the structure should therefore be reviewed by the IAPB Executive Committee.**

Presently, the dues structure for members of Group E was based on their annual budgets:

- Over US$ 10 million - US$ 10 000 annually
- US$ 5 to 10 million - US$ 5000 annually
- Under US$ 5 million - US$ 2500 annually

The current members of Group E of IAPB (NGOs) were:

1. Christoffel Blindenmission (CBM)
2. Helen Keller International (HKI)
3. International Eye Foundation (IEF)
4. North African Center for Sight (Nadi Al Bassar)
5. Norwegian Association for the Blind and Partially Sighted (NABP)
6. Organizacion Nacional de Ciegos de España (ONCE)
7. Organisation pour la Prévention de la Cécité (OPC)
8. ORBIS International
9. Seva Foundation
10. Sight Savers International
11. Lions Clubs International Foundation/SightFirst Programme

## 7. DOCUMENTATION

(i) *Eye Care Strategies document - 1994*

Information was presented, noting that the development of the Eye Care Strategies document was a project of the former Consultative Group. The document was intended to serve as an information piece describing the strategies employed by members of the Partnership Committee of NGOs working in blindness prevention in developing countries. Suggestions and comments could be sent directly to CBM, in time to be finalized at the next meeting of the Task Force in May 1995.

It was noted that this was a useful document, as it complemented the WHO documents; it should be updated regularly, printed and distributed to interested parties.

**It was agreed that the Eye Care Strategies document would be placed on the agenda for the next meeting and that it should perhaps be considered as a permanent agenda item if it was to be a working document under continual revision.**

(ii) *How to Make Spectacles at Low Cost* (P. Spoerer)

On this information item, it was noted that it was not about refraction, but rather on how to make spectacles and low vision aids. It was available from CBM for photocopying.

(iii) *Childhood Blindness Data*

Mention was made of the availability of guidelines on collecting data on childhood blindness (by Dr Clare Gilbert, of the International Centre for Eye Health [ICEH] in London), in the form of a manual including a survey form and protocol. Also a report on *Childhood Blindness in South-East Asia* had been produced. Both were available from ICEH: Department of Preventive Ophthalmology, International Centre for Eye Health, Institute of Ophthalmology, Bath Street, London EC1V 9EL, UK.

## 8. REVIEW OF THE Vth GENERAL ASSEMBLY OF IAPB, BERLIN, MAY 1994

It was noted that the meeting was extremely active, with 350 delegates present. An overall conclusion was that future meetings should reduce the number of single speakers and provide expanded opportunities for group discussion. The high cost of holding the meeting in Berlin was recognized and, thus, the need for IAPB to have regular financing.

The expansion of regional meetings was noted and further regional activities were encouraged, as they engaged wider interest for the participants.

The IAPB Secretariat had decided to produce the proceedings of the Vth General Assembly in a spiral-bound set of proceedings to reduce cost and speed release and distribution. It was expected that the report would be sent out shortly, in place of the next IAPB Newsletter. A hard-cover volume might be produced at a later date.

## 9. UPDATE ON BULK BUYING OF INSTRUMENTS AND EQUIPMENT

A catalogue, or "buyer's guide", on low-cost equipment/technology and procurement guidelines was being finalized at ORBIS International. Given the wealth of ophthalmic equipment, instruments and supplies now available in India, it was suggested that a consortium of buyers be considered by members of the Partnership Committee which purchased items for their projects. The following suggestions were received:

- It was proposed to encourage UNICEF to produce basic surgical kits; it could be that kits developed regionally would be most relevant. Furthermore, there was a need to train technicians on equipment maintenance and repair.

- It was noted that a basic cataract surgery kit, kept simple, would be useful, as would a kit with low-cost low vision aids; the importance of quality control was recognized.

- A basic lid surgery kit for trichiasis/entropion due to trachoma was being considered by the Trachoma Task Force based at HKI.

- The American Academy of Ophthalmology's Committee on International Ophthalmology was preparing a catalogue of available equipment, instruments and supplies which would be affordable and relevant for use in the developing world.

CBM, IEF and Sight Savers noted that they were all buying in bulk from India and other sources, and had basic lists for surgical kits, etc., available to members as needed.

**Action:**

**It was therefore suggested that a group be formed to pull together available information and to work with ORBIS on the development of the catalogue. HKI agreed to chair that group, which would work with other members over the coming year, and would report to the Committee at the next meeting.**

## 10. UPDATE ON NEEDS ASSESSMENT INFORMATION FORMS

The Committee was informed of the development of ORBIS's assessment forms, noting that they would be available through the ICEH Resource Centre (discussed below).

The ICEH Resource Centre offered to serve as a clearing-house for information on this subject. Information was provided on training and other materials produced by NGOs in various countries and on their availability through the ICEH Resource Centre.

It was also noted that the American Academy of Ophthalmology might consider serving as a storage centre for articles and materials from NGOs. Furthermore, IAPB wished to obtain basic data from countries using the regional structure.

There was also an assessment form available through WHO, presently being reduced in format.

**Action:**

**It was suggested that members provide copies of their materials along with order forms to the ICEH Resource Centre.**

## 11. UPDATE ON TRACHOMA

The Committee was informed by the Task Force on Trachoma, based at Helen Keller International, of the progress of various material on trachoma being developed with support from The Edna McConnell Clark Foundation.

A handy prevention mnemonic had been developed to encourage community support to trachoma control:

**S** - Surgery

**A** - Antibiotics

**F** - Clean Faces

**E** - Environmental Change

It was noted that a slide/script set on trachoma was available from ICEH and the next *Community Eye Health* bulletin would concentrate on trachoma. Additionally, four modules on trachoma would be available on CD-ROM soon, with support from the Wellcome Trust.

The WHO/PBL Programme noted that the major problem was low economic development, and few countries were now interested in trachoma control because of other priorities. Progress had been made in Saudi Arabia and Tunisia, mainly due to accelerated economic development in those countries. Medical therapy alone was not the answer, and compliance was a problem. Current thinking emphasized hygiene and noted that very little water was needed to keep the eyes clean. A future therapy was azithromycin, although it was prohibitively expensive at present. It was hoped that Pfizer would make a donation of the drug, similar to Merck's donation of ivermectin. However, even if trachoma were prevented today, there would still be a need to deal with hundreds of thousands of cases of entropion/trichiasis needing surgery over the next 20 years.

## 12. ELECTION OF ASSOCIATE MEMBERS TO THE PARTNERSHIP COMMITTEE

The Chairman noted that two members, The Pacific Islands Council for Blind Persons and WORLDCATS (World Cataract Surgeons), had asked to be considered for associate membership but were not present.

**It was suggested that their candidacy be deferred.**

The following NGOs had requested membership in the Partnership Committee:

- Al-Noor Eye Foundation - Saudi Arabia
- Associates for World Action in Rehabilitation and Education (AWARE) - USA
- EyeTech - France
- The Lighthouse, Inc. - USA

- Lions Clubs International Foundation/SightFirst Programme - USA
- Overbrook School for the Blind - USA

**After closed discussion, all were elected unanimously by the members. They would be associate members for a period of two years, after which they would be eligible for full membership. There were no associate members eligible for full membership this year.**

## 13. ELECTION OF CHAIRMAN OF THE PARTNERSHIP COMMITTEE FOR 1995 TO 1997

As the names put forward were not able to accept their nomination, it was suggested that Ms Sheffield, IEF, continue in the chair for another period, while a nomination committee sought candidates for the next meeting. Ms Sheffield agreed to carry on for one more year.

**Action:**

**Mr Palmer (HKI) and Mr Porter (SSI) agreed to serve as the Nominating Committee and would present names of candidates for election at the next meeting.**

**The Chairman of the Partnership Committee would serve as an *ex-officio* Vice President of IAPB during his/her term as Chairman.**

The agreement and consensus on the above points were noted.

## 14. ANY OTHER BUSINESS

The Fred Hollows Foundation discussed their factory in Asmara, Eritrea, which now produced high-quality, low-cost intraocular lenses (IOLs). A report was available which outlined how to budget a programme in order to determine the correct cost of cataract surgery, highlighting the fact that high volume is the key to low cost. Sources of funding came from government, NGOs, private donations and patients. All four could be accessed in order to run a cost-effective cataract programme.

## 15. DATE OF THE NEXT MEETING

Invitations were received from the National Eye Institute (USA), Nadi Al Bassar (Tunisia) and the Perkins School for the Blind (USA). After discussion and in consideration of the dissolution of the Consultative Group, it was suggested that the Partnership Committee meet in Geneva, at WHO headquarters, in order to increase the visibility of prevention of blindness and the collaboration of the NGOs with the WHO/PBL Programme. After a written vote, it was agreed that the next meeting should be held in Geneva.

**The next meeting would be held on 6 and 7 February 1996, in order to keep the meetings 12 months apart. The meeting would be in Geneva.**

Given the new relationship of the Partnership Committee to the PBL Programme, it was suggested that there be a report from WHO on each meeting, as was the case for the Consultative Group. It was agreed accordingly.

**Action:**

**It was suggested that one of the points for the next meeting be vitamin A and malnutrition, and HKI offered to help shape a presentation on that theme.**

## CONCLUSIONS AND RECOMMENDATIONS

1. A positive and fruitful collaboration with the NGDOs had been developed since the inception of the WHO Programme for the Prevention of Blindness. It was of great importance that such collaboration continue and be expanded to include increasingly joint activities.

2. The Consultative Group of NGOs, having fulfilled its role in strengthening collaboration with the WHO Programme over the past decade, should be disestablished to avoid future duplication of work. The Partnership Committee would replace the Consultative Group for the purpose of information exchange, with a Task Force of the Partnership Committee for the mobilization of resources and joint activities with the WHO Programme.

3. It was recommended that the Partnership Committee meet annually, whereas the Task Force would meet at least four times a year. It was decided that the venue of the Partnership Committee meetings should initially be at WHO headquarters in Geneva, to increase visibility of the existing collaboration.

4. The Partnership Committee shall continue to elect 10 members involved in blindness prevention to Group E of IAPB. Group E would also include up to two service organizations involved in international prevention of blindness activities.

5. It was recommended that the possibility of bulk procurement of equipment and surgical instruments should be further considered by the Committee, in view of the substantial savings such schemes could produce. A working group would report back to the Committee at its 1996 meeting.

6. The Committee noted the ongoing promotion of trachoma control, in particular the provision of manuals through the WHO Programme and The Edna McConnell Clark Foundation, and its Task Force within HKI. The need for greater priority to be given to trachoma control was recognized, as well as potential new approaches with hygiene promotion and better medical therapy if azithromycin became available on a large scale.

## SECTION B

# EDUCATION AND REHABILITATION

## 1. INTRODUCTION

Ms Sheffield once again welcomed the participants. She noted that the day's meeting would be co-chaired by Messrs Larry Campbell, Vice President of the International Council for Education of People with Visual Impairment (ICEVI), and Pedro Zurita, Secretary General of the World Blind Union (WBU). Ms Sheffield served as Rapporteur.

Messrs Campbell and Zurita greeted the participants. Mr Zurita noted that he had attended a meeting at the International Labour Organisation the day before and felt somewhat discouraged that little interest had been given to collaboration with NGOs. That issue would be discussed through the present day's meeting.

Mr Zurita commented that many participants had a limited command of English and stressed that speakers should speak slowly and clearly to facilitate translation and understanding. Additionally, he and Mr Mondaca asked that all documents distributed be provided on diskette to the blind and visually impaired participants to facilitate computer audio access.

A new item was added on "The role of the Partnership Committee in promoting cooperation in the fields of E&R", which became item 7.

## 2. OVERVIEW OF NGO ACTIVITIES (E&R AGENCIES)

The NGO members and observers provided brief overviews of their activities. Partnership members provided programming in either prevention of blindness or education and rehabilitation of the blind, or in both.

Agencies with E&R activities presented an update for the last year. Programmes focused on the following:

- Low vision services
- Services for the blind
- Training of E&R personnel
- Technology transfer
- Institutional development
- Development of services in underserved areas

- Development of high-quality, low-cost, high-technology resources (low vision aids, computers, etc.)

- Capital development

The major differences that existed between agencies carrying out E&R work were noted; some were focusing on educational services for children, others concentrating on rehabilitation services for blind adults, etc.

The experience of ONCE was that there were almost no blind people gainfully employed after their training. It was stressed that all NGOs must work harder to place blind people in jobs for economic employment. Furthermore, there must be an improvement in communication between the E&R groups to improve efficiency of programming.

It was noted that, in Eastern Europe, the link between clinical/surgical/prevention and E&R was low vision, and more attention should be paid to that area.

***Summary of WBU activities***

The Institutional Development Programme and organizational strategies for advocacy and service delivery were discussed. Collaborative support from the Hilton/Perkins Program, the Canadian National Institute for the Blind and Sight Savers continued for programmes to improve managerial capabilities in the Caribbean, The Gambia, Ghana, Kenya, the South Pacific, Tanzania and Uganda.

The Programme was considering the transfer of the Office of Coordination to Africa, possibly South Africa, thus allowing the coordinator to be as close to the field sites as possible.

A very important development, resulting from meetings held in December 1994 and December 1995 in Paris, was that Belgium, Canada, France, Switzerland and the Francophone countries would seek to improve better coordination of their work in Africa. The concept of an institutional development programme was accepted as a way of working together. A Steering Committee would move forward with this concept experimentally over the next 12 months.

***Summary of ICEVI activities***

The following points were highlighted:

(i) ICEVI was moving away from direct service in favour of strengthening regional units and advocacy. ICEVI appreciated the support of INGOs, several of whom were present at the meeting.

(ii) WBU and ICEVI had agreed upon a joint policy statement concerning education of blind and visually impaired children and would, in April 1995, develop a joint action plan to foster practical implementation of ICEVI/WBU educational activities.

(iii) In collaboration with WHO, ICEVI hosted a consultation on low vision which resulted in the WHO document "Management of low vision in children". ICEVI had also collaborated with the University of Melbourne in an effort to develop a practical low-cost approach to assessment and training of children with low vision, with special attention to the needs of children in developing countries.

(iv) ICEVI and UNESCO had undertaken a joint consultation to assess needs and attempt to develop a regional strategy to improve and expand educational services for the blind and visually impaired in Francophone West Africa. It was hoped that Partnership members would be able to collaborate in a scheme that would strengthen teacher training and educational service delivery in the region.

(v) ICEVI continued to publish *The Educator* to more than 3000 individuals and organizations in all regions. ICEVI had also published an *International Resource Directory* of educational sites and services for the blind and visually impaired throughout the world.

(vi) ICEVI had recently adopted a revised Constitution and was in the process of becoming officially incorporated as a Foundation in the Netherlands, the country of its birth.

## 3. REPORT ON UNITED NATIONS WORLD SUMMIT ON SOCIAL DEVELOPMENT

Messrs Campbell and Zurita referred to a series of "summits" organized by the United Nations on the areas of environment, population, poverty and women's rights, and noted that WBU and ICEVI were working together to see that matters related to disability received appropriate attention within those meetings.

Regarding the upcoming Social Summit, international rehabilitation organizations were lobbying groups of countries, NGOs and the UN system to ensure that disabilities received appropriate mention in the declaration and plan of action. Messrs Campbell and Zurita had attended the PrepCom January 1994 which prepared the draft for Copenhagen. The initial document had no mention of disabilities. The revised document would have a substantial number of references to disability and its prevention. As a result of the efforts of the Disability Caucus, it was hoped that national delegations would include disabilities in their agendas in almost all statements. They noted that this sort of dialogue had to be encouraged by all and their community be ever aware and vigilant to see that disability issues had appropriate visibility. It was noted that the European Union and the G7 plus China were extremely effective in helping shape issues on the agenda.

It was also noted that, in 1993, the United Nations General Assembly had adopted a report entitled "Standard rules for equalization of opportunities for people with disabilities". This report was available from the WBU office or through country ministries.

## 4. THE ROLE OF THE PARTNERSHIP COMMITTEE IN PROMOTING COOPERATION IN THE FIELDS OF E&R

In the discussion of this matter, it was noted that the E&R community was envious of the excellent collaboration between the "prevention" NGOs and WHO. However, when the E&R community wished to collaborate with the UN agencies, it had to deal with UNICEF, ILO and UNESCO, with no single focal point as with WHO/PBL. There had been exploration of a parallel relationship including collaboration with WHO's Rehabilitation unit, but efforts had not been fruitful. The question was how the Partnership Committee members could encourage more effective exchange of information, with or separate from the UN agencies. Members of the E&R community and the Partnership Committee should be encouraged to promote cooperative programming and activities between two or more organizations.

The possible collaboration with the Special Education and Rehabilitation Division of ILO seemed more promising. Members of the E&R group had communicated with Mr Willie Momm, head of the E&R branch of ILO, in September 1994 to advise him of the Partnership Committee, the number of members and their budgets dedicated to E&R. They wished to explore with ILO ways of developing a structure for operational collaboration, noting that the Partnership would be "supplementary" and not redundant. Four steps were outlined:

- ILO was invited to develop a dialogue
- Mr Palmer would get input from the relevant members
- Plan a conjunctive meeting of Partnership members at ILO
- Plan a joint meeting of ILO and the Partnership Committee

Mr Momm responded that it was too early to commit to any of the steps and suggested that the members wait until after the present meeting and explore working with ILO collaborating centres.

Messrs Campbell and Zurita then shared the developments of the conjunctive meeting held at ILO the previous day. ILO was developing a network of "collaborative centres" principally to do research in the area of employment for people with disabilities. Partners would be mainly universities with research departments. However, it was felt that the Partnership members needed to do something more relevant and energetic, showing commitment to programming and service delivery.

It was suggested that ICEVI was parallel to the Partnership Committee and perhaps both could become closer, possibly having combined meetings.

**Action:**

**There were two specific suggestions:**

- **To create a task force for E&R within the Partnership Committee**
- **To combine the activities of ICEVI and the Partnership Committee**

**At the next meeting of the Partnership Committee, various issues of common interest could be discussed, for example integrated education of blind children in regular schools.**

It was noted that ICEVI concentrated on education of schoolchildren and youth, whereas WBU concentrated on rehabilitation of adults. The two organizations had formed a joint working party to promote cooperation. It was felt that the members should move forward proactively, and not wait for collaboration with the UN agencies.

One of the frustrations lay in the fact that the personnel time involved in E&R versus prevention was much greater and more intense, thus more expensive. Primary eye care workers could be trained in groups, whereas E&R workers were almost one to one. Primary eye care workers, however, were also trained in orientation and mobility.

Furthermore, one of the problems could be that the members in E&R were doing both "education" and "rehabilitation". Education was done at a static base and rehabilitation on a community basis. The E&R members should not only create policy, but also be involved in education and advocacy.

It was stated that low vision was the area of "rehabilitation" within the prevention field, therefore screening for low vision in children for the purpose of rehabilitation was a specific activity for collaboration between all partnership members.

Continuing the discussion on the same theme, the following suggestions were made:

- To focus on subjects and activities within E&R, such as the integration of blind children into regular schools
- To clarify goals and objectives which would work
- To focus on low vision as an area of collaboration within the Partnership Committee
- To explore close collaboration between the Partnership and ICEVI

It was proposed that the foci of the Partnership Committee be *prevention* and *rehabilitation*, as education was too technical for most members of the Partnership and should be left for other conferences (WBU, ICEVI). The emphasis for the rehabilitation agencies within the Partnership Committee should be *information exchange* and promoting *awareness* of E&R issues.

**It was felt that the Partnership Committee should, in future, focus on a particular topic, such as:**

- **community-based rehabilitation to help the incurably blind;**
- **support for blind children; one half of the children in blind schools could see to read and simply needed proper spectacles;**
- **the importance of getting children out of blind schools, rehabilitated, and into regular schools.**

WHO/PBL had a mandate to deal with low vision and was listing it as a way to build up national programmes. This would also keep PBL on WHO's agenda.

UNICEF, UNESCO and UNDP were all doing rehabilitation, but they were not interested in blindness because of competing priorities.

**In the further discussion, it was decided:**

- **to establish strategies and concepts for the E&R field and to prepare a "strategies document", as had been done for prevention;**

- **to choose topics for the agenda, to evaluate projects and to use UN sites for discussion;**

- **to agree to separate education and rehabilitation.**

**Mr Campbell summarized with the following conclusions:**

- **To promote information exchange by providing reports in advance and to foster question-and-answer discussions**

- **To focus topics on themes which fostered collaboration**

- **He would serve as the point person for that approach**

## 5. PARTNERSHIP COMMITTEE REPRESENTATION TO ICEVI

ICEVI's revised Constitution stated that two (2) of the six INGOs on the Partnership Committee which were involved in education and rehabilitation could represent the Partnership Committee on ICEVI's Executive Committee. They were:

Christoffel Blindenmission (CBM)

Helen Keller International (HKI)

Norwegian Association for the Blind and Partially Sighted (NABP)

Organizacion Nacional de Ciegos de España (ONCE)

Sight Savers International (SSI)

Swedish Association of the Visually Impaired (SRF)

It was noted that not all members had returned their voting forms. Additionally, some members wished to be considered as candidates for the vote and felt it unfair that only six candidates had been named by ICEVI.

As two of the six agencies eligible to represent the Partnership Committee to ICEVI were not present at the meeting, it was suggested that this matter be revisited at the ICEVI meeting in April 1995.

Messrs Campbell and Zurita thanked the group for a very useful and enlightening discussion which had helped to clarify the role of the Partnership Committee for its E&R members and to strengthen future planning for collaboration.

The meeting was then closed.

ANNEX 1

# AGENDA

1. Welcome and opening remarks
2. Approval of minutes
3. Overview of NGO activities - prevention agencies: Brief summary report by NGO representatives
4. Overview of WHO activities: General review
5. Overview of Consultative Group activities
6. Report from the Task Force
7. Dues structure for members of IAPB Group E
8. Eye Care Strategies document - 1994 (information item)
9. *How to make spectacles at low cost*, by P. Spoerer (information item)
10. Review of IAPB General Assembly, Berlin, May 1994
11. Update on bulk buying of pharmaceuticals and equipment
12. Update on needs assessment information forms developed by ORBIS International
13. Update on trachoma
14. Election of associate members to the Partnership Committee
15. Election of Chair of Partnership Committee for 1995 to 1997
16. Any other business: "Cost recovery and sustainability" paper
17. Closure

ANNEX 2

# LIST OF PARTICIPANTS

**Full members**

| | |
|---|---|
| Christoffel Blindenmission, e.V. (CBM) | Mr Christian Garms, Executive Director<br>Dr Allen Foster, Medical Director |
| Foresight | Professor Frank Billson, President |
| Helen Keller International (HKI) | Mr John M. Palmer, Executive Director<br>Dr Louis D. Pizzarello, Medical Director<br>Dr Virginia M. Turner, Director, Trachoma Task Force |
| HelpAge International | Dr Murray McGavin, Ophthalmic Consultant |
| International Eye Foundation (IEF) | Ms Victoria Sheffield, Executive Director |
| Nadi Al Bassar | Professor Ridha Mabrouk, President<br>Dr Ahmed Trabelsi, Vice President |
| ORBIS International | Dr James Martone, Medical Director |
| Organisation pour la Prévention de la Cécité (OPC) | Dr Marcel Chovet, Médecin Général inspecteur |
| Organizacion de Ciegos de España (ONCE) | Mr Rafael Mondaca M., President, International Relations Commission<br>Dr Elvira Martin, Ophthalmology Adviser |
| Perkins School for the Blind | Mr Kevin Lessard, Director |
| Seva Foundation | Dr Nicole Grasset, Medical Adviser |
| Sight Savers International | Mr Richard Porter, Executive Director<br>Ms Catherine Cross, Director, Overseas Services |

Annex 2

**Associate members**

| Organization | Representatives |
|---|---|
| Fédération internationale des Associations catholiques d'Aveugles (FIDACA) | Mr Dirk van Litsenborgh, Secretary General<br>Mrs Rosmarie Segrada, President |
| The Fred Hollows Foundation | Mr Mike Lynskey, Executive Director, Marketing and Public Affairs |
| Mekong Eye Doctors (MED) | Dr Eric J. van Agtmaal, Secretary |
| Vision Aid Overseas (VAO) | Dr Rachel North, Chairman |

**Candidates for membership**

| Organization | Representatives |
|---|---|
| Al-Noor Eye Foundation | Dr Akef El-Maghraby, Director<br>Dr Sawson El-Messiri |
| Associates for World Action in Education and Rehabilitation (AWARE) | Mrs Anne Yeadon, President |
| Eyetech Foundation | Mr Claude Amar, President<br>Ms Adeline Guilhen |
| The Lighthouse, Inc. | Ms Mary Ann Lang, Coordinator, International Programs<br>Ms Barbara Silverstone, President |
| Lions Clubs International Foundation (LCIF) | Mr Michael Pajonk, Manager, SightFirst Department |
| Overbrook School for the Blind | Mr Lawrence F. Campbell, Administrator, International Program |
| Pacific Islands Council for Blind Persons | Ms Margaret R. Misso, Executive Director |

Annex 2

**Observers**

| | |
|---|---|
| American Academy of Ophthalmology (AAO) | Dr Marilyn Miller, Chairman, International Committee of Ophthalmology |
| International Agency for the Prevention of Blindness (IAPB) | Dr R. Pararajasegaram, President<br>Mr Alan W. Johns, Secretary General<br>Mrs Maggie Haws |
| International Council for Education of People with Visual Impairment (ICEVI) | Mr Lawrence F. Campbell, Vice President |
| National Eye Institute/USA (NEI) | Dr Carl Kupfer, Director |
| Royal National Institute for the Blind (RNIB) | Mr Paul Ennals, Director, Education & Leisure |
| Task Force "Sight & Life" | Dr Martin Frigg, Secretary |
| World Blind Union (WBU) | Mr Pedro Zurita, Secretary General |
| World Health Organization (WHO/PBL) | Dr Björn Thylefors, Programme Manager, Programme for the Prevention of Blindness<br>Dr A.-Dominique Négrel |

Annex 2

**Absent with reason**

| | |
|---|---|
| The Edna McConnell Clark Foundation | Dr Joseph A. Cook, Director, Tropical Disease Research Program |
| International Centre for Eye Health/London (ICEH) | Professor Gordon J. Johnson, Director |
| International Council for Education of People with Visual Impairment (ICEVI) | Dr Herman A. A. Gresnigt, Regional Chairman - Europe (*ICEVI represented by Mr Lawrence F. Campbell*) |
| Laboratoire MSD (Merck, Sharp & Dohme) | Dr Philippe Gaxotte, Directeur médical |
| Norwegian Association of the Blind and Partially Sighted (NABP) | Mr Arne J. Husveg, Secretary General |
| Operation Eyesight Universal | Mr Don O'Dwyer, President |
| Ocil sur les Tropiques/Oog vor de Tropen (OST) | Dr Jerome Vryghem, President |
| Pennsylvania College of Optometry | Dr Louis J. Catania, Executive Director |
| Seva Foundation | Dr Suzanne Gilbert, Director, Blindness Programs (*Seva represented by Dr Nicole Grasset*) |
| Swedish Association of the Visually Impaired (SRF) | Mr Lennart Nolte, President |
| World Cataract Surgeons (WORLDCATS) | Professor Arthur S. M. Lim, President |

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