

Meeting minutes

INTERNATIONAL COPD COALITION (ICC) EXECUTIVE COMMITTEE MEETING WITH SPONSORS

Saturday, January 29, 1–4 PM Hotel Bernini Bristol, Rome, Italy

Appendix: Meeting Agenda

In attendance from ICC Executive Committee: Helmut Berck (German Airways Patient League), Mariadelaide Franchi (Associazione Italiana Pazienti BPCO and EFA), Yoshinosuke Fukuchi (APSR), Lawrence Grouse (MCR), John W. Walsh (US COPD Coalition).

In attendance from ICC Sponsors: Jorgen Book (AstraZeneca), Antje-Henriette Fink Wagner (Altana Pharma), Lukas Helmrich (Boehringer Ingelheim), Gilbert Nadeau (GlaxoSmithKline).

Moderator: Dmitry Nonikov (MCR)

Dr. Dmitry Nonikov welcomed the Executive Committee members and Sponsors of the ICC and pointed out the great value for international collaboration to improve patient care in COPD and introduced the agenda of the meeting (see Appendix).

Dr. Larry Grouse, ICC Coordinator, described the progress of ICC organization since the previous meeting in Glasgow in September 2004 during the ERS Congress. With more than 120 COPD patient organizations identified worldwide and with the support of the US COPD Coalition, EFA, and APSR as well as a committed group of 75 COPD patient organization members, ICC has the momentum to accomplish major campaigns and collaborations. Following the Glasgow meeting, a Delphi technique was used to provide communication among the Executive Committee members. It was used to revise and update the three year plan of the ICC. Dr. Grouse also provided an update on the ICC's leadership in the new WHO-endorsed Global Alliance for Respiratory Disease (GARD) Initiative and the potential role of GARD in strengthening ICC activities globally.

Prof. Yoshinosuke Fukuchi provided an update on the activities of patient organizations in Japan and Asian Pacific Region. As President of APSR, he emphasized the valuable collaboration between APSR and JRS with the 7 major Japanese COPD patient

organizations. He outlined the White Paper that these organizations are now completing on home health care for COPD patients. This will be placed on the ICC website and translated so that this important study can be shared worldwide. He also outlined plans for WCD 2005 in Japan. Prof. Fukuchi also emphasized the importance of reaching more global members with the ICC, and in particular establishing contacts in India.

Mariadelaide Franchi, on behalf of EF President Svein Eric Myrseth provided a presentation of EFA's progress. She emphasized the importance of patient associations in raising the issues of COPD with healthcare policy makers. Franchi confirmed EFA's strong commitment to share information and work with COPD patient organizations worldwide through active participation in ICC. Concerning Italy, the Italian government healthcare plan is considering the inclusion of chronic respiratory diseases, which were previously not covered by the program. Dr. Franchi observed that it is challenging to identify patients who would represent patient groups in official negotiations with the authorities. Dr. Franchi demonstrated to the group a number of patient education materials developed by the Italian patient association. Operational plans of Italian COPD patient association include the development of educational materials in languages of immigrant communities.

Mr. John Walsh, CEO of the Alpha-1 Foundation and Executive Committee member representative of the US COPD Coalition updated the group on the progress the Coalition has made over the past year. The organization now includes about 40 patient, professional and government groups. Active communications by the group members resulted in the formation of a dedicated COPD Caucus in the US Congress led by Senators Crapo and Lincoln. The support of the Caucus greatly facilitated the interaction of the COPD Coalition with various other organizations. Among of the recently approved measures were the new regulations for air travel with oxygen, which significantly improved the freedom of travel for US COPD patients. A strategic focus on COPD was taken by NHLBI by development of forums to assess the gaps in COPD, and by CDC which included COPD research data in its research. Mr. Walsh emphasized that the infrastructure developed by asthma patient advocacy in the recent years may also be expanded in COPD.

Dr. Helmut Berck, Chairperson of the German League of Patients with Airways Diseases, greeted the group as a new ICC Executive Committee member and introduced his organization and its activities. The League works in collaboration with about 50% of the German outpatient pulmonologist practices and with the National Association of Patients with Allergy and Asthma. With regard to the current move of the German Health funds to promote disease management programs, the League has applied for the evaluation of a respiratory disease management program. The League's theme of 2005 is "quality of life". Dr Berck presented some of the materials published by the group on federal and local level.

An update on behalf on the group of sponsors was presented by Dr. Antje Fink-Wagner. The sponsors had met before their meeting with the ICC EC members to discuss the progress and goals of the initiative and the possible role of the sponsors in optimizing internal/ external communications of ICC. The three year plan of ICC was discussed. The sponsors confirmed their commitment to the goals of ICC, such as raising awareness of potential COPD sufferers in order to improve primary prevention, diagnosis, and treatment of COPD. It was emphasized that adequate infrastructure should be built by the ICC to enable primary and secondary objectives. The sponsors group also noted that ICC communications should include political and payer organizations to increase awareness and support for COPD. The sponsors agreed to meet 3 times a year to help ICC develop coordinated communications for the ICC. They asked the coordinators and the Executive Committee to provide them with as much information as possible relevant to the coming joint meetings in advance of the meeting date.

The sponsors also welcomed two new sponsors of the project: GSK and Mitsubishi Pharma. Dr. Fink-Wagner also presented an example of communication campaign materials which could be used exclusively by the ICC.

DISCUSSION

The group reviewed and approved the ICC 3-year plan.. It was noted that specific objectives and activities should be further defined for 2005. The group agreed that the most urgent action for the coming period is working together with GOLD to prepare for the World COPD Day in November 2005.

With regard to World COPD Day it was suggested that while the suggested COPD Day theme adequately represents the goal of the campaign from the professional perspective, it should be supplemented with agreed theme(s) which would be more involving for public and patient audiences. It was also noted that COPD should be communicated in a more positive way and move away from the stigma of a lethal incurable condition. In that context the group discussed the theme "Breathless not Helpless" presented earlier in the meeting and agreed to send it for review to other Executive Committee members. At the same time it was observed that the theme does not translate easily into all languages and some local customization may be needed.

The group also observed that communications should be customized to the target audience. In particular, it was noted that the epidemiologic data on the burden COPD may have a higher impact for policy makers than for individual patients and healthcare workers.

The group emphasized the importance of best practice sharing, and in particular the role of the ICC website in this process. The issue of availability of patient information in multiple languages was discussed. It was observed that COPD patient education materials exist in all major languages and should be reviewed to identify best materials in each language and share them via the web site. Dr Berck referred to patient education materials developed in New Zealand as an example of best practice.

It was discussed if and how the impact of the group's individual activities may be measured more specifically in order to optimize the use of the available resources. Dr. Franchi observed that some of the real benefits of patient communications are not immediately tangible, but without such advocacy COPD would not have the place it has now on healthcare agenda in many countries.

The next meeting of the ICC Executive Committee and the sponsor group was scheduled for May 2005 during the ATS Conference in San Diego, CA.

AGENDA

International COPD Coalition Meeting with Sponsors

Saturday January 29, 2005 1 PM in the Salla Viola Hotel Bernini
Bristol, Piazza Barberini, Roma

1. Welcome and Introductions
 1. Brief Presentations by ICC Executive Committee Members
 1. Prof. Larry Grouse- US
 2. Dr. Lally Franchi- Italy Prof.
 3. Yoshi Fukuchi- Japan
 4. Mr. John Walsh- US
 5. Dr. Helmut Berck- Germany\
 6. Dr. Antje Fink-Wagner- Germany
2. Topics for Discussion
 1. ICC Three Year Plan
 2. Coordinator's Report - Establishing a Communicating Infrastructure
 3. Specific 2005 aims
 4. Working plan for the ICC Executive Committee
 5. Coordination and Implementation at the Member Level
 6. Sharing Resources
 7. Patient Organizations - Opportunities and Challenges
 8. World COPD Day 2005
3. ICC Website and eNewsletter
 1. Maintenance
 2. Website construction
 3. Representative input
 4. Translations
4. Sponsor Participation
 1. Active Role of Sponsors
 2. Future ICC Meetings with Sponsors
 3. Sponsors needs for long term plans
5. Future
 1. Plans and meetings for 2005 and 2006
 2. Progress expectations
 3. Reaching and Adding Global members
6. Closing remarks