



## ICC Meeting Minutes May 16, 2010

### Participants:

R. Chen (China); A. Fink-Wagner (Germany); C. Garvey (US); R. Goldstein (Canada); L. Grouse (US); E. Irusen (South Africa); S. Prete (US); Y. Shim (South Korea); K. Allan (Novartis Pharma); G. Eriksson (AstraZeneca); D. Geick (Boehringer Ingelheim); E. Hackbarth (Forest); T. Haydon (Nonin); Y. Leonard (Nonin); J. Loftus (Merck & Co., Inc.); C. Maden (GlaxoSmithKline); S. Mehra (Dey, L.P.); G. Nadeau (GlaxoSmithKline); J. Robertson (Novartis Pharma); G. Tornling (AstraZeneca); D. Tosi (Chiesi Farmaceutici S.p.A); R. Wolf (Dey, L.P.).

### Introductions

- Dr. Grouse gave an overview of the meeting agenda and asked for feedback from attendees throughout the meeting.
- Ms. Sarah DeWeerd, Editor for ICC, was introduced and Dr. Grouse announced the new ICC Executive Committee members, chairs, and the key organizational liaisons.
- Dr. Grouse reviewed the COPD Patients' Bill of Rights document, its distribution, and the goal to use it globally for national and international advocacy activities.
- The group all introduced themselves.

### COPD Patients' Bill of Rights Initiative

- Dr. Grouse introduced Ms. Sarah DeWeerd and her work on the ICC website, with the COPD Patients' Bill of Rights, and the Member Organization survey.
- Ms. DeWeerd explained that ICC has been collecting the translations of the COPD Bill of Rights. Close to a dozen have been posted, and we are continuing to post additional translations. Sarah suggested that the group provide input concerning promotion and dissemination of the Bill of Rights and suggest activities that the member organizations could use to spread awareness, advocacy, and action with this document in their countries.
- Sarah's ICC Global Survey was sent out several weeks ago and we have had about 20 responses. Sarah thanked those that completed the survey and noted that those responses received provided a very broad mix of different socio-economic circumstances and therefore a good picture of how COPD patient rights are looking in different places worldwide. Sarah noted that we appreciate the MO's effort as it was a long and detailed survey.
- People are in most cases in the beginning stages of promotion and dissemination activities, and they would appreciate additional guidance on how to make the Bill of Rights a part of their regular campaigns.

- There were a number of other questions about the actual rights themselves. An interesting point was the responses on spirometry and the patterns of spirometry availability. It was quite widely available in specialist settings, but not in primary care settings.
- That shows us the importance of targeting GPs in an effort to help them get objective pulmonary function measures on a routine basis. In most countries, GPs and primary care professionals play the major role in COPD care.
- Most countries have national COPD guidelines, which are based on GOLD, and are widely accepted.
- Some level of awareness of proper procedures for diagnosis was indicated in most countries. Still there are early obstacles to COPD diagnosis and care, which were noted as being quite consistent. Despite other differences concerning COPD in different countries, they consistently identify a lack of COPD awareness among the general population and among primary care doctors.
- Building increased awareness of COPD was the most emphasized point on the surveys.
- One issue is that in some areas patient-directed education programs and access to educational materials is very limited. It was suggested that ICC can help with translation of materials to more languages and posting these translations on the ICC website.
- Again, there is a problem that physicians don't have time or funds to increase awareness, do COPD education, or to actively pursue COPD diagnosis. There is relatively little information on quality of life of COPD patients, which is another perceived need.
- Sarah closed her presentation with some good news: the number of COPD patient groups was increasing in most countries, with more new groups starting all over. We need to keep reaching out to all the new groups to work with us.
- Sarah noted that an exchange of best practices would be helpful. When a member organization does something that works well we need to let other groups know about it. These best practices may jog others creativity. Perhaps at the 2<sup>nd</sup> World Conference of COPD Patients that we are holding in Shanghai we could include a poster session on best practices and creative approaches, and provide a way that people could present those success stories so that others can replicate them. In short a best practices success stories session or an inspirational session of presentations of successful practices.

## Second World Conference of COPD Patients

There was a lengthy discussion and a request for continued input from the group regarding the Second World Conference of COPD Patients.

A few key decisions were made by the group:

- Month/Date – November 2011 prior to the 16<sup>th</sup> APSR Congress. The specific date will be locked in after discussion with APSR's leadership.

- Location – the group decided on Shanghai over Guangzhou.
- Format of meeting and agenda – it will be similar to Rome as a meeting for committed COPD leaders, patients, member organization leaders, involved health care professionals, and media. The agenda will be focused on matters related to the COPD Patients' Bill of Rights and its implementation. It will have presentations that reflect on the issues of bringing the Bill of Rights to reality worldwide.
- Also, it was mentioned that some sessions on eastern medicine at the World Conference would be of interest.
- The group also noted that the conference should have clear action items and take-home messages that reflect ICC's overall goals. We should include success stories from various countries and a workshop on ways to work with health ministries to advocate for COPD patients and how to participate in the GARD national implementation activities.
- There should be a review during the conference of improving medication access globally in each of the different regions and how to get help in seeking reimbursement.
- There should also be a clear review of what is available in terms of educational and health economic data concerning COPD. We should also emphasize working together on a regional and global basis in the conference, starting with ICC regional meetings within the structure of the Conference.
- There should be increased emphasis on involving politicians and health ministers with an eye to improved advocacy and public communication. Sessions on telemedicine would be new and exciting at the Conference. We should also work to increase partnering with GARD and WHO, including sessions on this in the Conference.
- The group indicated that we should work hard to increase local governmental participation and to have politicians, regulatory authorities, media, and health ministers to be present and involved at the conference.

### Plans for the Coming Year

- The group discussed the idea of ICC developing an evidence-based database and resource center website related to COPD and organized by including background topics such as COPD, the disease, and Burden of COPD globally, as well as structuring the website with information concerning the 7 points of the COPD Patients' Bill of Rights and the data concerning the benefits and cost-effectiveness to society as well as patients in having patients be able to function better, continue to be employed, and participate in the countries' economic systems.
- This open database for health ministries, COPD advocates, media, HCPs, industry, and patient organizations would greatly facilitate global COPD advocacy and help the stakeholders unify the data and the points that they are making.

- This topic of evidence-based cost-effectiveness and health economics in the ICC database would also be a topic for emphasis and the 2<sup>nd</sup> World Conference.
- ICC Partners offered suggestions of studies and data sets that could be helpful to include, and there was a request for a follow-up meeting in Toronto, Ontario, Canada during the IPCRG/GARD meetings to discuss and agree on a plan for collecting this information and funding the Resource Center. This meeting has since been planned as a lunch meeting at 12 noon on June 3<sup>rd</sup>, 2010 at the Westin Harbour Castle hotel in Toronto.

### Budgetary Report

- Dr. Grouse had copies of the complete 2010 revenue and expense statement for ICC that were available for all ICC partners and members to take. There being no further business to be conducted and the allotted time expired, he then closed the meeting.