Minutes of the 10th Round Table
held on 7 & 8 October 2011
at Ferney-Voltaire

Present:
- Presidency: Winds of Hope,
- Associate Member: Centre Nopoko.
- Partner Members: WHO/AFRO, FDI

Guests: Jean Ziegler and Ioana Cismas (Droits Humains), Dr Oumarou Djibo (Niger), Antonio Palma, Cédric Anker et Charles-Louis de Laguiche (Banque Mirabaud), Marianne Wanstall (Interpreter)

Apologies: Fondation Hirzel, GIGIP, Campaner, Facing Africa, Prométhée
Absent: Enfants du Monde

Friday 7 October
The Round Table (henceforth RT) was declared open at 15h45 by the presidency, Winds of Hope (henceforth WoH).

1. Adoption of the Minutes of the 9th Round Table 2010.

Patrick Joly pointed out that, in the description of his presentation in 2010, a total of 162 agents had been trained.

Members unanimously adopted the Minutes of the sessions of 1st and 2nd October 2010.

A request was made that in future a list of persons present, showing their email addresses, be made available. Philippe Rathle undertook to ensure that this was the case in 2012 and stated that this information would be brought up to date on the new NoNoma.org website.

2. Partnership WHO/AFRO - Winds of Hope

2.1. Regional Program for the Fight against Noma (RPFN)

Philippe Rathle outlined the progress made since the signature on 1 October 2010 of the contract between WoH and WHO/AFRO, with the launch of the Regional Program for the Fight against Noma, and the holding of the first inter-country coordination workshop, in December 2010 at Niamey. This had brought together the coordinators from six different countries, those responsible for the campaign against non-contagious diseases as well as the people in charge of the local WHO offices.
Four local NGOs were invited to attend: Sentinelles, Hilfsaktion, Campaner and Nomafrica, in order to promote the collaborative links between NGOs and the Ministry of Health. In the same spirit, an invitation had been issued today to Dr Oumarou Djibo to present his National Plan for the Fight against Noma (NPFN) to the Assembly.

Benoît Varenne reminded delegates that the RPFN had as its goal the elimination of noma from Africa. Its aims were to design, implement, supervise and evaluate activities in the field, in the areas of prevention; early detection; raising awareness; training; primary health care; and epidemiological monitoring. The program was sub-divided into separate national action plans for each of the 6 countries financed by Winds of Hope: Niger, Benin, Burkina Faso, Mali, Togo and Senegal.

From the moment of its implementation one year previously, the program had set about bringing together those responsible for national programs, so as to draw lessons from past experience, improve effectiveness, find ways of integrating action better, and develop partnerships. To this end, an inter-country workshop had been held from 7 to 9 December 2010 in Niamey at which national action plans for 2011 were finalized. The four main axes for action were: reinforcement of capabilities; tracking down cases and administering first aid; raising awareness and mobilizing society; monitoring; and supervision.

It had taken more time than expected after the workshop to validate these plans. It appeared that the objectives set for each country had been too ambitious. The six national plans were therefore modified in consultation between WHO/AFRO and WoH, and then validated at the end of the first quarter of 2012. They were launched in the field at the end of the second quarter. A critical analysis of this re-launching year will take place in Ouidah from 14 to 16 November 2011, with the aim of strengthening the monitoring of activities, working on their content, and re-launching epidemiological monitoring.

In reply to a question asked by the Assembly, Philippe Rathle confirmed that WoH does not commit to countries that are at war, or are politically unstable or riddled with corruption, even if they are confronted with noma.

2.2. Presentation of the National Plan of Action against Noma in Niger

Dr Oumarou Djibo, coordinator du National Plan of Action against Noma (NPAN), first gave some information about Niger:

- 15.2 million inhabitants
- Surface area of 1’267’000 km²
- Health care system covering 71 % of the population
- 80 % of the population resident in rural areas
- 62% of the population living below the poverty line
- Maternal mortality rate of 648 per 100 000 live births
- Infant/juvenile mortality rate of 198 per 1000

The healthcare system comprises three levels, together forming a health pyramid:

- The Health District, run by a district management team and itself comprising 3 levels, with 2160 Village Nursing Stations, 829 Integrated Health Centres and the District Hospitals;
- The 6 Regional Hospitals (RH) and the 2 Regional Maternity Hospitals (RMH);
- The National Hospitals at Niamey, Lamordé and Zinder.
The Niger NPAN was launched on 30 November 1999 under the auspices of the Secretariat General of the Ministry of Public Health, which is responsible for designing, implementing, and evaluating national policy with regard to action against Noma. The priority tasks are:

- Prevention of the disease and early detection of declared cases;
- Rapid treatment of declared cases, as soon as first symptoms appear;
- Educating and raising awareness of the population;
- Treatment of the long-term effects of the disease;
- Research into the disease.

These translate into the following concrete actions:

1. Reinforcement of capabilities of health workers to prevent and correctly treat Noma;
2. Early detection of cases and administration of immediate medical care;
3. Raising awareness in communities and mobilizing them to fight against Noma;
4. Creation of educational and training materials for action against Noma;
5. Countrywide epidemiological monitoring of the disease;
6. Coordination of the various program activities.

The results obtained are:

- 150 health-workers in the regions of Maradi and Tillabéri trained in the prevention and correct initial treatment of Noma (with a test at the beginning and end of the training course);
- Supervision (using a supervisory check-list) of the level of training of 26 workers trained at their place of work in the Maradi and Tillabéri areas;
- Better knowledge of the clinical indicators of Noma, allowing earlier detection and immediate initiation of treatment;
- Improved integration of action against Noma in the first aid posts of peripheral healthcare institutions (Village Nursing Stations, Integrated Health Centres and District Hospitals);
- Improved levels of awareness in quite a large number of people, notably women attending mother and baby clinics and field briefings;
- Coordination of activities with NGOs fighting Noma in the regions.

Training was for nurses and midwives, who especially have the ear of women who are pregnant or have recently given birth. The trained personnel then wrote aide-memoires for those not able to benefit from the training.

Sessions on how to detect bucco-dental infections and noma were organized in the NIRECs (Nutritional and Infant Recovery and Education Centres) of the departmental District Hospitals in 4 of the 8 regions of Niger. That is where the most severely malnourished children are taken in for treatment.

The NPAN and the NGOs identified 85 cases of noma during the first 8 months of 2011.

Philippe introduced the presentation of the projects supported by funds from Noma Day, collected by Winds of Hope and reserved for members of the Federation.
3. Noma Assembly in the North of Burkina Faso – Persis and Voix du Paysan

Dr Lassara Zala, Persis Burkina, and Adama Sougouri from La Voix du Paysan, presented the project for raising awareness about preventing the disease of noma in the North of Burkina, a project which had involved 12 villages in 2009-2010 and 18 in 2010/2011 (the 12 original villages + 6 new ones).

Three films were presented, together with photos, to illustrate the Noma Assemblies. The results obtained by the 2010/2011 campaign:

- High participation, with an average of 800 people in each village, thanks to high mobilisation prior to the awareness-raising sessions;
- A wide audience, thanks to the broadcasting of La Voix du Paysan’s programs;
- 120 opinion-formers pledged support for the project following the appeals made;
- 100 health-workers, 60 traditional healers and 60 community core points of contact were given effective training;
- More than 15,000 people had their levels of awareness raised;
- 18 radio broadcasts reached a population estimated at more than a million;
- 10 to 15 children in each village were seen by the nurse immediately after the educational briefing for mouth infections.

The perspectives for 2011/2012 are:

- resume the 2010-2011 project in 18 villages, of which 6 will be new;
- ensure follow-up in the 18 villages which had already received awareness education, by reminding people of the principles of prevention;
- continue the training of health workers, traditional healers and points of contact;
- train another 100 health-workers, 60 traditional healers and 60 community points of contact.

Asked about the incidence of Noma in Burkina Faso, Dr. Zala responded that there was about one case in 10'000 hospitalizations. Sentinelles added that they had identified 280 children in the last 10 years, which is an average of 28 children per year.

4. Awareness-raising and early detection campaign in Burkina Faso – Sentinelles

Patrick Joly from Sentinelles presented the awareness-raising and early detection campaign for Noma in the central Western region, in collaboration with the NPAN. The widespread poverty and under-development which prevail in Africa, and especially in Burkina Faso, expose the populations to more and more infections of various sorts and pose a dangerous threat to the survival and prospects of the children.

A NPAN aimed at reducing the prevalence of noma in Burkina Faso was put in place by the Ministry of Health under the supervision of OMS/AFRO and with the support of the Winds of Hope Foundation. The plan’s objectives are based on the training of health-workers, community
representatives, teachers, traditional healers, NGO staff members and opinion-formers, so as to raise awareness in the population about noma, bucco-dental hygiene and a balanced diet. To this end, a guidebook and a training manual on noma have been produced.

Since 1989, the Sentinelles Foundation, the first organisation for action against noma, put together a concrete program of aid for the child victims of noma in Burkina Faso. In the country, focused on the reception centre in Ouagadougou, Sentinelles takes in children both in emergency cases and for long-term monitoring and treatment. The most serious cases that cannot be treated locally are generally operated on in Switzerland, thanks to a medico-surgical network established and coordinated by Sentinelles. In the last ten years, Sentinelles has taken under its wing and provided medico-social follow-up for 276 children in Burkina Faso, of which 81 were operated on in Europe and almost 90 in Burkina Faso during surgical field missions.

In the period from its establishment until today, Sentinelles has noted that the number of noma cases has unfortunately not diminished. Health-workers, authorities and the general population do not know this disease, or at least not well enough; deaths due to noma in the villages are rarely recorded as such, and often are not declared at all. Of the children referred to Sentinelles at an advanced stage of the disease, several died simply because they did not receive the correct treatment in time.

When Sentinelles identifies an affected child, their agents inform and educate the family, the village folk, the authorities and health-workers about noma. To date, 556 health organizations and 653 health-workers have had their levels of awareness raised in this manner, as have schools in Ouagadougou and traditional healers in the Gorom Gorom region. Thus, the villages in which Sentinelles has intervened are well informed and the message about prevention through oral hygiene has been well absorbed. Unfortunately, the villages and areas where Sentinelles is not active do not receive such information and education and children in the acute phase of noma are often not taken in hand quickly enough to avoid grave lesions or death.

To complement the efforts made under the NPAN and in coordination with the Ministry of Health, Sentinelles launched a campaign to spread information, educate people and detect noma cases early, so as to reinforce its Burkina Faso activities. The work of educating health-care personnel in the central western district of Burkina Faso began with a course of training for regional trainers on how to initiate treatment of noma sufferers. This took place at Koudougou from 9 to 11 December 2009, and was conducted by the NPAN. It was intended primarily for those in posts of responsibility in the district health authorities, where we wished to raise awareness-levels, and it allowed us to evaluate local officials’ levels of knowledge about noma.

After this training course, we started training in five selected health areas according to the following program:

- Arrival formalities and introduction of participants
- Pre-test on knowledge about noma
- Presentation of the program and its objectives
- General background and national program
- Definition of noma
- Clinical manifestations of noma
- Treatment of noma
- Clinical cases
- Prevention of noma
- Post-test.
The results of the 2 to 3 day training courses were quite disappointing. The pre-test administered at the start of the course gave an average of 10 correct answers and the post-test, with the same questions, only 14 correct answers, so not a great deal of progress there!

In Niger two types of action have been carried out:

- Individual training of health-workers: Sentinelles visited each field nursing station in order to administer personalized training;
- Communal awareness-raising educational sessions were held in 2010 in each district of the urban area of Zinder, and then in the surrounding villages: explanations, oral hygiene checks of children, projection of a film. 109 urban districts and villages were visited.

This educational process allows for early detection of noma cases, so that faces can be saved. Since the beginning of 2011, 30 children were detected in the acute phase of noma and could thus be spared from the consequences. We need to carry on educating and training, so that the children can open their mouths!

5. Rehabilitation from after-effects of noma - Physionoma

Stéphanie Caline and Emilie Tissot, Physionoma, started by reminding the meeting of:

- The anatomical sequelae of noma, with orostoma (loss of skin and mucous membrane tissue, muscle and bone) and the formation of fibrous, retractable, adhesive scar-tissue between the different layers of tissue;
- Functional after-effects, such as nasal speech, difficulties in chewing and swallowing, voice control problems, loss of lip control, and eating and articulation disorders.

In each patient, the tissue loss, the frequently anarchic scar-tissue formation, the pain, the impossibility of making certain movements, and changes in ability to execute key functions will interact in a specific and unique way. These will determine the extent of the sequelae.

The refilling of the orostoma through surgical application of flaps allows for aesthetic and functional reconstruction, but this does not restore lost muscles, or the role they play in executing certain movements. It carries certain risks of:

- infection and necrosis of the graft;
- shrinkage of the flap;
- shrinkage of the new scar-tissue.

The easing of PCJ (permanent constriction of the jaw) allows for the mechanical opening of the jaw to be restored, but does not restore:

- the fibrotic muscles on the affected side, which are responsible for opening and closing the mouth;
- immobilised contro-lateral and peripheral muscles, also responsible for opening and closing the mouth;
- lost motor patterns, does not modifie compensatory patterns put in place.
The absence of rehabilitation increases the risk of reoccurrence of PCJ. By rehabilitation we mean here the whole range of measures taken to restore use of a person’s limb, organ or function: massages, heat therapy, active or passive mobility, sensorial and tactile stimulation, stretching etc. If it is to restore the use of lost functions and organs, it must take into account all the parameters of the previously mentioned lesions. Therefore, rehabilitation requires detailed preliminary analysis as well as the specialized techniques practised here by speech-therapists and physiotherapists.

Each patient has specific characteristics: type of sequelae, scarring, personal history, age, etc. Each must be evaluated by establishing a detailed appraisal, and the rehabilitation regime has to be adapted to suit the patient and his sequelae, so as to avoid useless or even damaging forms of treatment. This is the ideal kind of rehabilitation, because it is tailor-made for the patient and his sequelae, it allows for detailed knowledge of the mechanisms at work, and for a good vision of the likely outcome. But it requires a lot of presence and time!

An alternative does exist, in the form of schedules. These propose standardized rehabilitation programs, capable of being adapted for particular groups. The advantage is that these are less time-consuming, and more easily administered by less highly qualified staff. The disadvantages are that they are not suitable for all patients, that they sometimes need to be modified, and that they can sometimes be damaging if they are inexpertly carried out or contra-indicated. What is essential is a stable team and a trained rehabilitation worker who must always conduct a precise evaluation of each patient.

Physionoma carried out a dual mission at Ouagadougou, with Sentinelles:

- Production of a video aid to support internal training of new members and those leaving on field missions, and for training of local personnel and general awareness-raising;
- Trials and research on the use of a new tool, Therabite®.

6. Awareness-raising in south-eastern Mali – Au Fil de la Vie

Sylvie Pialoux, Au Fil de la Vie (AFV), explained that the structure of the association had changed following the dismissal of the coordinator for grave misconduct. A young doctor, Dr Modibo Kanté, who had already been active in the association’s work, had been engaged in his place. For the future, the association was starting with a new team for a two year campaign to get closer to the local populations.

Previously, AFV had already covered the regions of Tombouctou, Mopti, Gao and more recently Kayes. Much work remained to be done in these regions as a result of the frequent movements of health-workers and the inaccessibility of certain areas, so it was important to make people aware of the reality of noma in the south-eastern part of the country, where until now no mobilization had taken place.
This part of the country consisting of two vast regions, AFV started by concentrating on two districts that are relatively close to one another, so as to allow for better follow-up and evaluation of the action taken, namely:

- In Koulikoro region, the district of Diolia (99 villages, 491,000 inhabitants);
- In Ségou region, the district of Baraoueli (98 villages, 218,000 inhabitants).

Three communes in each district were covered, as well as all the villages under their administrative control. The methodology was as follows:

- Mobilisation of human resources through presentation of the program; distribution of documents and raising of awareness amongst the local administrative, civil and religious authorities, with particular attention directed at teachers;
- Training of health-workers at all levels of the healthcare pyramid (points of contact and traditional healers) with distribution of documents ensuring that action will be taken on a continuous basis;
- Community education in each of the villages.

The overall goals of the program are to improve: prevention; the training of health-workers; community education; treatment; and optimization of referencing of noma. The specific objectives are to:

- Reinforce and develop capacity of communal health-workers to identify and treat gingivitis and cases of noma;
- Detect cases of gingivitis and noma early after onset;
- Educate and mobilize the communities;
- Develop training and educational materials;
- Carry out epidemiological surveillance;
- Ensure proper coordination of the program and its different activities;
- Conduct follow-up monitoring and evaluation of the program and its different activities.

The strategic axes are:

- Training, by providing training for health-workers using technical modules relating to mouth and dental disease;
- Educational work, using events in rural areas and media coverage to raise consciousness and impart information to target groups.
- Prevention, using seminars and meetings to remove government restrictions so as to promote understanding of messages about prevention and how to implement it.

The target groups in the different associations and organizations will benefit from the support of a specially trained monitor.

The results expected are:

- The training module for early detection and treatment of gingivitis and noma and its risk factors is distributed;
• Health and social workers are trained in the prevention and treatment of gingivitis and noma and its risk factors;
• Traditional healers are trained in the detection and referral of cases of gingivitis and/or noma and its risk factors;
• Community points of contact are trained to monitor children’s health, hygiene and nutrition and to raise public awareness in their respective villages.

The projected length of this project is two years. This can be modified as a function of unforeseen events and the realities encountered on the ground. Such modifications may lead to logistical adjustments to obtain better results.

7. Training of traditional midwives in Mali – Idées’Elles

Elisabeth Sola, Idées’Elles, presented the program launched in 2009 to train traditional birth attendants in the villages of Mopti district and the Dogon area. Three years into the program, 488 traditional birth attendants have completed this training, about 160 per year. As a result, 83 villages now have trained birth attendants.

The programs for these training weeks are organised in agreement with the health authorities in each of the areas concerned. The training is carried out under the responsibility and supervision of their partner for almost 10 years, the NGO Prométhée, and in particular its health program director, Dr. Yansian Koné. Over three years, Winds of Hope allocated 90’000 CHF to allow this program to be carried out.

To combat noma, action needs to be taken as close as possible to the mothers. And closest to the mothers are the traditional birth attendants... To be a traditional birth attendant is not a career choice, but simply a service rendered to the rural community. The skills are passed on from mother to daughter, hence the absolute need for a very practical kind of training – the women are illiterate – which will give them the knowledge necessary to limit the risk factors associated with giving birth in the bush, and to discourage practices arising purely from tabous or superstitions.

The program ranges from measures to ensure good hygiene to the mother’s and baby’s nutritional needs, preparation for monitoring a pregnant woman, and evacuating her to a health centre if a major problem arises. Of course it also includes the birth itself, breast feeding, vaccinations, the detection of noma symptoms and the prevention of various pathologies such as malaria and gastro-enteritis.

The results achieved after 3 years of training emerge from discussions and exchanges with the traditional birth attendants and health centre managers. No statistical data is available for the moment. At the end of this year, Idées’Elles is expecting to receive the results of an evaluation of the impact of this fieldwork, and evaluation that was requested and financed by our association. These are therefore not scientific data, but empirical information gathered in the field.

Ancestral practices have been abandoned, such as:

• Cutting the umbilical cord with any available sharp object;
• Cauterising the umbilical cord, after cutting, with shea butter;
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- Bathing the mother and infant immediately after the birth (now: 6 hours later);
- The tradition of refusing to give certain foods to children for superstitious reasons (e.g., eggs, for fear that the child would become a thief);
- It is traditionally said that a baby is «born under a lucky star», a sign of good fortune, when it is still encased in the amniotic sac at birth. This sac is traditionally an object of value and is conserved. The birth attendants have now understood that this sac has no real medical importance and that it is necessary to remove it quickly so as to prevent asphyxiatiion.

Changes have been observed in the way traditional birth attendants now operate:

- Numerous women in difficulty and sick children are evacuated in good time to health centres;
- Monitoring of pregnancies has allowed numerous miscarriages and pregnancy problems to be prevented;
- Birth attendants are now keeping careful records of births and there has been an increasing number of registrations and drawing up of birth certificates (the records are kept by the local primary school-teacher or by some other literate person in the village);
- Birth attendants have become conscious of the risks associated with contagious diseases (coughs, dermatosis) which can easily be transmitted to a new-born child. They are now using gloves for the birth;
- They are encouraging mothers to participate in prevention campaigns;
- Thanks to the basic knowledge about hygiene transmitted to mothers, there are fewer miscarriages, neonatal deaths and deaths due to malaria in children;
- The birth attendants’ medical kits are regularly renewed;
- The status of birth attendants has been raised and they are winning the confidence of the inhabitants. These women have become the primary healthcare contact points for village people, whom they treat or refer to trained health workers or health centres.

Generally, the health authorities participate at the conclusion of each week of training, and so they have an opportunity to discuss with birth attendants, and to thank and encourage them. In all areas where training has been carried out, the nurses and the top doctors agree that:

- The birth attendants participate actively in vaccination campaigns and efforts to prevent disease, above all malaria. Local health centres have been happy to observe a notable reduction in the frequency of certain tropical diseases;
- Some doctors have suggested joining forces with NGO Prométhée to supervise birth attendants, and they note that there are fewer health problems in villages where the birth attendants have been properly trained. They stress the importance of birth attendants’ role and of the knowledge they have, given that of every 10 deaths in childbirth, 6 are due to haemorrhage and the others to postpartum infections;
- The doctors encourage birth attendants to act as health officials, so great is the need and so short-staffed the authorities;
- The health centres have all confirmed that this training has contributed enormously to the improvement of the well-being of the population.

The difficulties encountered by the birth attendants are:

- Difficulty in convincing the women to go to the health centre so that difficult deliveries can be closely monitored;
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- Difficulty in transporting them to health centres, often a long distance away, because of lack of available carts or motor bikes;
- Certain areas need more education and training, because they are very conservative societies characterised by tabous and reluctance to change;
- In some villages, birth attendants are not accepted by all the families for reasons of ethnicity or hierarchical social status;
- In other villages, old birth attendants are unwilling to allow the younger ones who have been properly trained to work.

The birth attendants have developed a taste for training and are asking for more training in the following areas:

- Better detection of malnutrition in children aged from 6 months to 5 years;
- Prevention of infectious diseases;
- Reanimation of new-born infants.

They would like to see days organised on which they can have discussions with professionals, so that they can tell them about the problems they encounter in their daily work.

The knowledge acquired by the birth attendants is still inadequate and some of them have not yet had any training at all. It is important to consolidate what has been achieved and to continue transmitting new knowledge to these illiterate bush birth attendants, who have no access to scientific knowledge, and who – although minimally equipped – preside over the arrival in this world of many thousands of babies.

8. Maquis Bébé (« Bush Babies ») – Centre Nopoko (Label Vert)

Joël Sinaré, of Centre Nopoko, sponsored by Label Vert, launched a project entitled « Bush Babies » within the framework of his prevention activities. This project supports children aged between 6 months and 5 years and pregnant women in the villages of the rural district of Nasséré.

Starting with the observation made by Gesnoma that malnourished pregnant women gave birth to underweight babies, who very often themselves became malnourished themselves, the Nopoko Centre decided to help the pregnant women and children in the medical department of the Nasséré CSPS (Centre de santé et de promotion sociale – Health and social welfare centre) health centre, so as to attack the problem at its roots.

The food aid consists of bean-based cereals, dried fish, oil, and medical supervision given by the staff of the Nasséré CSPS, with the support of a midwife from the Kongoussi CMA (Centre médical avec antenne chirurgicale – Medical and Surgical Centre). A highly nutritional porridge, made from local products, is also given. In this way, the women received foodstuffs twice a month, from June to December 2011.

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The medical supervision consists of carrying out prenatal and immediate post-birth consultations, with records being kept of weight and other anthropometric measurements. The weight of the neonate is compared with that of the same mother’s previous children. When these data are analysed, this allows the impact of the food aid in preventing low birth weights to be evaluated. As regards Bush Babies, porridge is served to the children every morning.

The project’s overall goal is to improve the level of nutrition both of the children in the NIREC at Nassere and its «Bush-Babies », and of the pregnant women so that they do not give birth to babies of low weight, which would be more vulnerable to noma. This goal breaks down into four specific objectives:

- Communication to change the behaviour of nursing mothers and pregnant women with regard to malnutrition;
- Improve pregnant women’s knowledge about the causes and consequences of their malnutrition during pregnancy, and improve their level of nutrition;
- Ensure that « Bush Babies » and pregnant women have access to local produce of high nutritional value, so as to prevent malnutrition;
- Monitoring of women throughout their pregnancies and for several months beyond.

The results obtained are:

- The women in charge of Bush Babies have been trained in the technique of preparing the enriched porridge and have received basic information on the prevention of noma;
- The mothers of 300 children have visited the Bush Babies stations;
- 297 pregnant women have been monitored and have received nutritious foodstuffs.

The lessons to be drawn are:

- The establishment of the Bush Babies stations has allowed the nursing mothers of the same village to intermingle, helping create a culture of solidarity, mutual assistance and sharing. It was observed that the community health workers were able to take advantage of these sessions of collecting porridge from Bush Babies in order to pass their messages of strategic preventive medicine, thus allowing the maximum number of children to be reached for all the other aspects of healthcare;
- The assistance and monitoring of pregnant women led to a doubling of the numbers attending the maternity clinic at the Health and social welfare centre (CSPS) of Nasséré, and this constitutes a major advance in the monitoring of weight and nutrition.

The difficulties encountered were:

- As for Bush Babies, we have to admit that, with the arrival of the rainy season, some families moved off to fields situated a very long distance from the villages in search of fertile areas to cultivate, which meant that not so many mothers came to the Bush Babies stations. The Centre at Nopoko refused to admit defeat and found an alternative, consisting of giving a supply of baby cereal to these families so that they could continue to feed their children.
- The lack of baby-scales to allow the babies to be weighed each month;
- The increase in the number of pregnant women as time went by led to inaccuracies in the forecasts of requirements for medicines and foodstuffs.
9. Integrated project for action to combat Noma and poverty - Label VerT

We know today that the disease of noma is an indication of poverty. This extreme poverty is particularly prevalent in the countries of sub-Saharan Africa, amongst them Burkina Faso. To fight noma, we need to educate, train and raise awareness, but also to combat this tenacious form of poverty. But it is not enough simply to put in place measures « in favour » of the target populations. We need to act « with them », to mobilise so as to « change together » the social reality that gives rise to this scourge. We must listen, take advantage of the survival techniques of these populations faced with poverty, and observe their creativity and imagination, their capacity to “make do”. It's only in this way that we may see emerging new and multiple ways of achieving development.

For Label VerT it is plainly obvious that we need to innovate in the fight against noma. We must act with « a set of different complementary projects in the same locality "; This is the goal of the present Integrated Project of Action against Noma, launched in response to an appeal for help from a primary school teacher in the region of Fara, province of Balé, to the south of the trunk road from Koudougou to Bobo Dioulasso. It introduces a new strategic approach to the fight against noma, as follows :

The innovation consists of including in the same project :

- Education appropriate to several target groups in the village ;
- A direct link between messages urging changes in behaviour and concrete measures to reduce poverty ;
- The identification of ways of reducing poverty by those who stand to benefit themselves;
- Putting in place of these resources thanks to a financial grant ;
- Making best use of natural resources ;
- Supporting each village in this campaign for several months.

The general goal is to prevent noma through education and reduction of poverty. The specific objectives are to :

- Raise awareness by target groups in the five villages covered by the project ;
- Make the ultimate beneficiaries responsible for identifying useful ways of fighting against poverty ;
- Put in place the identified resources for combatting poverty ;
- Optimize the use of natural resources ;
- Give support, and conduct an evaluation after eight months.

The project is taking place in five villages situated between the provinces of Balé and Boulkiemde. These localities, lying some 200 km from the capital, were selected because several cases of noma had already been diagnosed in the area, and because of availability of local human resources (women primary teachers in Fara, birth attendants at Bourou). These villages are well removed from tarmac-surfaced trunk roads, and at a very low stage of development. Poverty prevails there at all levels.
The educational work is targeted at specific well-defined groups:

- Primary school children (about 2500 pupils);
- Pregnant women and those likely to become pregnant, via women’s groups;
- Traditional birth attendants, the NIREC volunteers, traditional healers, local leaders;
- The general public.

The methods used to fight against poverty are absolutely essential in IEC messages (Information, Education, Communication), and allow those benefitting to anchor the behavioural changes required. Therefore it is vital that they themselves should identify these methods, according to their needs. A budget of 1000 Euros is allocated to each village in which at least a glimmer of hope is permissible! As examples of feasible microprojects, one could imagine a village shop, a storage point for pharmaceuticals, seeds for out-of-season crops, small-scale animal husbandry, the planting of trees that have nutritional and commercial value (nere, moringa, shea etc.), donkey-carts, etc.

The exploitation of natural resources consists first of evaluating the environmental situation in each village, and then proposing varieties to plant, giving priority to species with high nutritional and commercial value, so as to contribute to the improvement of living conditions.

Assistance or monitoring is not just necessary, but indispensable, in a process that requires solutions to be found at every stage. Conceived as a partnership, based on respect and dialogue, this monitoring will promote the feeling of ownership of the project by the different parties, as well as their involvement in the sustainability of the positive results it engenders.

10. Surgical Missions – Enfants du Noma

Dr. Pierre Seguin, Enfants du Noma (EDN), informed the meeting that the association’s office had been transferred to St Etienne, and gave an account of the surgical missions that had taken place during the winter of 2010:

- 7 missions to Burkina Faso, divided equally between maxillo-facial and orthopaedic surgery, with about 30 children operated on per mission;
- 1 exploratory mission to Benin, mostly for orthopaedics.

He stressed the good cooperation with Ensemble Pour Eux, Action Enfant Chirurgie, and Maison de Fati.

In Mali, the missions had been suspended because of problems with security and the cessation of cooperation with Au Fil de la Vie. There was a desire to go back there, but this could only happen when political stability was restored and new partners found.

In the winter of 2011, 8 missions were planned to Ouagadougou and 1 mission to Ouahigouya, where Dr Zala practises. An orthopaedic mission is planned for Kové in Benin, a country in which EDN would like to establish a long-term presence.
He noted that over the last 11 years the following progress had been made:

- Large increase in paediatric orthopaedic treatment;
- Stability in labio-alveolar-palatal clefts, in maxillo-facial tumours, and in sequelae from burns or facial traumatology;
- Reduction in fresh cases of noma and in its sequelae.

To close the first day, Philippe Rathle gave the word to Jean Ziegler.

The right to nourishment is a Human Right. Noma is a violation of the right to nourishment. We are trying to obtain a Human Rights Council resolution with prescriptive force declaring noma to be a Human Rights violation. A regulatory basis is needed to allow for effective action against Noma. A coalition of States will present this resolution to the general assembly of the WHO. It is not enough that civil society mobilises – the WHO must too.

Saturday 8 October

The Round Table restarted at 9h15.

Philippe Rathle paid tribute to the remarkable work of Aviation sans frontières and addressed his warmest thanks to the Association, through Michel Poitevin. In 2010, ASF transported:

- 5000 WHO posters;
- 450 packages of milk;
- Radiological equipment for Persis Centre;
- Conveying children to Europe for Sentinelles.

11. Reconstructing faces, changing lives – Project Harar Ethiopia

Tom Hoyle presented his association, which aims to reach the poorest of the poor.

Since 2004, the project has grown up around the town of Harar, a very large muslim town. Then the regional government asked us to extend our action to other areas. In the rural areas, health education leaves a lot to be desired, and pathologies are legion. The project does not discriminate, and it treats not only noma, but also cleft lips, and other traumas (hyena bites, for example).
Population: 90.9 million inhabitants most of them rural, of which 46% aged under 15 ans, 38% living in extreme poverty, 20% living more than 10 km away from a medical station. The great difficulty is to find the target groups, the poorest of the poor, who are spread out over an enormous area. Another difficulty is that of language. There are 84 indigenous languages, of which 3 main ones: Amharic, Oromo and Somali.

Priority is given first to collaboration between local and foreign doctors and secondly to training nurses. The method consists of an interview and a preliminary auscultation. In facial reconstruction, we insist on the functional aspects. Rehabilitation through physiotherapy then takes place before the patient returns to the village.

Since 2007, we have had 115 noma patients, of which 52% were women and 50% less than 18 years old. In recent years, we have realised that our project will have to continue for a long time.

12. For children, against prejudice – Peter Ustinov Foundation

Gunther Bitzer, Peter Ustinov Foundation, presented the Foundation launched in 1999 by Sir Peter Ustinov, actor, writer and for many years a UNICEF ambassador. Children are our future, and we need to create an environment that allows them to tackle global social challenges in a spirit of fairness.

The Foundation is involved in 3 types of project:

- International, thanks to a presence in more than 30 countries;
- National, in Germany, notably with educational programs;
- Contributions to international debates and civic engagement.

The Foundation has been active in noma since its creation, supporting Hilfsaktion Noma e.V. to a value of 3 million Euros. In Niger this has consisted since 2000 in the development, training and funding of salaries for emergency programs and interventions, notably during periods of famine. Since 2008, support has been given to Guinée-Bissau.

The Foundation is in the process of defining its strategy towards noma. It is likely to concentrate initially on the following three areas, with the aim of eradicating Noma:

- Engagement and civic dialogue as well as education to promote better knowledge of the disease;
- The reduction of re-infections through improved nutrition and better access to primary healthcare;
- The fight against marginalisation and social exclusion by promoting inclusive education, which aims to raise awareness against discrimination and its consequences;
- Medical treatment, by facilitating access to healthcare.
13. Rural health programme in Burkina Faso – A Better Life Foundation

Philippe Bédat, A Better Life Foundation, presented the community health program at Fada and its extension to Ziniari. Since 2008, the objectives have been the prevention of noma, together with the reduction of the spread of malaria and detection of cleft palate and club foot.

Following coordination with the Ministry of Health, the project took place in the health district of Fada Ngourma and concerned 458 villages, 332,000 inhabitants and 34 CSPSs (Health and social welfare centres). In 2008, 31 ICPs (head nurses) and 66 CHWs (community health workers) were trained and evaluated, which represents two volunteers per CSPS. In 2010, refresher training of existing CHWs took place and 34 new ones were trained. In 2011, refresher training was provided to CHWs and head nurses.

The number of people who received awareness training between 2008 and August 2011 was:

- 19,445 in the concessions;
- 6,479 in schools;
- 14,827 in the community;
- 1,165 sick people in dispensaries.

In September 2010, a training seminar for 334 primary and secondary teachers was organized.

From January 2012, the program will also be applied in the Ziniare health district, with the aim of training 212 community health workers, one for each of the 212 villages, and 49 head nurses. Training of 40 new CHWs in the health district of Fada Ngourma will also continue. The Ministry of Health of Burkina Faso refuses to allow the CHWs to open the mouths of children, under the pretext that they are not nurses. We must fight against this prejudice, so as to facilitate detection.

14. Initial Results of Noma Surgery – Dutch Noma Foundation

Dr Klaas W. Marck, Dutch Noma Foundation, presented the results of the first clinical investigation on noma surgery.

After a maxillo-facial mission, surgeons tend to describe the scientific reality in rather embellished and unrealistic terms. In so doing, they create a scientific virtual reality, that many people take to be the truth. But what we read is not necessarily reality. How can we tell the difference between claims and truth? What are the real outcomes of surgical missions?

In 2007 and 2008, we conducted four studies of outcomes on 74 noma patients, made three weeks after the surgical teams had left, two in Sokoto, Nigeria, and two in Addis Ababa, Ethiopia, identifying complications (infections, necrosis) and other post-operative problems.

The complication rate of the 74 patients proved quite high: 64% (47 cases out of 74), far more than in any of the literature reporting the results of surgical missions.

- 36% excellent (no complications);
- 23% good (minor complications), a total of 59% of good results;
- 16% poor (medium-level complications);
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• 11% bad (serious complications);
• 14% very poor (severe complications), in total 31% of poor outcomes.

This result is highly dependent on the complexity of the cases: in simple cases, there are 79% good results, but only 39% good results in difficult cases. Two factors have a negative influence regardless of the technical quality of the surgery: the complexity of treatment and the constriction of the jaws. In conclusion:
• The complication rate is much higher than expected;
• Clinical outcomes are worse than expected;
• Clinical outcomes are better in simple cases than in complex cases;
• This measurement should feature in the reports of surgical missions.

In particular, all operations need to be critically evaluated and we should ask whether we are serving the interests of the patients in our care. Is it enough just to be a good Samaritan? Clearly not!

Sentinel emphasized the need for good record-keeping on operations to improve surgical outcomes.

15. Prevention Project in Burkina Faso – Hymne aux Enfants

Martine Jaquier and Mao Savadogo, Hymne aux Enfants, presented their projects in Burkina Faso in the absence of Kam Madibèlè, the consultant physician of the Foundation, which accommodates 40 children at a boarding school in Ouagadougou. The first project focuses on the integrated management of cleft lips and palates. If such a thing exists at all, it is difficult to access, and clinical monitoring is sorely lacking: associated malformations, nutritional problems, psychological problems, etc. In collaboration with the health authorities, the Foundation began an information campaign for parents and health personnel. This began in Ouagadougou and will extend to the rest of the country. A poster was produced and distributed in the health districts. The results were not long in coming: one case per week was identified. Surgical missions will be organized for these operations.

The second project was expected to begin in 2012 and focused on prevention through the organization of medical check-ups in primary schools carried out by local doctors from the Chaînes de la Solidarité association. Beyond the preventive aspect, the project aims to persuade the authorities to make school medical examinations compulsory. These are virtually unknown in Burkina Faso.

16. Treatment of noma – Non au Noma en RDC

Dr. Sady Kipasa, of Non au Noma en RDC (No to Noma in the Democratic Republic of Congo), indicated that the association was undergoing a very critical period, because its main partner had abruptly ceased giving support, leaving the association without any support or resources. It lacked in particular a vehicle, essential for achieving its mission. The difficulty with the vast dimensions of the DRC was that they were forced to restrict themselves to certain areas. The Bukavu region, for example, is located 2,500 km south of Dr. Sady Kipasa’s clinic and it is very difficult to access. Moreover, this clinic is not equipped with residential accommodation for
admissions, which limits the number of interventions. In addition, the building had recently been bought by a politician, which would mean a move.

Many cases of cleft lip and palate are detected and surgically treated by Dr. Sady Kipasa. It is also essential to treat children with congenital lip and palate malformations. The WHO is present in the DRC, but it is not active in the fight against noma, so there again the association lacks support.
At the core of the fight against noma, there is inevitably the fight against malnutrition, which is why the association has planted corn crops. They quickly come up against dietary traditions that obstruct the introduction of new types of food.

17. Activities and support - Noma-Hilfe Schweiz
Adeyinka Onabanjo of Noma Hilfe Schweiz presented his association, whose goal was to raise funds to finance prevention projects in the fight against noma in Africa. The projects supported are:

• Preventive campaigns;
• Training and coaching of local staff on site;
• Medical treatment on site, distribution of antibiotics and tropical medical care;
• Surgery in specialized hospitals (facial reconstruction and plastic surgery);
• Psychosocial support for children and their immediate families;
• Monitoring of children operated on, and financial support for their home environment to improve hygiene.

Associations supported were:
• Sentinel in Niger for awareness-raising and surgical missions;
• Hilfsaktion Noma in Niger and Guinea-Bissau for hospital infrastructure;
• Ensemble Pour Eux (Together For Them) in Mali, Burkina Faso and Niger;
• Physionoma in Mali, Burkina Faso and Niger;
• Persis in Burkina Faso for awareness-raising;
• Dutch Noma Foundation in Nigeria for surgical missions;
• Project Harar in Ethiopia for awareness-raising.

Noma-Hilfe Schweiz offers an excellent opportunity for cooperation, and we are open to hearing about all worthwhile projects!

18. Research Work – Gesnoma
Dr. Denise Baratti-Mayer, of Gesnoma – the plastic and reconstructive surgery unit at the University Hospital in Geneva (HUG) presented two studies.

The first assessed the impact of the sequelae of noma surgery on the social integration of the children operated on. The sequelae are crippling, aesthetically and functionally. The impact on the children’s social life is high: rejection, schooling problems, difficulties in getting married and problematical professional integration. The aim of the study was to determine if surgery had a favorable impact on the children’s future life, socially.
The method was to examine 800 cases of children and adults who suffered from noma and were monitored by Sentinels. A cohort of 350 cases with the following inclusion criteria was used: originating from Niger, minimum of 2 years’ monitoring, availability of a complete file containing basic demographic data, and children of school age at the beginning of surgical treatment, that is between ages 7 and 13.

Of these 350 children, 203 (58%) were female, and 147 (42%) male. 259 (74%) had undergone surgery, 35.5% of these during a field mission and 64.5% after transfer to Geneva.

Following the classification of the sequelae of noma into four types, plus internal noma, the proportions of subject individuals enrolled at school before and after surgery was determined. The overall results are:

- Only 15% of children with noma and of school age are at school;
- After surgery, 60% of these children are in school (national average: 58.6%);
- This difference is statistically significant (p < 0.05);
- The benefits of surgery seem to be observed regardless of the type of lesion or sex of the pupil.

We then determined the proportion of subjects married after noma surgery. The overall results are:

- 44% of surgically treated patients got married;
- There does not seem to be any differences between the types of lesion;
- On the other hand, girls seem to marry more frequently than boys (56% vs 28%).

Following this study, discussion is open as to whether:

- Surgical treatment in Switzerland would make it more difficult to reintegrate into the community than the sequelae of noma themselves or
  Transfer to care in Europe can offer forms of treatment that they would not be able to receive in Niger and improves the final result;
- Cultural differences would make any return back home very difficult or
  The figures on school attendance suggest that children were well integrated after their return to Niger.

Finally, our data show that reparative surgery has improved school enrolment and allowed a good many of them to proceed to marriage, provided that surgery is always accompanied by subsequent medical and social monitoring.

The second study established the link between maternal malnutrition during pregnancy and noma. In 2010, Gesnoma had established that the risk factors for noma were malnutrition, malaria, numerous siblings, ranking position amongst the siblings (above N° 3), and the probable exhaustion of the mother.

The process whereby the risk of noma develops is therefore the following:
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- Maternal nutritional deficiencies during pregnancy;
- Delayed intrauterine growth;
- Low birth weight;
- Immune deficiencies in babies;
- Decreased resistance to infections;
- Susceptibility to noma a few years later

Niger experienced a major food crisis in 2005. Knowing that malnutrition was the primary risk factor for noma, the study investigated retrospectively whether this famine had had an impact on the appearance of noma. The results are that there was no surge of new cases in the year of food shortages (2005), nor in the two following years, 2006 and 2007 (about a dozen cases per year). However, a significant increase in new cases (39) was observed in 2008 with Sentinelles, 3 years after the famine. The average age of children with noma in 2008 was 3.4 years. These children were in utero during the famine.

This study gives some preliminary validation to the theory of perinatal nutritional deficiency. So therefore what is now needed is an intensification of information campaigns targeted on women about food intake during pregnancy.

19. Project for a Care Manual - WHO / AFRO

Diseases of the oral cavity are increasing in Africa, whilst they are tending to decrease in Europe and other Western countries. Access to basic health care is very low. Access to primary health care is essential.
Hence the idea of compiling a Care Manual, funded largely by Hilfsaktion Noma. The objective is to provide nurses in the field with a practical manual, consisting of guidelines for treating, with available resources, the diseases of the oral cavity.

Three phases are planned:

- December 2011: meeting for an exchange of experience of those individuals involved in the practical care of these conditions;
- consultations with international specialists, and cross-referencing of information gained in the field with scientific information;
- test the first draft in selected countries
20. **Human Rights and the Fight against Noma**

Ms. Ioana Cismas, legal researcher in the field of human rights and assistant to Prof. Jean Ziegler, Vice President of the Human Rights Council Advisory Committee of began by introducing him. Between 2000 and 2008, Jean Ziegler was the UN Special Rapporteur on the right to food. During a mission to Niger in 2005, he encountered noma when with Sentinelles, and this triggered his deep conviction that Noma is a violation of human rights, and in particular the right to food, because of the link between malnutrition and the appearance of noma.

The Human Rights Council Advisory Committee, of which Jean Ziegler became a member in 2009, is a body made up of 18 independent experts and serves as a think-tank for the Human Rights Council. This Council, based in Geneva and composed of 47 ambassadors, adopts resolutions on important human rights issues. They do not have the force of law because states are not obliged to implement the decisions. However, they are important tools of legitimization and are taken seriously by governments.

In 2009, Jean Ziegler entrusted his noma file to Ioana Cismas and tasked her with bringing the question of noma before the Human Rights Council, and thus help to legitimize the work done on the ground by NGOs. The idea was to make States admit that noma was a human rights issue, and remind them of their obligations in this regard.

The first paper, "The Tragedy of Noma", was presented to the Advisory Committee in August 2009 in order to show the link between noma and children’s human rights. As this report had not been mandated by the Human Rights Council, it had no formal value, but it served as a basis for obtaining the Council’s mandate, in March 2011, to "undertake a comprehensive study on the relationship between severe malnutrition and childhood diseases, taking children suffering from noma as an example."

In August 2011, Jean Ziegler presented a preliminary study to the Advisory Committee: "Severe Malnutrition and Childhood Diseases, taking children with noma as an example." This report showed that malnutrition was the key risk factor for noma, and that this was a neglected disease. It concluded that the human rights of children, the most vulnerable members of the international community, were being seriously ignored and violated. States and international organizations had a duty to act.

In February 2012, the Advisory Committee was scheduled to adopt the final version of the study, for submission to the Human Rights Council at its meeting in March 2012. NoNoma members would receive document of the preliminary study to allow them to make comments, which would be warmly welcomed.

Jean Ziegler intervened to emphasize the absolute necessity of an alliance between states in order to obtain a majority in the Human Rights Council for the adoption of the report in March 2012. He would contact the members of NoNoma to ask that they approach their governments, through their contacts, so that these governments charge their ambassadors with voting positively. As for the WHO, despite their obvious financial difficulties, a change of language and position towards noma was required.
21. Questions from Members

In response to a question, Philip Rathle stated that all 2011 and preceding years’ presentations would be available on the future website: www.nonoma.org.

In 2010, there was talk of a new noma map. The positioning system used by the revolutions in the Arab Spring could be taken as an example. There were also methods that operated like “oral health” on Google Map. A working group was formed with Robert Klaas, Patrick, Denise and Carole as members.

The patient’s index-card is used when the patient is first contacted. The Monitoring sheet keeps a record of the follow-up after six months and then a further two months. This document is essential to know the surgical history of a child, and so improve child care. Missions took place in Niger from December 2010 onwards, and the sheets were filled in by Sentinelles. Then, the Monitoring sheets of these patients arrived in May 2011. No records have been received from other members. Why not? When we know that surgical missions took place! With Persis, the surgeon did not come on two occasions, because of the terrorist threat hanging over Ouahigouya. As for Enfants du Noma, they were absent last year, so the info was probably lost. No information available on Hilfsaktion’s missions! Project Harar requires that surgeons be trained to fill in these sheets. This may take some time. In addition it is necessary to translate these forms into English. Carole will again send the sheet out to the new members and to Hilfsaktion, insisting that everyone fill them in.

With regard to the issuance of a certificate of training on noma, Physionoma currently issues a certificate of attendance at training that mentions specifically everything that has been learned during training. It would be interesting to work towards a certificate that confirms not only completion of training, but also levels of competence and autonomy achieved. According to Dutch Noma Foundation, it is only possible to give a certificate of attendance. Diplomas or certificates are the responsibility of local authorities, which should organize the exams. We did not have the standing to administer exams to local workers. According to Philippe Rathle, the problem is that local authorities are not yet familiar with the kinds of training provided by Physionoma. But we should make these better known, so that the authorities can agree to issue recognized certificates. According to Michèle Piccard, one should also consider a certificate of training for health workers trained by member organizations.

Dutch Noma suggested that each member should transfer its publications, medical or otherwise, onto the NoNoma website, to make them available to other members. This would constitute a library or database. The question was then raised as to whether it was necessary to have a system for checking the content of the quality of proposed publications. These just needed to be scientific publications (medical or otherwise) and not newsletters... And we had to be careful about the question of copyright. Pubmed is a medical search engine that allows people to find any publication by entering keywords and searching. You could find abstracts and links to sites containing publications.

Michèle Piccard suggested that Winds of Hope should make contact with organizations such as Médecins sans frontières (Doctors Without Borders), Red Cross, etc., who were present at the scene of crises, so that they know how to communicate about the cases of noma they detect.
5) Bilan et clôture

Summary and Closing

Philippe Rathle noted with satisfaction the increase in membership and the wealth of discussion during these two days. He wondered which ideas would improve the usefulness of the Round Table: Should working groups be formed, or should a theme be selected? Should part of the Round Table be open to the public?

Thank you for sending in your ideas and suggestions.

Jean Ziegler thanked Philippe and Carole for their excellent work in organizing these debates.

Philippe warmly thanked Marianne for her faithful commitment to interpretation, and Ariane for taking valuable notes.

Roundtable adjourned at 3.15 p.m.

Presidency:

Winds of Hope

Lausanne 24 September 2012