

Summary of lectures given at the

FIRST WORLD CONFERENCE OF COPD PATIENTS

June 14, 2009
Rome, Italy

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Welcome

Chair: M. Franchi, Italy

Ms. Franchi opens the conference and welcomes the participants. She reads a letter from Mr. F. Fazio of the Italian Welfare Ministry, welcoming the conference participants to Italy and praising the initiative taken by the COPD patient organizations all over the world to fight COPD together. Ms. Franchi also presents greetings from patient associations all over the world.

Session 1: Impact of Co-morbid Conditions on Care of COPD Patients

Chair: S. Hurd, USA

Prof. Sue Hurd, representing the Global Initiative for Chronic Obstructive Lung Disease (GOLD), introduces Prof. Leo Fabbri as the session's first speaker and presents the GOLD guidelines, announcing that future updates of the guidelines will have a greater focus on COPD co-morbidities.

Prof. Leo Fabbri states that co-morbid conditions should receive greater focus in the treatment of COPD. He points out that when COPD patients smoke, this not only amplifies the underlying inflammation in COPD but also contributes to many other diseases, including cardiovascular diseases, metabolic syndrome, infertility, etc. Spirometry is the main diagnostic tool for COPD, but only covers 70% of COPD patients. In addition, because most COPD patients have co-morbid conditions, assessment of COPD severity by spirometry alone doesn't give the full clinical picture: the co-morbid conditions and their effect on the patient's health status also have to be taken into account. For example, a COPD patient who is in Stage I COPD according to the current GOLD classification, but who also suffers from hypertension, cardiovascular disease, and metabolic syndrome, is clinically similar to a patient with Very Severe COPD and should be treated accordingly. He draws a comparison to some nephrology guidelines, which have long incorporated co-morbid conditions in the assessment of disease severity, and argues that this approach should be adopted for COPD guidelines.

Session 2: Implementation of Effective COPD Management Programs

Chair: M. Salapatas, Greece, & Y. Mohammad, Syria

Ms. Salapatas welcomes and introduces the second speaker, Prof. Lorenzo Corbetta, who will report his experiences of implementing the GOLD guidelines in Italy.

Prof. Corbetta summarizes the efforts that have been made in Italy since 2006 to organize World COPD Day activities, including translating all materials into Italian and setting up the GOLD Italy Website. Translating the GOLD and other respiratory guidelines (GINA and ARIA) into Italian was the largest part of this effort. Useful strategies to build support for and awareness of the group's activities included collaborating with the media; linking to the Websites of different patient organizations; and adding an educational video to the homepage. Prof. Corbetta argues that improving the doctor-patient relationship is mandatory for the successful treatment of COPD, and that linking researchers, physicians and other health-care professionals, and patient organizations is needed to improve the common fight against COPD.

Prof. Grouse highlights Italy's marvellous network between patient organizations, physicians, and government to fight COPD and asks Prof. Hoshino about the situation in Japan. Prof. Hoshino explains that in Japan there are very strong relationships between the GOLD committee, rehabilitation centers, and patient associations.

Prof. Mohammad welcomes Prof. Zhong, the head of the Chinese Medical Association.

Prof. Zhong reports about efforts in China to fight COPD. He notes that two points are stressed in China these days: reducing risk factors and intervention as early as possible at the community level. He reports that a survey recently carried out in China found that only 60 % of patients who have been diagnosed with COPD have symptoms. One-third of COPD patients do not have symptoms yet, but these patients are not treated. He raises the question of whether it wouldn't make more sense to treat these pre-symptomatic patients, since their disease is at an early stage. For these patients, early community intervention with education and support in smoking cessation will have a positive result. Smoking cessation in an early stage is the better way to slow lung function decline than pharmacological treatment. Therefore, regular lung-function tests at the community level are needed in China, in order to enable early smoking cessation intervention. Prof. Zhong states that affordable medication is also needed, which will require collaboration with the pharmaceutical industry.

Session 3: Barriers to Care of COPD Patients

Chair: V. Lopez, Uruguay, & S. E. Myrseth, Norway

Prof. Lopez opens the third session, regarding the barriers to care and unmet needs of COPD patients, and introduces Prof. Yuma Hoshino from Japan.

Prof. Hoshino reports that according to a 2000 survey there are some 5 million COPD patients in Japan, with 95% undiagnosed. There is a huge need to properly diagnose and treat COPD patients in Japan, and raising awareness of COPD is critical. The first steps in this effort have been made during World COPD Day activities, with public spirometry screening in the street and huge anti-smoking campaigns in the media. The economic burden of COPD is large in Japan due to direct treatment costs (10,000 yen/month). The biggest barriers to COPD care in Japan, however, are the lack of public awareness regarding COPD and the lack of pulmonary rehabilitation centers.

Prof. Lopez mentions that the availability of portable oxygen in Latin America is low and in general not covered by health insurance. The representative of the Swiss Lung Association explains that a new agreement with the Swiss railway will make liquid oxygen available at railway stations for patients to refill their oxygen tanks.

Mr. Myrseth introduces Dr. Thoonen from the Netherlands, representing WONCA. Dr. Thoonen highlights that patient self-management of COPD can be very successful and should be enabled by physicians. A key aspect in COPD is the restriction of day-to-day activities that the patient must learn how to cope with. Most patients talk with their health care professional about symptoms and exacerbations, but do not report difficulties with daily activities. Therefore, the physician should make the initial step to raise this topic. A main requirement for self-management of the disease is that the physician must provide education and improve the patient's knowledge. Patients should also be able to monitor their own disease and to correctly react if their condition worsens. Finally, Dr. Thoonen said, continuity of care is also critical together with the knowledge of co-morbidities of the patient.

Session 4: Implementation of National/Regional Programs to Prevent COPD
Chair J. Walsh, USA, & E. Mantzouranis, Switzerland

Mr. Walsh welcomes the representative of "The Union," Prof. J.-P. Zellweger from Switzerland.

Prof. Zellweger states that smoking cessation is the only intervention proven to decrease the risk of COPD. Furthermore, smoking cessation is the only way to slow the decline of lung function in COPD patients. Therefore, Prof. Zellweger argues, smoking cessation has to be part of COPD treatment! The smoking patient has to change habits and overcome challenges to quitting. The role of the physician is to support the patient's efforts and, if necessary, to provide nicotine replacement, other medical support, and social support. Surveys have shown that training of physicians in smoking cessation generates higher cessation rates in patients. Constant contact between the physician and the patient (in-person, email, sms, etc.) is also helpful to maintain the cessation effort. Prof. Zellweger emphasizes that tobacco addiction is a chronic condition! The biggest hurdle to quitting smoking is the social environment: Living with a partner or parents who smoke makes it nearly impossible to quit. Furthermore, many smokers exhibit an addiction to nicotine. Patients get nervous about quitting and fear the inconvenience. Physicians must address all of these barriers. Avoiding a relapse after some months of smoking cessation is the next hurdle for the patient, and physicians must warn patients to avoid the attitude that "just one cigarette doesn't damage anything." Medical treatment to support the cessation is available, effective, and has only minor side effects. Finally, Prof. Zellweger notes that COPD and tuberculosis are linked together, and in a non-smoking society 20% of tuberculosis cases could be avoided.

Dr. Mantzouranis from the WHO again welcomes Prof. Zhong, who gives an overview of how the Chinese government tries to prevent COPD.

Prof. Zhong states that COPD is third leading cause of death in China (after cerebrovascular diseases and cancer)! The China COPD Alliance and the Ministry of Public Health have worked together with GARD (Global Alliance against Respiratory Diseases), which was launched in Beijing in 2006. The government has included

COPD on a list of the most important chronic diseases to fight in the next 15 years (along with heart disease, diabetes, cancer, etc.). Because of the high rate of smoking in China (about 60 % of male *physicians* smoke), tobacco control will not be successful without government support. The government has decided that smoking will be forbidden in public places! The aim is to cut the numbers of Chinese smokers in half by the end of 2010. Air pollution is a next hurdle the government must address.

Prof. Zhong again notes that early intervention is also an aim for the government. China is about to change its medical system to a more community-focused model, which will enable community hospitals to diagnose COPD. Additionally, more money will be allocated to public health care over the next three years. The success of all these activities will be tracked by surveys in the following years.

Session 5: Raising Awareness of COPD: What Can be Done to Improve COPD Care?

Chairs: G. Viegi, Italy, & M. Fletcher, UK

Prof. Viegi introduces the topic of the session and welcomes and introduces Dr. Claude Lenfant from GOLD.

Dr. Lenfant analyzes the physician-patient relationship. Today many physicians do not have the time to carefully listen to their patients, and the computer takes over the task of tracking patient progress. Interpersonal skills vital to successful treatment are becoming lost. Additionally, implementing international guidelines for COPD treatment seems to be another problem. The other weak point in the chain of treatment is the patient. The patient's lack of awareness about the disease, its possible consequences, and its treatment decreases the likelihood of adherence to treatment. Dr. Lenfant states that a very intense relationship between the physician and the patient and his family is critical for a successful treatment regimen – they should be partners! To achieve maximal disease control, both must be aligned and responsible. There is evidence that patient organizations or clubs are also very effective, because patients can talk to each other, share experiences, and learn more about their disease.

A participant mentions that nurses should be included in the relation between physician and patient, because in some countries nurses play a major role in the COPD treatment. This idea was broadly agreed with by the audience.

Dr. Viegi welcomes and introduces Dr. Giulio Gallo, Luxembourg, from the public health care department of the European Union.

Dr. Gallo describes the EU's efforts to implement regulations to reduce environmental pollution and gas emissions in big cities. Current legislation contains plans to reduce industry pollutants. The EU spent 300 million on improving air quality last year. This process is ongoing.

In the EU today the prevalence of smoking is estimated to be 30%. Dr. Gallo describes some smoking reduction initiatives that have been introduced by the EU. In cigarette advertising the words "light" and "mild" are forbidden to use, because they

are misleading. Warning labels on cigarette packs include graphic pictures of smoking-related diseases, such as lung-cancer. A total of 7.2 billion Euros have been spent on anti-smoking campaigns. Increased taxes additionally discourage smokers from buying cigarettes (e.g., cigarettes cost 8.00 Euros per pack in the UK!). Smoking-free policies have been introduced in most EU countries.

Ms. Salapatras mentions that on July 1 a ban on smoking in public places went into effect in Greece. Prof. Lopez mentions that in 2006 Uruguay became the first Latin American country to ban smoking in public places, with very positive reactions from both smokers and non-smokers!

Ms. Monica Fletcher from the UK welcomes and introduces the next speaker, Prof. Jean Bousquet, who informs the audience about the GARD initiative and its strategy to fight COPD.

Prof. Bousquet points out the magnitude of chronic respiratory diseases: Roughly 1 billion people suffer from chronic respiratory diseases, among which the main conditions are asthma, COPD, allergic rhinitis, non-allergic rhinitis, sleep apnoea, and pulmonary hypertension. In the year 2030 COPD is projected to be the 4th leading cause of death: Eight million deaths will be caused by tobacco, and biomass fuels will kill some 10 million people, while probably 50% of the world population will be allergic.

The cost of inaction is clear and unacceptable, Prof. Bousquet argues. This led to the GARD initiative to reduce the global burden of chronic respiratory diseases. GARD's vision is a world where all people breathe freely! Its objective is to initiate a comprehensive and cost-effective approach to fight chronic respiratory disease. Four pillars are critical to the fight against COPD: surveillance, advocacy, prevention and health promotion, and control. GARD addresses all of them. Over 150 associations have joined GARD, which is aligned with the WHO. Prof. Bousquet advocates an action plan to ban tobacco but points out that the bigger problem in developing countries is biomass fuel. The costs of drugs must also be reduced, and governments should grant patients access to medications. Prof. Bousquet emphasizes that GARD works for and with patients: Only a consolidated, united effort will be able to fight COPD successfully.

Session 6: Establishing COPD Patient Organizations

Chair: O. Spranger, Austria, & D. Nonikov, Germany

Dr. Spranger welcomes and introduces the next speaker, Ms. Mariadelaide Franchi, the president of the Italian COPD Patient Association.

Ms. Mariadelaide Franchi gives an overview of how to establish a COPD patient organization. First one must know the legal requirements of the country where the patient organization will be established. The mission has then to be developed: Ms. Franchi suggests that a patient organization's mission should be to improve the health conditions, quality of life, the life expectancy of people with COPD; and to safeguard the rights of patients, their families, and caregivers. Patient organizations must represent the opinions, views, and expectations of COPD patients.

Another basic need is to have experts on your side: physicians, other health-care professionals, industry, researchers. Communication with patients should be up-to-date, using new media (internet, help-line, sms) and social networks to attract public attention. Leaflets with information in the local language are needed. Members are needed to support and sustain the work and financial support has to be secured. For the implementation of various activities, partnerships will be critical, and effective alliances have to be established with specialists, general practitioners, nurses, and other health-care specialists.

Dr. Nonikov welcomes and announces the next speaker, Prof. Peter Frith, Australia, member of the Australian Lung Foundation.

Prof. Frith gives an overview of the Australian Lung Foundation, which was established 1990 with headquarters in Brisbane, and is financially supported by the pharmaceutical industry, government, and private sponsors. The ALF is an independent non-profit institution and works closely with other Australian associations. Its mission is to ameliorate lung diseases, educate the community about lung diseases, raise funds, and work with other associations to fight general lung diseases. In Australia, however, the biggest problem in lung diseases is asthma, not COPD.

The national program to reduce the burden of COPD consists of clinical support, community awareness campaigns, patient support, research, and government advocacy. The Australian COPD guidelines are mainly based on the GOLD guidelines. In addition to World COPD Day there are ongoing COPD programs run by the government, as well as awareness-raising campaigns in the media. A “train the trainer” program has also been established to train physicians and nurses to better treat COPD.

Session 7: Conference Summary and COPD Patients’ “Bill of Rights”

Chair: M. Franchi, Italy & Y. Mohammad, Syria

Ms. Franchi starts the last session by providing a summary of the day and introducing the COPD patients’ bill of rights, then introduces Prof. Vicky Lopez from Uruguay as the first speaker.

Prof. Lopez reports on the Latin American PLATINO study, carried out in five cities in Mexico, Venezuela, Brazil, Chile, and Uruguay. Altogether 5,500 people over age 40 were visited at home and screened for COPD with questionnaires. Some 758 people had COPD, 89 of whom had not been previously diagnosed. The reason for this large proportion of undiagnosed patients, Prof. Lopez believes, is probably the lack of spirometry in medical care and the lack of knowledge among physicians about how to diagnose and treat COPD. Furthermore, basic medications such as bronchodilators are unavailable or unaffordable for most patients.

Prof. Lopez describes a Latin American Thoracic Society (ALAT) training and education program for primary care physicians and pneumologists about the diagnosis and treatment of COPD. There are plans to implement smoking bans in the future. The main goals in the fight against COPD in Latin America are increasing awareness (diagnosis, disease, treatment), addressing smoking as a major cause of

COPD, securing smoking bans in public places, and introducing the four-letter abbreviation “COPD” to the public.

Prof. Yousser Mohammad introduces Ms. Marianella Salapatras from Greece, head of the European Federation of Allergy and Airway Diseases Patients Associations (EFA).

Ms. Salapatras introduces EFA to the audience: the organization was founded in 1991 to have one strong voice throughout Europe to fight respiratory diseases. EFA unites 33 member organizations from 21 countries in Europe, and the executive board consists of 5 bodies from different EU respiratory associations. The mission of EFA is to reduce the frequency and severity of allergies, asthma and COPD, minimize their social implications, improve health-related quality of life for patients, ensure full citizenship of people with these conditions, and pursue equal health opportunities in the field of allergy and airways in Europe. Together with the European Lung Foundation, EFA is advocating a complete ban on tobacco smoking in all public places across Europe, and held a press event in 2007 at which 220 members of the European Parliament in Strasburg pledged to increase awareness of and fight against COPD. In addition to various campaigns all over Europe to increase awareness and knowledge about COPD, EFA has produced the EFA Book of COPD and organized World No Tobacco Day 2008. Ms. Salapatras closes her talk by highlighting that EFA is quite strong today, but could be even more powerful if everyone gets aligned and united to commonly fight COPD.

In a lively discussion following the lecture, during which different experiences of collaboration with respiratory associations and patient organizations are shared, Prof. Mohammad explains that newly founded patient organizations are more than welcome to participate in the global fight against COPD and that only a common effort of all different parties worldwide will have the power to successfully fight COPD.

Prof. Mohammad welcomes and introduces the last speaker of the conference, Dr. Jochen Scheld, ICC coordinator from Switzerland, presenting the COPD Patients’ “Bill of Rights.”

Dr. Scheld presents the seven articles of the COPD Patients’ “Bill of Rights” and draws parallels to the original bill of rights, hoping that these new rights will become as famous:

- The right to receive early and accurate diagnosis
- The right for information and education about COPD
- The right for support and understanding
- The right to receive care and treatment that will benefit them
- The right to their fair share of society’s involvement and investment in their welfare and care
- The right to advocate with other COPD patients and supporters for improved COPD care and COPD prevention
- The right to safe air and environment

To secure these rights for all COPD patients worldwide, continuous training and education of patients and physicians is needed. Appropriate medication should be available and affordable for all patients. Public awareness must be increased to

obtain more understanding for COPD patients and to strengthen the common fight against the number-one cause of COPD: cigarette smoking! Joint efforts are necessary, including governmental bodies and health-care institutions, to implement complete smoking bans in public places. Additionally, the warnings on cigarette packs have to mention COPD as a consequence of cigarette smoking. If smoking is abandoned, we can have a world where everyone can breathe freely!

Ms. Franchi closes the meeting, highlighting that the COPD Patients' Bill of Rights will be translated into different languages. She also announces that on World COPD Day, November 18, these rights will be presented and implemented to a wider public. She thanks the organizers, in particular Prof. Larry Grouse from ICC, all the supporting organizations (ICC, EFA, GARD, IPCRG, WONCA, Italian COPD Patient Organization), all speakers and presenters, and the Italian Ministry of Health for their support. Special thanks also go to the industry sponsors for their financial support.