

## BRIEF COMMUNICATION

# International Confederation for Cleft Lip and Palate and Related Craniofacial Anomalies Task Force Report: Beyond Eurocleft

Gunvor Semb, D.D.S., Ph.D., for the Beyond Eurocleft Task Force

The assigned objective for the Task Force Beyond Eurocleft was "to make recommendations for initiations of local and/or participation in multi-national cleft outcome studies and consist of individuals from the European experience with cleft outcome studies (Scandcleft, Eurocleft) and those who have initiated, or intend to initiate, similar studies in other geographical areas." By May 2013 the Task Force (TF) consisted of 183 members from 59 countries. It was agreed that this initiative should be truly global and include all cleft specialties as well as representatives from cleft support groups in recognition of the huge commitment for improving cleft care worldwide. The vision for this group is to build a dynamic, well-functioning TF that will work globally and be multidisciplinary with inclusive and respectful behavior to improve care for all individuals born with cleft lip and/or palate.

As there is a large diversity in needs and interest in the group a range of parallel approaches would be required depending on the experience, resources, and challenges of regions, teams, and individuals. Important ideas for future work were: (1) Work on a global survey of access, existing outcome studies, current collaborations, and lessons learned. (2) Work towards the creation of a lasting, living resource for newcomers to intercenter collaboration that is kept fresh with new reports, copies of relevant publications, model grant applications, and a list of volunteers with the right experience to provide support and guidance for new initiatives. (3) Develop simple online training modules to provide information about the benefits and principles of multidisciplinary care, collaborative data collection and auditing short and longer-term outcomes. (4) Establish subgroups that will work within all regions of the world with regional and national leaders identified. An evaluation of current standards of care should be undertaken and country/region specific remedies to optimize treatment outcome suggested. (5) Reach agreement on minimum standards of care, minimum record collection, and reach consensus on simple outcome measures in all disciplines. This should include all cleft types and all ages. These standards could be used to encourage governments to fund multidisciplinary care. (6) Teams will be encouraged to start and continue recordkeeping using simple and agreed protocols, according to agreed standards of minimum records and later share their data with other teams and then, embark on outcome studies. (7) Teams already active in research should: Create a register for cleft professionals and teams to reach agreement of contemporary and comprehensive multidisciplinary outcome measures, explore the possibilities using modern technology and plan large multi-national studies. A patient/parent centered data collection should always be included. These studies need funding. One task could also be exploring whether health care at a distance could be initiated using new technology.

KEY WORDS: *Global Cleft Team Network, international collaboration, outcome measures, regional subgroups*

### ASSIGNED OBJECTIVES OF THE TASK FORCE

The organizers of Cleft 2013 proposed that the objective for this task force would be "to make recommendations for initiations of local and/or participation in multi-national cleft outcome studies." It was suggested that the task force "should consist of individuals from the European experience with cleft outcome studies (Scandcleft, Eurocleft) and those who have initiated, or intend to initiate, similar studies in other geographical areas."

The suggestions and comments from colleagues who had participated in multicenter studies showed that the

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Dr. Semb, Senior Lecturer in Craniofacial Anomalies, School of Dentistry, University of Manchester, Manchester, United Kingdom.

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Address correspondence to: Dr. Gunvor Semb, School of Dentistry, University of Manchester, Higher Cambridge Street, Manchester M15 6FH, United Kingdom. E-mail: [gunvor.semb@manchester.ac.uk](mailto:gunvor.semb@manchester.ac.uk).

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assigned objective left room for different interpretations. Because this was an international congress with participants from many different disciplines and cleft interest groups, it was decided that this initiative should be truly global and include all the specialties involved in cleft care as well as representatives from affected families and/or patients.

## TASK FORCE FUNCTIONING

### Membership Acquisition and Demographics

To identify possible members representing all cleft specialties in all parts of the world, a letter of invitation was sent to known colleagues together with a questionnaire to obtain information about members' motivation for joining the task force, their experience in planning and/or participating in intercenter outcome studies, and their ideas for the organization and direction of this specific task force. By May 1, 2013, 220 persons had been invited to participate, and the response rate was 86%. Of the 189 who replied, 183 said "yes" and 6 said "no" or "not now"; the reason given for declining the invitation was work overload. The different specialties and their geographical regions are presented in the Table.

### Survey of Members

The survey was completed by 168 (92.8%) members, and their answers and contact details were disseminated to all participants.

#### *Members' Motivation for Joining This Specific Task Force*

The vast majority answered that the main motivation for joining the task force was their passion to improve cleft care not only in their own countries but also worldwide. They wanted to learn from others and work together toward agreement on global standards for documentation and outcome measures for all disciplines and all cleft types. They were eager to collaborate, because multinational or international collaboration is the only way to achieve evidence-based care for all.

#### *Members' Involvement With Collaborative Cleft Care*

Of the 168 task force members, 114 (68%) were working in multidisciplinary teams that are participating in multicenter or multinational comparative outcome studies; 54 (32%) had limited experience in outcome studies. In the latter group teams not yet fully established, and systematic documentation and follow-up is difficult; and some were at the beginning of establishing teams. However, all expressed an interest in

standardized record keeping that would enable them to participate in future outcome studies.

The members had many ideas for the direction and the organization of this task force. As these suggestions were discussed further at the task force meeting at the Orlando conference a summary will be presented later in the report.

### How Issues Evolved During the Process and Preparations for Orlando Task Force Meeting

The agenda at Orlando task force meeting consisted of presentations from members and roundtable discussions. It was first decided to set up subgroups according to specialty, and a lead for each group was appointed and asked to present a brief report. At this meeting, 121 members confirmed their participation and were asked to choose one of the following eight focus groups established for roundtable discussions:

1. Focus Group on Development of a Cleft Lip and Palate Team
2. Focus Group for Intercentre Comparison Studies
3. Focus Group on Documentation and Outcome Measures
4. Focus Group for Studies Beyond Eurocleft, Creating a Website, and Establishing and Maintaining "Beyond Eurocleft"
5. Focus Group on Communication Between Researchers and Clinicians
6. Focus Group on the Establishment of Cleft Confederations in Different Parts of the World.
7. Focus Group for Specialist Nurses
8. Focus Group for Sub-Saharan African Countries

Before the meeting participants were informed of their allocated focus group and sent a list of possible discussion points. The European Recommendation and Guidelines for Cleft Care was also disseminated before the meeting (Shaw et al., 2001).

## TASK FORCE MEETING AT ORLANDO

Summaries from the leads of specialty groups for surgeons, nurses, speech pathologists, psychologists, and orthodontists all recognized the importance of holistic care for patients born with clefts. There was a strong expression of the importance of multicenter studies to improve the evidence base for cleft care, both by those who had already participated in such research and those who were yet to do so. It is important to agree on standardized outcome measures for each specialty and the timing of record collection. Standardized common treatment protocols between centers would help with cooperation, help with assessment of outcomes, and increase sample size. A range of parallel approaches would be required depending on the experience, resources, and challenges of regions, teams, and

**TABLE Task Force Members**

<i>Region</i>	<i>North America</i>	<i>South America</i>	<i>Europe</i>
Nurse specialist, 6.6% of task force	Clarke, Noreen (USA)		Bannister, Patricia (UK); Hudson, Nichola (UK); Bojikova, Kostadinka (Bulgaria); Elfving-Little, Ulla (Finland); Hashova, Nedlalka (Bulgaria); Jonsson, Anette (Sweden); Latter, Katrine (UK); Lindberg, Nina (Norway); Paganini, Anna (Sweden); Smedegaard, Lisa (Denmark); Uvemark, Annika (Sweden)
Speech pathology, 16.9% of task force	Chapman, Kathy (USA); Scherer, Nancy (USA); Cohen, Marilyn (USA)	del Pilar Echeverri, Maria (Colombia); Dutka, Jeniffer (Brazil); Fukushiro, Ana Paula (Brazil); Jury, Silvia (Argentina); Pergoraro-Krook, Maria Ines (Brazil); Yamashita, Renata (Brazil); Coelho, Micheline (Brazil)	Lohmander, Anette (Sweden); Sell, Debbie (UK); Sweeney, Triona (Ireland); Willadsen, Elisabeth (Denmark); Aukner, Ragnhild (Norway); Bogh Nielsen, Joan (Denmark); Dahl Jørgensen, Line (Denmark); Kasakova, Maria (Bulgaria); Neuman, Sandra (Germany); Nyberg, Jill (Sweden); Oravkinova, Zuzana (Slovakia); Pedersen, Nina-Helen (Norway); Persson, Christina (Sweden); Koenig, Caroline (Austria); Kulak, Kayikci Mavis (Turkey)
Surgery, 32.8% of task force	Fisher, David (Canada); Courtemanche, Douglas (Canada); Kirschner, Richard (USA); Matic, Damir (Canada); Samson, Thomas (USA)	Martinelli, Roberta (Brazil); Alonso, Nivaldo (Brazil); Bermudez, Luis (Colombia); Marchino, Margarita (Peru); Morovic, Carmen Gloria (Chile); Pereira, Rui (Brazil); Prada, Rolando (Columbia); Rocha, Diogenes (Brazil); Souza, Telma (Brazil)	Berenguer, Beatriz (Spain); Breuegum, Corstiaan (Belgium); Brusati, Roberto (Italy); Filip, Charles (Norway); Lilja, Jan (Sweden); Mehendale, Felicity (UK); Pellerin, Philippe (France); Rautio, Jorma (Finland); Schachner, Peter (Austria); Gundlach, Karsten (Germany); Koselj, Vesna (Slovenia); Lenz, Jan-Hendrick (Germany); Sader, Robert (Germany); Zaleckas, Linas (Lithuania); Gonzalez-Landa, Gonzalo (Spain); Spataru, Radu (Romania); Anastassov, Youri (Bulgaria); Andersen, Mikael (Denmark); Becker, Magnus (Sweden); deMey, Albert (Belgium); Gonzalez-Meli, Beatriz (Spain); Hakelius, Malin (Sweden); Mark, Hans (Sweden); Tosun, Zekeriya (Turkey); Vindenes, Hallvard (Norway); Vrtiskova, Jitka (Czech Republic); Akota, Ilze (Latvia)
Psychology/social work, 3.8% task force		Garcia, Regina Celia (Brazil); Mazioero Custodio, Sivana Aparecida (Brazil); Mesuita, Sonia Tebet (Brazil)	Billaud Feragen, Kristin (Norway); Persson, Martin (UK); Rumsey, Nichola (UK)
Orthodontic, dental specialists, 32.8% of task force	Daskalogianniakis, John (Canada); Hathaway, Ron (USA); Long, Ross (USA); Mercado, Ana (USA); Oberoi, Sneha (USA); Russel, Kathy (Canada),	Okada Ozawa, Terumi (Brazil); Costa de Melo, Edna (Brazil); DoVale, Dione (Brazil); Escobedo, Margot (Peru); Siqueira, Niedje (Brazil); Velez, Juanita (Colombia); Pinto, Joao (Brazil)	Bellardie, Haydn (UK/South Africa); Dominguez-Gonzalez, Susana (UK); Friede, Hans (Sweden); Heliövaara, Arja (Finland); Kuijpers-Jagtman, Anne-Marie (The Netherlands); Mølsted, Kirsten (Denmark); Mooney, Jeanette (UK); Mossey, Peter (UK); Sandy, Jonathan (UK); Semb, Gunvor (Norway/UK); Shaw, Bill (UK); Boboc, Lidia (Romania); Dogan, Servet (Turkey); Fudalej, Piotr (Poland); Garattini, Giovanna (Italy); Herzog, Georges (Switzerland); Jagomägi, Triin (Estonia); Jost-Brinkmann, Paul-Georg (Germany); Karsten, Agneta L-A (Sweden); Katsaros, Christos (Switzerland); Klimova, Irena (Slovakia); Küsel, Annelise (Denmark); Marcusson, Agneta (Sweden); Maulina, Inese (Latvia); Mølsted, Kirsten (Denmark); Ongkusuwito, Edwin (The Netherlands); Rizell, Sara (Sweden); Sierwald, Ira (Germany); Uzel, Aslihan (Turkey); Paul, Sæle (Norway); Dogan, Ege (Turkey); Kuijpers, Mette (The Netherlands)
Epidemiology scientists, geneticists, 1.6% of task force		Trindade, Inge (Brazil)	Clayton-Smith, Jill (UK)
Ear, nose, and throat and audiology, 4.4% of task force		Piazzentin Penna, Silvia (Brazil); Antonelli, Melissa (Brazil); Brandao, Giovana Rinalde (Brazil)	Painter, Gill (UK); Hjertman, Helene (Sweden); Loven, Jens-Øyvind (Norway); Ogut, Fatih (Turkey); Chorbachi, Raouf (UK)
Support, 1% of task force			Davies, Gareth (France); Andersen, Bjørn Terje (Norway)

**TABLE Task Force Members**

<i>Africa</i>	<i>Asia</i>	<i>Middle East</i>	<i>Austral-asia</i>
Habte Mesay, Gebrehanna (Ethiopia)	Fujiwara, Yuri (Japan); Hariharan, Savitha (India); Pereira, Valerie (China); Wahyuni, Luh K. (Indonesia)	Derakhshandeh, Fatemeh (Iran)	
Adam, Saleigh (South Africa); Donkor, Peter (Ghana)	Bonanthaya, Kristnamurthy (India); Murthy, Jyotsna (India); Tansipek, Bernard (Philippines); Kogo, Mikihiko (Japan); Karunathilleke, Tharushie (Sri Lanka); Chowchuen, Bowornsilp (Thailand); Fayyaz Ghulam, Qadir (Pakistan); Gundsekera, Romesh (Sri Lanka); Handayani, Siti (Indonesia); Khondoker, Sazzad (Bangladesh); Yeow, Vincent (Singapore); Kresante, Prasetyanugraheni (Indonesia); Ma Lian (China)	Bakri, Sherif (Egypt); Al-Khaja, Anwar (Dubai)	Gillett, David (Australia)
Cooper, Daphne (South Africa)			
Abbas, Shaza (Sudan); Adeyemi, Abigail Toluwani (Nigeria); Bataringaya-Sekalala, Aisha (Uganda); Bellardie, Haydn (UK/South Africa); daCosta, Ranti (Nigeria); Ghabrial, Emad (South Africa); Newman-Nartey, Merley (Ghana); Ngom, Papa Ibrahima (Senegal)	Basnayake, Sriyani (Sri Lanka); Batra, Puneet (India); Huang, Daniel C. Shing (Taiwan); Kharbanda, Omprakash (India); Susami, Takafumi (Japan); Moghe-Ghadyalpati, Gayatri (India)	Aljohar, Aziza (Saudi-Arabia); Kerameddin, Sharareh (Iran)	Fowler, Peter (New Zealand); Kilpatrick, Nicky (Australia)
			Thompson, John (New Zealand)

individuals. There was a call for integrating cleft care and research at the national level, but some thought regional and interdisciplinary rivalries made collaboration across borders easier than within one's own country.

### **Report from the Surgeons' Specialty Group**

Jorma Rautio (Finland) reported from the surgeons' group, which consisted of 59 members from 28 countries. All continents were represented. Many of the European respondents had a background in the 1996–2000 Eurocleft Project (Standards of Care for Cleft Lip and Palate in Europe) that set guidelines for the treatment of patients with clefts, surveyed how treatment was set up in the different countries, and provided a registry of cleft units. There was interest in updating this information.

More work is needed on assessment of nasolabial appearance. Three-dimensional image scanning may be helpful in this respect. Techniques of optimal bone grafting procedures may warrant a trial, as would defining the role of cone-beam tomography in analyzing the results. Other areas of particular interest are the best technique for primary rhinoplasty in clefts or how to best repair the lip and nose in patients born with bilateral cleft lip and palate. Closing the cleft in unilateral cleft lip and palate in a one-stage procedure should be compared with a suitable two-stage approach in a randomized trial.

There was widespread interest in multicenter trials, although many group members had no experience of such studies. Keys to success were keeping the amount of participants to a manageable level, establishing simple protocols that do not overtax centers with more sparse resources, establishing a good personal relationship between the specialists involved, and scheduling regular, preferably annual, meetings between the research group members involving lectures and discussions.

About 15% of the surgeons work in areas where there is very uneven access to care for the poorest populations, which is a big problem. Record keeping is difficult, and long-term outcomes are hard to assess. Many have found cooperation and assistance from Smile Train to be helpful. In contrast, brief cleft missions by foreign surgeons were considered to produce poor results and no continuity of care. (The challenges of these difficult working conditions are discussed later in this report.)

### **Report from the Speech Pathologists' Specialty Group**

Elisabeth Willadsen (Denmark) and Kathy Chapman (USA) reported from the speech pathologists' group, which consisted of 29 members from 19 countries. Most participants expressed an interest in taking part in multidisciplinary, intercenter, and interlanguage out-

come studies. They expressed a need for developing rigorous methodology regarding speech outcome measures and analyses to be used in intercenter studies. The prevailing view of the group was to establish subgroups in topics of interest.

The following suggestions were made for areas of future work:

1. Organize a practical seminar on methodology for collecting outcomes, record keeping, speech outcome measures, and common terminology.
2. Support colleagues in developing countries and those with few economic resources by pairing experienced and inexperienced task force members to help jump-start outcome studies.
3. Collaborate in early intervention studies for speech and language, incorporating the International Classification of Functioning, Disability and Health perspective.
4. Create a website or agree to use an existing resource ([www.clispi.org](http://www.clispi.org)) for discussions and development of ideas.

### **Report from the Orthodontists' and Dental Specialists' Specialty Group**

Ron Hathaway (USA) reported from the orthodontists' and dental specialists' group, which consisted of 57 orthodontists, 2 pediatric dentists, and 1 dental therapist representing 34 countries. All continents were represented.

Most of the responding orthodontists had some experience of intercenter comparisons, including a smaller group that had been involved in at least one randomized trial. A significant proportion was enthusiastic about participating in such studies but thought they lacked the knowledge, opportunity, or resources to embark upon this.

The prevalent proposal for the task force's direction was to create a website to provide a resource for teams and individuals wishing to start standardized record collection and embark upon outcome studies, whether local or multicenter. Several respondents with experience in rating outcomes expressed a willingness to provide help and support for newcomers to this activity.

Nasoalveolar molding was considered to be a subject of urgent multicenter research.

Attention was drawn to the need for groups in different countries to work in a collective manner in defining outcome measures to avoid producing reports that could not be compared.

A register of teams and research interests needs to be created, similar to that developed in the Eurocleft Project "Standards of Care for Cleft Lip and Palate in Europe 1996–2000" (which now needs revision).

### Report from the Nurses' Specialty Group

Patricia Bannister (UK) reported from the nurses' group, which consisted of 11 members, 10 from Europe and 1 from the United States. As the role of the nurses varies considerably across the world, a key task would be to collect information on the contribution of nurses to the model of care from diagnosis to adulthood as part of both hospital and outreach teams.

Suggestions for collaborative projects were as follows:

- Investigate the support needs of parents at diagnosis.
- Study parents' empowering cultural factors to make suggestions to improve care.
- Study parents' perspective of the antenatal face at diagnosis and after birth.
- Investigate models of care and outcomes for infants born with Pierre Robin sequence.
- Make an overview of pain assessment, length and level of hospital stay, and feeding after surgery in different countries, looking at factors influencing any given model.
- Study the information and education needs of families throughout the treatment period.
- Design a training package/passport for nurses delivering care.
- Study the needs of adopted children and looked after children and their families/care providers.

The president of Cleft 2017 asked task forces to look at developing a feeding program for neonates and infants born in areas of the world where mortality and morbidity is high. There is evidence in the available literature, for non-cleft children, of some very successful regional programs addressing nutrition in parts of India. The combination of professional and locally trained support workers appears to be having a positive impact on reducing malnutrition in this group. A development plan is underway.

### Report from the Psychologists' Specialty Group

Nichola Rumsey (UK) reported from the psychologists' group, which had four members, three from Europe and one from South Africa. As cleft/craniofacial professionals around the world are at very different stages of development this group concluded that a key task was facilitating their development. Other key tasks include the following.

- Conduct a simple survey to establish patients'/parents' views about any psychosocial support needs they may have and what should be the key outcomes in assessing the impact of treatment. The results of this survey could inform shared protocols in multinational outcomes studies

- Develop online training modules designed to raise awareness of psychosocial factors playing a part in responses to treatment and in outcomes, promote the use of patient-centered process and outcome measures for audit and research processes, and demonstrate how to provide psychosocial support and care within a multidisciplinary team.
- Conduct research on long-term outcomes in adulthood (in order to inform future protocols of care and for research).

The process of developing networks and designing and delivering training should be collaborative and should avoid domination of the process by the more advanced countries. A key priority is to identify the next generation of enthusiasts for collaborative work. Both national and disciplinary representatives are needed to drive these initiatives forward. For those ready to engage in research, existing European networks could perhaps be extended beyond Europe, or international delegates could join the European networks if funding can be found for travel.

### Involvement of Cleft Interest Groups

Gareth Davies (France) was one of two members in attendance from the cleft interest support group; the other member was also from Europe. None of the members participated at the congress. The European Cleft Organization is currently embarking on a project under the auspices of the European Standards Agency in Brussels to produce a set of guidelines on early cleft care. These guidelines, when published, will provide a useful template for cleft care services.

Another initiative is the EUROcleftNet's establishment of a European network of health professionals and scientists to make recommendations on future research in treatment and prevention of clefts. As part of this program, the European Cleft Organization is building a Web-based resource, the European Cleft Gateway, to provide a directory of cleft services in Europe and a list of past and present research studies. In time it will host an online research library for the benefit of worldwide health professionals and users alike.

### Report from the Focus Group for Sub-Saharan African Countries

Haydn Bellardie (UK and South Africa) reported that the sub-Saharan Africa focus group was very well received, and there was much interest and enthusiasm from the delegates in establishing a task force. The group consisted of five orthodontists from the 27 sub-Saharan African congress delegates.

Many gaps exist in our knowledge of the incidence and provision of cleft care in sub-Saharan Africa, and a main concern is the shortage of multidisciplinary cleft

care services and the shortage of cleft specialists. The challenge is to improve the quality of the current services. In many countries surgical care is provided but other cleft-related specialties are poorly represented in the care pathway.

The task force should establish Africacleft to encourage intercenter collaboration. This collaboration should be under the umbrella of an advisory body that has the most experience. In time the group, which should be multinational, will develop into regional units and groups. Because of the great cultural and language diversity in sub-Saharan Africa, language and geographic subgroups should be formed. These groups will provide mutual support and opportunities to collaborate in development and research.

Those involved in cleft care, with the help of the task force, should be encouraged to engage with government health departments, professional bodies, and universities and promote the provision of multidisciplinary services.

In the whole of eastern and southern Africa (Angola, Botswana, Kenya, Lesotho, Madagascar, Malawi, Mozambique, South Africa, Swaziland, Tanzania, Uganda, Zambia, and Zimbabwe; population ~270 million) there are approximately 4000 dentists, 4000 psychologists, 2100 speech therapists, 130 plastic surgeons, 120 maxillofacial surgeons, 120 orthodontists, and no clinical nurse specialists. Most of these professionals are in South Africa, and only a handful have experience in or provide cleft care. In most countries care is from general and pediatric surgeons and nonspecialist practitioners.

Problems beyond the cleft include travel, social, and work conditions. Access to health professionals from distant rural areas can involve a 3-day journey to the nearest health facility. Transport, even for urban people, is a challenge. In many countries the cost burden for care and transport is with the family not the state or health department.

A significant and often mentioned concern amongst the delegates was the subject of aid, how and who provides it and the way certain images are used to portray Africa. The consensus was that aid should be more closely monitored and that all health aid organizations should work with established medical, nursing, and dental schools and professional bodies, societies, and teams.

In most of sub-Saharan Africa the main priorities are education, health, and economics. However, concerns and challenges of the Sub-Saharan Africa Focus Group were the following:

- Shortage of personnel
- Need to improve availability and access to care
- Training and support for local care providers
- Establishment of multidisciplinary care
- Linking with established units

### Report from the Focus Group on Development of a Cleft Lip and Palate Team

Bernard Tansipek (Philippines), Gayatri Moghe-Ghadyalpati (India), and Debbie Sell (UK) reported from the discussion in the focus group on developing cleft teams. About 25% of task force members work in areas with few or no comprehensive cleft teams, few resources, and very difficult working conditions. This group consisted of 17 congress attendees from 13 countries (9 surgeons, 5 speech pathologists, 2 orthodontists, and 1 pedodontist).

The overwhelming views expressed were dedication, enthusiasm, willingness, and commitment to cleft care; a wish to improve knowledge and services to patients; an appreciation of the need to evaluate outcome; and a desire to learn from others' experiences.

Their main motivations to join the Task Force were

1. To support global cleft initiatives on research, treatment protocols, and evidence-based care in the developing world. Many respondents had not been able to undertake any research but were very enthusiastic to do so. There were some excellent examples of well-established centers active in collaborative research. Many viewed Eurocleft and Scandcleft as models for intercenter outcome study.
2. To improve the quality of care for patients with clefts by stimulating record collection and outcome studies; however, there are many challenges in undertaking outcome studies including the following:
  - Women and newborn health are considered a low priority
  - Poor patient recall leads to lack of adequate follow-up and no database registries
  - Difficulties in access to care and affording treatment
  - Poor patient/family understanding of the typical pathway of cleft intervention
  - Lack of appropriately trained team personnel, equipment, and resources
  - Untrained personnel who provide dubious treatment and increase the burden of care
  - Lack of financial help from nongovernmental organizations for recordkeeping and outcome studies
  - No funding for professionals to attend meetings and get involved in intercenter studies
  - Understanding the impact of socioeconomic conditions on outcomes
  - Limited experience of research
3. To use the group and standards for cleft care as political leverage to improve awareness, funding, and resources, thereby acting as quality control for cleft care.

## Missions

An area of much comment was the impact of missions by local and foreign groups, even where local teams exist. Issues raised include the following:

- Missions do not provide holistic care; patients are often left with poor or inadequate follow-up. Ancillary care is considered a must for rehabilitation.
- Families often believe that treatment by missions is superior to that of the local teams, and therefore do not seek timely treatment for a newborn child with a cleft.
- Recording of the true incidence and prevalence of persons with a cleft is disturbed by missions, potentially limiting the number of patients in outcome studies.

Indeed an interesting view expressed was that “the mission method of providing care is an old model and must be reserved for areas that do not have ANY capability of providing cleft care. There should be national and international coordination and cooperation in their delivery where these are undertaken.”

The end goal of the mission approach must be to

- provide cleft treatment for patients
- coordinate with the local staff and begin forming a local team to provide care
- begin disseminating information regarding cleft care to the local population.

## RECOMMENDATIONS FOR THE TASK FORCE

The following recommendations for the task force were developed.

- Cleft lip and palate should be listed as a notifiable anomaly worldwide. This would automatically facilitate formation of cleft registries and generate a realistic picture of the burden of care.
- The task force should function as the “heartbeat” and/or support center for outcome studies globally and develop a road map/template for undertaking single-center or multicenter studies.
- Follow the principles of small steps and simple targets when starting out.
- Create regional groups to form liaisons with an umbrella group.
- Identify centers with a lack of specialties.
- Set up teams in the developing world, initiate interdisciplinary care rather than multidisciplinary treatment, set up protocols of care, and develop the standards for evaluating the simpler outcomes.
- Develop processes for clinical situations unique to the developing world where the patient does not return

for follow-up, and encourage cleft care with minimum burden in terms of finances.

- Look to set up access to telemedicine and Web medicine by remote units.
- Start community outreach programs for continued care after surgery.
- Help provide education for staff.
- Appreciate the social and holistic issues that can lead to failure or poor outcomes.
- Encourage nongovernmental organizations to work closely with and support cleft teams.
- Twin with established centers.

## EXAMPLE OF BUILDING UP A MULTICENTRE COLLABORATIVE INITIATIVE

Terumi Okada Ozawa and Jeniffer Dutka from Brasileft presented an example of how to build up a multicenter collaborative initiative. Brazil is the world’s fifth-largest country (population around 200 million). By 2011, the Ministry of Health had registered 26 cleft centers to treat patients born with cleft lip and palate. A large multidisciplinary cleft and craniofacial center in Bauru, University of São Paulo, started standardized record taking some time ago and intercenter outcome comparisons of dental arch relationship in unilateral and bilateral cleft lip and palate have been completed. The team completed a randomized controlled trial of primary surgery (Florida Project), initiated a cleft prevention project in the 1990s, and is presently participating in the randomized control trial TOPS (Timing of Palate Closure), all funded by the US National Institutes of Health.

Seventeen Brazilian centers, influenced and informed by Scandcleft, Eurocleft, and Americleft, formed a task force to establish parameters for outcome documentation: Following is the timeline for Brasileft Initiative, which has met regularly since 2011:

- 2011: First official meeting was held, and invitations were sent to all Brazilian teams to join to the initiative.
- 2012: Surgeons, speech-language pathologists (SLPs), and orthodontists met twice to discuss protocols, outcome measures, shared lectures, workshops, panel discussions, and training sessions.
- 2013: Two national multidisciplinary meetings were held to develop tools for outcome documentation and training of professionals.

Further plans for the Brasileft Initiative include the following:

- SLPs will meet experts from Europe and North America and improve the documentation protocol and start a reference data bank of speech samples.
- Beginning in 2014, all teams will use the same protocol for speech recording and editing.



- Workshops for training SLPs from all teams in multiple judges' ratings of speech are planned and should address the possibility of online ratings to avoid mobility problems.
- Issues of confidentiality and security of patients' and centers' data will be regulated before online ratings are established.
- The task force plans to address measures of quality of life and burden of care in 2014.
- Data collection, storage, scanning, and rating workshops are ongoing.
- A protocol for capturing, editing, and rating facial appearance will be completed in 2014.
- A protocol for describing the routine surgical procedure and modifications implemented during surgery will be developed.
- A protocol for documenting postsurgical complications (e.g., fistula, dehiscence, hemorrhage) is being written.

In addition, a Brasileft blog is being developed for team members to share the task activities and to communicate more effectively. Colleagues from other South American countries have also participated in these meetings. The final goal is to establish a South American Cleft.

#### CONCLUSIONS OF THE CLEFT 2013 TASK FORCE

This group has an overwhelming sense of passion, enthusiasm, collaboration, and willingness to improve cleft care. It is also very clear that the great majority of task force members want this to be a global initiative, recognizing the huge commitment for improving cleft care in the developing world and in countries with established multidisciplinary centers. It was suggested to change the title of the group to Global Cleft Team Network because the vision for this group is to build a dynamic, well-functioning task force that will work globally, will be multidisciplinary, and will be characterized by inclusive and respectful behavior in achieving the goal to improve care for all persons born with cleft lip and/or palate.

At the congress, members confirmed their motivation and ideas for the direction and organization of the task force. As there is a large diversity in needs and interest in the group a range of parallel approaches would be required depending on the experience, resources, and challenges of regions, teams, and individuals. Many recommendations for future work have also been listed in reports from the different specialty groups and focus groups.

The members' most common proposal was to make a global survey of access, existing outcome studies, current collaborations, and lessons learned. The task force should also work toward creating a lasting, living resource for newcomers to intercenter collaboration that is kept fresh with new reports, copies of relevant publications, model grant applications, and a list of volunteers with the right

experience to provide support and guidance for new initiatives.

Another key collaborative task would be to develop simple online training modules to provide information about the benefits and principles of multidisciplinary care, collaborative data collection, and methods of auditing short-term and longer-term outcomes. These could also be used to promote an ethos of collaboration among trainee and established professionals.

To ensure global multidisciplinary collaboration the task force should

- Raise awareness for comprehensive team care not just surgical repair
- Recruit task force participants in all countries and identify contact persons for regions and/or countries to drive the different initiatives forward
- Boost representations in specialty groups with few participants (e.g., develop an otolaryngology/audiology group)
- Encourage the participation of the next generation of cleft enthusiast
- Improve communication between colleagues, clinicians, and researchers

In addition, the task force should establish subgroups that will

1. Work within regions such as Africa, Asia, Australia/New Zealand, North America, Latin America, the Middle East, and Europe. Within these regions other subgroups could be established. National and regional leaders must be identified. An evaluation of current standards of care should be undertaken and country/region-specific remedies to optimize treatment outcome suggested.
2. Reach agreement on minimum standards of care and minimum record collection and reach consensus on simple outcome measures in all disciplines. This should include all cleft types and all ages. The basis for this would be scaled-down versions of standards already in existence. These could be shared and pared down by a working group with representatives from developed and less developed nations. Once different points for discussion have been listed separate e-mail threads could be set up for each. These standards could be used to encourage governments to fund multidisciplinary care.
3. Encourage teams to start and continue record keeping using simple and agreed-upon protocols according to agreed-upon standards of minimum records.
4. Encourage teams to share their data with other teams (one or two to start with to reduce the threat; then bigger groups).
5. Embark on outcome studies.

Finally, teams already active in research should create a register for cleft professionals and teams to reach agreement on contemporary and comprehensive multidisciplinary outcome measures, explore the possibilities using modern technology, and plan large multinational studies. Patient-/parent-centered data collection should always be included. These studies need a lot of funding. One task could also be exploring whether health care at a distance could be initiated using new technology.

### **Continuity**

Unfortunately, the confederation of countries that organize the four yearly conferences is not yet active between meetings, and some continuity is essential for a new initiative to take root. However, the commitment of any surplus funds arising from the four yearly conferences could provide some income.

Subject to the availability of funds, which also requires exploration, a possible home needs to be explored. This might be an existing organization, a university, a World Health Organization center, or some other permanent entity. Dissemination could possibly be assisted by the *Cleft Palate-Craniofacial Journal* or another similar publication.

### **Positive and Negative Critique of the Task Force Process**

From the beginning there was a lot of positive feedback during the process of building up the task force. There were many e-mails of appreciation of the inclusion of members from all parts of the world. Many showed great willingness to help find interested colleagues in their geographic or specialist area, a support

that was essential in the process. Many colleagues reported sharing e-mail and contact addresses. The document, including the individual summaries, was reported to be very helpful: this was an opportunity to hear the voice of individuals.

The group was large and had a large diversity between geographic areas as well as in what people needed, wanted, and were interested in achieving from the task force. A few members thought the motivation to join the workforce was sometimes rather distant from the original aim of “making recommendations for initiation of local and/or participation in multi-national cleft outcome studies.” This is not unexpected at the start of a global initiative. The main goal for the first meeting was for colleagues from all parts of the world to meet face-to-face, and together start discussions on goals, expectations, and visions and to brainstorm on different ways to take this initiative forward. Many members would have liked to have more time allocated for these discussions and connections.

Time will tell how easy the road ahead will be for this Global Cleft Team Network. It has been decided that the project will continue at least to Cleft 2017 Congress in India. The great majority of the members think the initiative has great potential. As one respondent wrote: “I appreciate very much the goals set for this task force, and it will be an exciting and wonderful pathway for recommendation of multicenter cleft outcome studies.”

### **REFERENCES**

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