



Cough, cough. Who's there?

World COPD Day 2004 was devoted to 'Don't Ignore COPD!', the aim being to encourage patient groups to join forces to enhance awareness of and make a call for action on this debilitating and deadly illness.

It's striking that although chronic obstructive pulmonary disease (COPD) is the fourth major cause of death worldwide, three-quarters of people affected are not diagnosed. COPD kills more people than lung cancer, causes more smoking-related deaths than cardiovascular disease and severely undermines the quality of life of those affected. From 4% to 10% of adults in Europe are estimated to have COPD and the total cost for the disease is 50 billion euros.

Patients with COPD are affected by a progressive, disabling deterioration in lung function and chronic shortness of breath that can severely limit their physical activity. It is a multi-factorial disease caused by lifestyle, and environmental and genetic factors. The biggest risk factor is cigarette smoke. An early diagnosis and treatment can reduce exacerbations and improve quality of life for COPD patients.

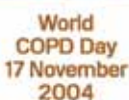
EFA calls on the European Union and governments to consider COPD a public health priority by launching a European awareness campaign. EFA's position is that things can be changed. One of the single most effective measures to raise awareness

Don't ignore COPD

COPD is the 4th leading cause of death, yet 75% of those affected remain untreated – this can be changed!

European Federation of Allergy and Airways Diseases Patients Associations, EFA – Working to improve the quality of life of patients with COPD.

www.efanet.org



of COPD would be to print early symptoms (shortness of breath, cough, wheezing and increased phlegm production) as health warnings on cigarette packages in Europe.

The public, particularly smokers, should be aware that a cough and phlegm could be an early sign of COPD and so seek early treatment and advice. The EFA network is in a prime position to convey this life-saving message to the public-at-large.

Svein-Erik Myrseth, EFA President

The Fear Factor

We are privileged to have been given permission to reprint in this issue of EFAnews an editorial entitled 'Beyond Fear' that appeared in OASIS Allergies, the magazine produced by the Fondation pour la Prévention des Allergies (Belgium) and AFPRAL – Association Française pour la Prévention des Allergies.

Fear is a factor not easily accepted by health professionals and is often downgraded to anxiety or concern. Nowhere is the effect of fear more apparent than in the person with an acute attack of a breathing disorder or with allergy-induced anaphylaxis. There is no medication for fear without compromising breathing and patients are often not confident in the efficacy of the treatment until it does actually take effect. When the acute phase finishes, there is the constant nagging fear of the next challenge. All this can be minimised with education on the role of the drugs used and the effects they will have. Learning how to help this process physically is also important.

So there it is – if we want to minimise the Fear Factor in allergy and asthma, education is a vital tool.

Elisabeth Bell, EFAnews Editor

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Beyond Fear

Fear, like love, anger and joy, is one of our emotions. It can save our life but it can also cast a shadow over it. It is fear that instantly makes us grasp our child by the hand to avoid a car that has suddenly appeared. And there is the other fear – the one that increases our distrust of the unknown.

Good fears warn us of danger and make us adopt appropriate behaviour. Bad fears paralyse us and leave us scared, withdrawn and powerless to act.

People who contact our emergency phone services are often distraught with fear, especially when the call concerns a child who has been recently diagnosed with allergy or when a newspaper article or TV programme has emphasised the fatal risks linked to that allergy.

Fear of fatal accidents makes us warn a child, to remind him or her to carry a first aid kit or medication when apart from us. But fear can paralyse some families to the point of denying the child a school outing or holiday camp. Parents try to control all aspects of the child's life and often ring us alarmed at the thought of school starting or the first school outing.

To everyone, we must repeat that there is no life without risk and that too much caution can be more dangerous than being daring. Children who have not been allowed to take control gradually, run more risks than those who are used to think for themselves.

This is an important message that we, the Founders of the *Fondation pour la Prévention des Allergies* who have run the association for 15 years, want to

pass on. Our children have grown; they are now young adults, and even if they have suffered or still suffer from severe

food allergies, they are coping very well in their everyday life. They study, work, go out with friends, eat in snack bars just like their peers. They are simply more careful and on their guard. They have learnt to ask questions, ponder on what they eat and know how to react and help one another in dire times. It is a difficult task based on communication and trust, but it is an essential task because it allows them to be part of society and not withdrawn.

Our hope is that this training, which has not always been easy, will also open our children's hearts and minds, leading them to accept others with all their differences.

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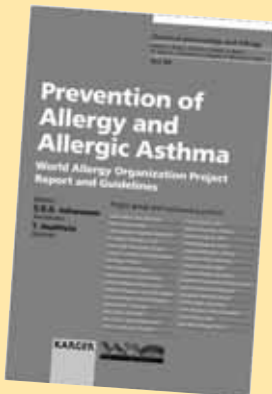
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Prevention of Allergy and Allergic Asthma

World Allergy Organization Project Report and Guidelines

Editors: S.G.O. Johansson & T. Haahtela



Prevention of allergy and allergic asthma was a collaborative project between the World Allergy Organization (WAO) and the WHO launched in 1999. This monograph is the final report of the group of international experts involved in the project. Both theoretical and practical aspects are discussed, and constructive advice is given.

Through its network of more than 70 member societies, the WAO will promote the concept of prevention of allergies and allergic asthma worldwide to benefit patients prone to become allergic, to prevent the worsening of existing allergic diseases, and to reduce their high cost to society. Only by increasing knowledge about allergic diseases throughout society can the right steps be taken for their effective prevention.

Johansson SGO, Haahtela T (eds): Prevention of Allergy and Allergic Asthma. World Allergy Organization Project Report and Guidelines. Chem Immunol Allergy. Basel, Karger, 2004, vol 84.

www.karger.com/chial

Respiratory Rehabilitation

An example of a patients' association supporting a local network



Respiratory rehabilitation consists in applying such good clinical techniques as physical retraining, education and formation.

For three years the patients' association ABIR21 in Dijon (France) has supported the creation and activity of a local network devoted to respiratory rehabilitation. About sixty patients took part in the network.

The project started with a three-month course (held twice weekly) in the Centre of Re-education. Subsequently, the patients were evaluated and continued their training at home under the supervision of a physiotherapist and of a home carer from *Alizé de Bourgogne*.

The respiratory home rehabilitation network functions in coordination with:

- Public health specialists (physicians, physiotherapists)
- Hospitals
- An Association Service of respiratory assistance (*Alizé de Bourgogne*) to teach patients who can benefit how to breathe to obtain better oxygenation.

Respiratory rehabilitation needs:

- Specialized material: exercise bicycles, cardiofrequency-meters, and specialized computer instruments.
- Assistance at the Re-education Centre, and assistance of health professionals (physicians, physiotherapists, *Alizé de Bourgogne*) at home.

The success of this project depends on the patient's motivation and a sense of rivalry among patients. This is where patients' associations can play an important role.

ABIR21 has invested greatly in this experience. They identified people who could benefit from retraining, helped communication between them, gave encouragement, reserved an hourly session in a local swimming-pool, and organized and accompanied patients in weekly walks 'adapted' to their needs and possibilities.

In general, the period of education is intense and is held in specialized centres or in an outpatient's department for, e.g., 3 half days a week for six weeks.

The patient can safely train at home with the exercise bicycle. Patients are instructed to control their heart beat and mark the sessions in a note-book, which is shown weekly to a trained physiotherapist or nurse.

The most difficult thing is to convince patients to continue their training, otherwise the benefit of rehabilitation soon disappears. To this aim, patients' associations can help form groups in which everyone motivates the others, and can organise more stimulating activities (collective 'soft' gymnastics, easy walks, bicycle tours, swimming-pool sessions).

Respiratory rehabilitation gives a benefit in terms of quality of life, by allowing patients to return to former activities. There is also a benefit in terms of reduction of hospitalisations. But the greatest benefit is to restore a joy of life.

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No Smoking in Scotland

First Minister Jack McConnell has announced in the Scottish Parliament that there is to be legislation to enact a comprehensive ban on smoking in enclosed public places.



This historic move is the most significant step Scotland can take to improve public health and save lives. Target date for implementation of this historic event is spring 2006.

Pubs, restaurants and private clubs will not be exempt, as a clear-cut policy is



easiest to understand and implement.

A Ministerial national smoke-free areas implementation group will be set up to guide the process and enable partnership work with those affected.

There is to be increased support for smoking cessation services in Scotland.

Licensees and employers who refuse to comply may face up to £2,500 fines and fixed penalty notices up to a maximum of £1,000 may be issued to individuals who repeatedly break the law.

PEER SUPPORT EMPOWERS!



In August 2001, the Finnish Allergy and Asthma Federation started a project on building a network of peer support for families with allergic or asthmatic children. The goal was to make peer support a permanent part of all 32 associations and their actions in order to help families cope with everyday life. Peer groups were created, and education was provided for peers as well as for relatives and professionals about allergies and asthma and on how to deal with the diseases in real life.

The project was funded by the Finnish Slot Association, and lasted three years. At the beginning of 2002, the project was introduced to the associations to recruit active members and others interested in peer activity. In parallel, 21 local courses on the basics of peer support were held throughout the country with an attendance of 179 persons.

The Federation also organized courses where educated peers shared their experiences with health care professionals. These courses did not include the care of allergy and asthma, but focused on everyday life, the experience and expertise of the peer persons, and on their role as a complement to the expertise of primary health care. A

leaflet on peer support and a poster was printed together with a handbook containing practical information and experiences on peer support. Information leaflets were also produced for families.

The number of peer persons has doubled from 75 in autumn 2001 to 150 in spring 2004. There are now peer persons in all five Finnish regions. Most peer persons attended the course on the basics of peer support. There are 57 peer groups throughout the country, and in some locations, such as Helsinki, there are several groups. Most discussion groups are intended for parents with allergic children, but there are also groups on adult allergies and asthma. The groups usually meet once a month, and their size and activities vary.

Particularly popular are the small information packages on food hypersensitivity, children's exercise and on where to get help for children's asthma and allergies. The latter is targeted at families where the disease is newly diagnosed.

In the project evaluation, peer persons were asked what peer activity had given them and what they had learned: 'Knowledge, support, understanding and empathy' was one reaction. Others have made new friends, and found new courage and enthusiasm. Many have also got concrete tips on dealing with everyday life, and talking to someone



who 'has been there' has made people realise that they are not alone.

The project ended in August 2004 but this does not mean that peer support ends. The associations will continue the work in co-operation with the Allergy and Asthma Federation by recruiting new peers, educating and supporting them, by passing on contact information, informing the general public and the members, and by making it possible for new peer groups to emerge and by supporting their activities.

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Ready-to-go on your website

Four Interactive Learning Experiences

AstraZeneca has, together with leading asthma experts, developed four interactive high-quality courses that, after translation, are ready for use on your website.



The courses explain asthma through the use of animations, text and a descriptive voice over in easy to understand language. Running approximately 15 minutes they give you an overview of the condition, the diagnostic tests and the treatment options available.

By giving your website visitors an opportunity to learn more about asthma you will help them to take an important step towards taking control of the condition and leading a

productive, physically active life.

The courses were presented at the annual EFA meeting in Oslo, Norway, in June. They have also been endorsed by GINA and can be found on the GINA website.

To learn more about how to use these courses on your own website please contact Birgitta Lyrdal, AstraZeneca Global E-Business Manager Marketing Communications TA Respiratory, PS&L, AstraZeneca S- 221 87 Lund, Sweden
 Tel: +46 46 33 68 07
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News from the Board

At the annual general meeting in Oslo in June 2004 EFA members voted to change the statutes to incorporate EFA in Belgium, and confirmed a new mission and objectives. Essentially, EFA aims are to:

- substantially reduce the frequency and severity of allergies, asthma and COPD
- minimize the social implications of these diseases
- improve the health-related quality of life of patients with allergy, asthma and COPD
- ensure full citizenship for patients
- obtain equal health opportunities across Europe

Guiding our work will be the patient's perspective, involvement, sharing knowledge and experience, partnership and co-operation, visibility and presence, and health equity in Europe.

To fulfil its mission, EFA will focus on three strategies: 1) influencing European Union policy making, 2) strengthening the EFA network and 3) empowering member organisations. In particular, the EU needs to focus more on the patient's right to healthy indoor and outdoor air, good quality accessible healthcare, social participation and adequate funding of demand-driven research. EFA will work to construct a strong, professional network of allergy, asthma and COPD patient organisations, and strengthen the capacity of the Central office in Brussels. By encouraging the sharing of experience about policymaking, products and services for patients and increasing awareness, EFA will help its member associations become more effective.

The participants of the Long-Range Planning workshop

held at the Oslo conference identified a number priorities within these programmes for the next three years. The Long-Range Planning Committee is compiling the results for the Board, who will complete a long-term plan of action, which in turn will be submitted to EFA member associations for endorsement.

We warmly thank all those who have contributed and helped us in this long, but essential work to ensure a fruitful future for EFA. The year 2004 has been very active for lobbying for a healthy environment for patients, particularly as regards indoor air quality. Our newly completed project THADE-Towards Healthy Indoor Air in Dwellings in Europe came right on time with important information on this subject across Europe and will encourage us to keep on working!

We would like to thank our members and honorary members for their voluntary time and effort, the many experts who keep us informed on latest scientific/medical/technical data, EAACI and EFA's main corporate partners AstraZeneca, BoehringerIngelheim, GlaxoSmithKline, Novartis and the new partner UCB Pharma for their continuous financial support.

Again this year, we thank the following people for their outstanding work on EFAnews: the Editor Elisabeth 'Liz' Bell, and Jean Gilder and Giuliana Pensa at the Editorial Office.

We send the season's greetings to all EFA's friends, and look forward to working with you in 2005 and beyond.

Happy New Year!

Donna, Marianella, Otto, Trudy and Svein-Erik

Tenth EFA Conference - Breaking Through Borders Noordwijkerhout, The Netherlands 2-4 June 2005

Starting with possibilities instead of limitations

Topics

- Update on facts and figures in Europe – Update on lifestyle interventions
- Sharing best practices of products and services for members
- Disease management and strategic alliances in the care field
- Capacity building
- EU policies

The 2005 EFA Conference is hosted by the Astmafonds. The venue is Congresshotel De Leeuwenhorst which is situated on the coast approximately 20 minutes from Schipol Airport and 30 minutes from the centre of Amsterdam (www.hotel-assist.nl/nl/noordwijkerhout/hotel_nh_leeuwenhorst/). The announcement, programme and registration forms will be posted on www.efanet.org as they become available.

Don't miss this opportunity of interacting with your colleagues throughout Europe!



Mark your diary: Invitation to the EFA Annual General Meeting of members on 2 June 2005

ENVIRONMENT AND HEALTH ACTION IN EUROPE



Will our 'right to breathe healthy indoor air' finally be enforced?

Current European actions on indoor and outdoor air quality have a potential to finally give indoor air quality the attention it deserves. An EFA dream come true? Both recently published action plans on the environment, the WHO's Europe's Children's Environment and Health Action Plan for Europe (CEHAPE) and the European Union's SCALE, acknowledge the health effects of the air we breathe. Although they call for more evidence on health effects and the complex relationship between environment and health, concrete actions are justified according to evidence we already have. In particular the evidence on the harmful effects of second-hand smoke is overwhelming.

The implementation of the EU action plan, including indoor air quality was scheduled for discussion in early December in a Conference of EU member states, the European Commission and non-governmental organisations, including EFA.



For more information contact the EFA Central Office efaoffice@skynet.be or visit SCALE http://europa.eu.int/comm/environment/health/index_en.htm or CEHAPE <http://www.who.dk/budapest2004>

EU Health Strategy

EFA attended the meeting of the EU Health Policy Forum, where the outgoing EU Commissioner for Health and Consumer Protection David Byrne presented his draft of a new EU Health Strategy (see http://www.europa.eu.int/comm/health/ph_overview/strategy/reflection_process_en.htm). EFA feels that the focus is on primary prevention with insufficient emphasis on secondary and tertiary prevention. Moreover, although respiratory diseases in general are recognised, COPD, asthma and allergy are not mentioned, although they represent a major public health problem in Europe. The document incorporating all the suggestions received from EFA members will be posted on www.efanet.org

AIRNET is finalising its work

Under the title 'Air Pollution and Health: Connecting Science, Policy and Practice', AIRNET's third and final conference took place in Prague, from 21–23 October 2004.

The first two years of AIRNET focussed on the collection and interpretation of air pollution and health data. 2004, the last year of the project, concerned the dissemination and communication of the knowledge obtained between scientists, policy makers and stakeholders.

The preliminary reports of the AIRNET working groups (toxicology, exposure, epidemiology, health impact assessment and science policy interface) were presented and discussed. And because communication,



exchange of knowledge and information, development and strengthening of networks and mutual relations are prime issues in AIRNET, the

conference was highly interactive.

The programme varied from plenary presentations in which the views of all parties involved were represented as well as research highlights with potential political spin-offs to parallel sessions on a great variety of subjects. The AIRNET reports and the WHO systemic review of the air quality guidelines were discussed in open groups as well as in plenary sessions, and the same models were used for regional European meetings.

Participants were able to contribute to the discussion on statements related to air pollution and health by writing their opinion on the papers mounted on the walls during the conference. A speakers' corner was another feature. All this made the conference very lively and it was fun to participate in this varied programme.

The final AIRNET reports will be easy to read: science journalists have been involved to make the text accessible for all the stakeholders in the project. A sixth report, containing the final conclusions, will be added to the others.

A Fourth AIRNETWork day will take place in Barcelona, on December 10 2004. The previous AIRNETWork days took place in the Netherlands, Sweden and Hungary.

I sincerely hope that the model of the AIRNETWork days at national/regional level will be used in the future to communicate about air pollution and health with all parties involved.

The Airnet website contains all the information collected in the network, including meetings and conferences. Please visit <http://airnet.iras.uu.nl>

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Children's health and pollution: the PINCHE project half-way

From 18 to 20 October 2004 the PINCHE project working groups met in Prague to evaluate the first 18 months of this project, which summarises the influences and consequences of pollution on children's health. PINCHE uses peer-reviewed literature to do this and covers the fields of air pollution (indoor and outdoor), noise, neurotoxins and carcinogens.

The outcomes of each field will be divided in outcomes of exposure, toxicology and epidemiology; and in risk assessment and socio-economic outcomes and there should be policy interpretations of all the outcomes. Quite a job, especially with the limited funds this project has.

The meeting in Prague started with a review meeting where working group leaders presented the work done to the external reviewers and the representative of the European Union.

EFA is a member of PINCHE, which means that the possibilities to be active in the network are rather limited due to the limited financial means. As an EFA representative it is therefore hard to be up to date with PINCHE



developments. Assisting in the review meeting was a good opportunity to learn about the project's progression – and to find out that the other members of the network have the same problem EFA has.

The meeting resulted in three days of hard work. I limited my participation to two working groups: 'Socio Economic Factors' and 'Policy Interpretation'.

In the Socio Economic Factors group the literature choice was discussed: most of which was constituted by reviews, which did not give much information on the subject. Environmental injustice is not well covered in Europe, therefore the

search for recent literature will be widened: and the use of the so-called 'grey' literature, publications in national languages was considered.

The outline of the final report on socio economic factors was discussed as well as the role of the factors themselves.

The Policy Interpretation Working group met for the first time. The work package leader Chris Busby only very recently joined the PINCHE network. His energetic approach and written introduction led to animated discussions about the deliverables of this working group. This group started working at the meeting in Prague. It was decided to use the outcomes of the Science Policy Interface working group in the AIRNET project as a start.

For more information visit:
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Europe invests in excellence to curb allergy escalation

The European Commission has recognised the growing concern among European citizens about allergy and asthma and their influence on the patient's health condition and quality of life. It has designated GA²LEN a 'Network of Excellence' linking 25 European research teams in allergy and asthma. Partners in the Network of Excellence are EFA and the European Academy of Allergology and Clinical Immunology (EAACI).

GA²LEN - Aims

- To address all aspects of allergy and asthma by tackling the fragmentation of European research, by integrating EU research centres on a long-term basis.
- To spread excellence and knowledge to interested targets.
- In the long-term, to decrease the burden of allergy and asthma in Europe.

GA²LEN workpackages

Nutrition; Infection; Environment, indoor and outdoor pollution; Occupation and pollution; Gender; IgE sensitization and allergic diseases; Early events in airway remodelling; Clinical care and quality of life; Genetics and genomics.

GA²LEN will adapt, translate and disseminate on a regular basis evidence-based information, data and guidelines for patients, for parents of allergic and asthmatic children, and for policymakers, authorities and opinion leaders. EFA plays a key role in translating the information from scientific data to European citizens. With new scientific data EFA and GA²LEN can increase awareness and patient education of allergy and asthma in Europe. Another role for EFA is the challenge of incorporating the patient's view in research policy on allergy and asthma.

EFA plays an active role in Workpackage 2.8, which is focused on clinical care and quality of life. EFA is represented in this WP by Dr Marianella Salapatras, EFA Board Secretary, from Greece. The first EFA-GA²LEN Workshop for members is scheduled to take place on 28 January 2005 in Athens, Greece to introduce GA²LEN, to plan a strategy of translating and disseminating the information emerging from GA²LEN and to encourage collaboration on national level with GA²LEN centres.



Erkka Valovirta MD
EFA-GA²LEN Project Member, www.ga2len.net

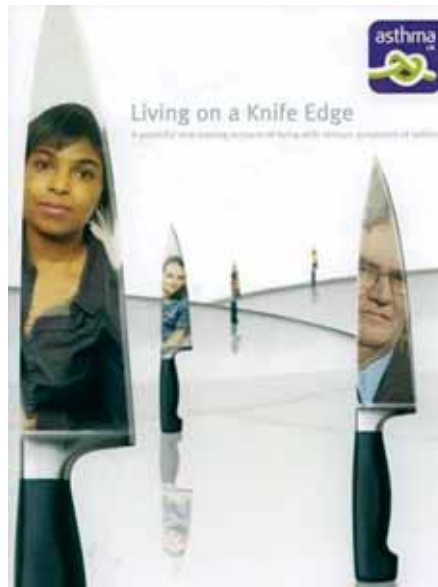
Perspectives on Successful Lobbying

Lobbying is one of the major activities of patients' organisations. Readers who were not able to attend the EFA Conference in Oslo might be interested in the following report of one of the workshops held at EFA's ninth conference.

Eighty persons from 20 European countries attended the workshop entitled 'Perspectives on Successful Lobbying' held on 26 June 2004. It was held on the basis that lobbying is of great importance to organisations wishing to drive progress at a policy level in under-represented areas of public interest such as asthma.

With many attendees having no personal experience of lobbying, the session concentrated on what it is, how it is done, and the powerful effect it can have on policy when used effectively.

As an example of successful lobbying in action, Donna Covey, Chief Executive of Asthma UK and Kate Webb, Senior Policy and Information Officer for the organisation, presented the outcomes of 'Living on a Knife Edge', a 500-



patient survey in the UK that revealed shocking statistics about the fear people with severe asthma in the UK live with every day. Through careful and applied lobbying by Asthma UK, these results appeared extensively in the national press, including national television and radio and were presented in a parliamentary reception held in the Houses of Parliament on World Asthma Day, 4 May 2004.

Bob Laxton, Member of Parliament and asthma sufferer, supported the

need for such a campaign, saying 'Public perception is distorted. People do not really understand the effects of asthma unless there is someone with asthma in their household'.

Workshop attendees participated in a focus group activity session at the end of the meeting, as a way to practise applying the principles they had learned about lobbying. They were also presented with a lobbying toolkit and a 'Living on a Knife Edge' survey. A policy scenario was presented to the groups and attendees were asked to identify the issues appropriate for lobbying and develop a campaign around them. Consultant Helen Johnson was very impressed with the results, saying 'The campaign ideas from this international group have been fantastic – particularly in the time available. Patient groups were very enthusiastic about using what they had learnt on a national level to benefit their patients. I expect some very successful lobbying initiatives to be developed as a result of what I've seen here today'.

A non vocal message!



In May 2004, the Association of Bulgarians with Bronchial Asthma (ABBA) organised a protest outside Parliament against the reduction in reimbursement of asthma medicines. About 100 asthma sufferers, members of ABBA, attended this event.

Upon their arrival, each member of parliament was given a gold fish in a plastic bag, whereas the President of the governmental Medical Committee received fish in a tank equipped with a tap. The message was: 'You control the tap. If you drain the water from the tank the fish will suffocate just like asthma

sufferers suffocate without medicines.' The event received wide media coverage. The Bulgarian National Health Insurance Fund recently decided that some inhalers for children will be reimbursed 100%.

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Improving Patient Outcomes in COPD: From Air Trapping to Quality of Life

Boehringer Ingelheim and Pfizer sponsored a symposium at EFA's 2004 conference highlighting healthcare professional and patient experiences with COPD. EFA President, Svein-Erik Myrseth, introduced the symposium with an overview of COPD, which currently claims 2.75 million lives annually. EFA's mission includes improving quality of life for people with COPD throughout Europe.

The healthcare professional's experience of COPD

Dr Anders Østrem, GP and President of the Respiratory of the International Primary Care Group (IPCRG), focussed on challenges in primary care:

- patient and public awareness of COPD
- differential diagnosis
- understanding the mechanism of COPD
- right treatment for the right patient.

In the US, COPD may be undiagnosed or misdiagnosed in up to 85% of sufferers. This may be because many likely COPD sufferers do not seek medical help, or have low expectations from a visit to a doctor. Research conducted by the IPCRG showed that many patients have been told by their doctor that 'nothing more can be done for them'; they therefore do not seek further help because they feel the situation is hopeless.

Another challenge is the need to distinguish between asthma and COPD. Although they are frequently confused, the etiology, pathology and therapeutic approach for COPD is different from asthma. Correct diagnosis is easily determined by assessing the patient's history, and by conducting an examination and spirometry test.

In terms of understanding the mechanism of COPD, the concept of "air trapping" was explained. Chronic airflow limitation associated with COPD leads to excess air being trapped in the lungs after a person has fully exhaled. Air trapping is a primary cause of breathlessness, which often restricts a patient's ability to perform daily activities such as walking up stairs or taking a shower.

In most cases, smoking cessation is first-line therapy for

COPD, followed by treatment of disease symptoms – finding the right treatment for the right patient is important.

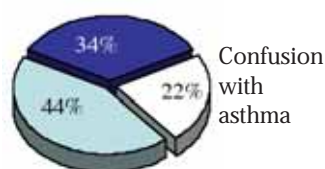
According to treatment guidelines of the Global Initiative for Chronic Obstructive Lung Disease (GOLD), long-acting bronchodilators are a preferred treatment option for COPD maintenance therapy. Published data show anticholinergics, such as tiotropium, to be among the most effective bronchodilators, providing symptom relief and sustained improvements in lung function so that COPD patients can enjoy a better quality of life.

The patient's experience of COPD

Candida Halton, from Shire Health International, discussed the patient's experience with COPD, including research on the causes of underdiagnosis.

Healthcare professional

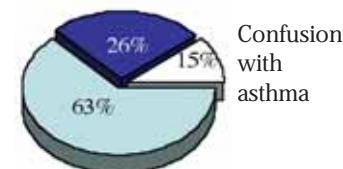
Late patient presentation



Lack of awareness of COPD

Patient

Late patient presentation



Lack of awareness of COPD

Further research profiled a 'day-in-the-life' of a COPD patient, describing the severity of breathlessness and the disabling effect this has on performing normal daily activities. Patients' views were presented in terms of living with COPD, and the social isolation experienced: embarrassment as others don't understand, isolation if housebound, and a feeling of 'pointlessness'.

The Symposium concluded with a discussion around World COPD Day (17 November 2004), and suggestions for maximising this opportunity to raise awareness of COPD. For more information on COPD, and World COPD Day, go to www.goldcopd.com

NEW RESEARCH



The 'Tobacco or Health in the European Union: Past, present and future' Report, was prepared by the ASPECT Consortium, which includes experts from the European Respiratory Society (ERS) and the European Network for Smoking Prevention (ENSP).

The report fills an important gap in tobacco control policy in Europe. It represents the first attempt to draw together in one comprehensive

book an analysis of tobacco control policy (past, present and future) in the EU.

Importantly, the report presents a set of recommendations which should feed into and inform policy discussions at European and national level and help to define a European tobacco control policy for the future.

The executive summary is available in 20 EU languages at http://www.europa.eu.int/comm/health/ph_determinants/life_style/Tobacco/ev_20041022_en.htm

News from EFA Member Associations

Italy

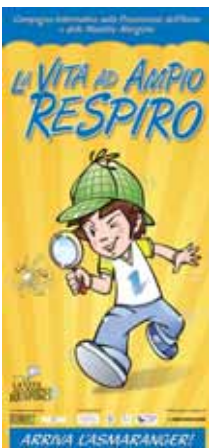
The *Associazione Italiana Pazienti BPCO (AIP BPCO)* in collaboration with GOLD-Italy and the *Fondazione Unione Italiana per la Pneumologia (UIP)* contributed to the organisation of various events to mark World COPD Day 2004:

- A workshop in Bologna entitled 'COPD: A Disease with an Enormous Socioeconomic Impact'. This event was video-recorded and a web seminar will be posted on www.gold-copd.it
- A workshop in Rome entitled 'WAD 2004: Research at the Service of the Citizen'
- A national press conference and a TV spot, with a help line.

These events were supported by the Italian Ministry of Health, the *Istituto Superiore Sanità*, all the scientific societies devoted to this field and GPs.

*Mariadelaide Franchi, AIP BPCO, franchima@tin.it
www.pazientibpcO.it*

The Asthma Ranger is on the look out!



In October 2004, *Federasma*, the Italian Asthma and Allergy Association, launched an information campaign entitled *La vita ad ampio respiro* (this is a very striking play on words, which cannot be translated) in 100 elementary schools for children aged between 6 and 11 years, in the *Lazio* region of Italy.

The 'Asthma Ranger' is the best 'investigator' of breathing in the world. With the help of Dr Dott and the asthma-detector, the Asthma Ranger is able to find the enemies of breathing and to banish them from the environment where children live.

The campaign includes a comic book written especially for children. The idea was that through children, parents and teachers can learn what should be done at home and at school to prevent and control asthma and allergies.

Mariadelaide Franchi, Federasma

The Netherlands

Celebrating the birth of the COPD Chain Quality Foundation

On 24 September the COPD Chain Quality Foundation was established. By signing the convention, the partners in COPD care have committed themselves to improve the quality of care for people with COPD. The Netherlands Asthma Foundation is the originator of the network and provides the necessary finances.

Chronic obstructive pulmonary disease is a chronic lung disease associated with airflow obstruction. The

common characteristics of COPD are progressive limitations of the airflow into and out of the lungs and shortness of breath. Smoking is the main cause of COPD, but other environmental and industrial pollutants can also result in COPD in someone who has never smoked.

The disease can be managed, controlled and slowed down with proper treatment and care. The COPD Chain Quality Foundation will improve the care for people with COPD by stimulating general practitioners, physiotherapists and pharmacists to come to an agreement about a guideline for COPD care. Furthermore, COPD care education for general practitioners is planned and telemonitoring of people with COPD is facilitated. Subsequently, patients are in direct contact with the hospital through an appliance, the Health Body.

The co-founders of the COPD Chain Quality Foundation

- Netherlands Asthma Foundation
- Dutch College of General Practitioners
- Federation of Medical Coordinating Centers
- Dutch Association of Pulmonary Rehabilitation Centers
- Netherlands Society of Respiratory Diseases
- Dutch Federation of Respiratory Nurse Specialists
- Scientific Institute Dutch Pharmacist
- Royal Dutch Society for Physical Therapy
- Homecare in the Netherlands

*Annette van der Goes, Netherlands Asthma Foundation,
Annette.van.der.Goes@astmafonds.nl*



Toasting the COPD Chain Quality Foundation

Slovenia

The annual meeting of the Pulmonary and Allergy Patients Association (PAPA) of Slovenia took place in September 2004 in western Slovenia and was attended by 400 members.



The meeting featured lectures on lung cancer, and gave ample opportunity for attendees to exchange experiences.

The association has organised four asthma schools for adults and three COPD schools in different parts of the country. We have started a new series entitled 'Think Out' targeted at the general public. Three flyers have already been printed on allergies, COPD and smoking, respectively. We have also produced a booklet on self management.

*Barbara Latkovic, PAPA, Slovenia,
dpbs@siol.net*

United Kingdom

Allergy UK

Allergy Magazine, produced by Allergy UK, was launched about one year ago. This bimonthly magazine, billed as 'the essential lifestyle guide for people with allergies', has a circulation of over 97,000 and is available at large supermarkets and selected news retailers. The magazine is also available to specific Allergy UK members, GP surgeries, NHS clinics and by subscription.



Asthma UK

Asthma UK launch a UK workplace asthma charter

A new workplace charter that is intended to significantly reduce the impact of asthma in the workplace has been launched in the UK by Asthma UK.

Each year in the UK, an estimated 750,000 workers with pre-existing asthma suffer attacks that are triggered by substances in the workplace, while a further 3000 develop occupational asthma due to exposure to dangerous substances.

'Asthma at Work - Your Charter', which is aimed at employers, employees and health professionals, incorporates ten recommendations to reduce the impact of asthma in the workplace, information on asthma triggers and symptoms, information about what to do if someone is having an asthma attack and guidelines for companies on how to make the workplace safer for people with asthma.



Although tobacco smoke in the workplace is a very common trigger for people with asthma, a variety of other substances can also cause problems for asthmatics working in a broad range of occupations. Such triggers include latex, flour, chemical dyes, dust, certain plastics and some types of metals.

Key recommendations in the charter, include creating smoke-free workplaces, protecting employees from triggers and substances that might cause them to develop asthma, and increased health monitoring for employees who cannot avoid some exposure to substances that are known to increase the risk of asthma. The Charter is posted at

www.asthma.org.uk/bits/images/workplace_charter.pdf

INTERNATIONAL HIGHLIGHTS

EFA-GA²LEN

Global Allergy and Asthma European Network Workshop (WS)

January 28, 2005, Athens, Greece

10th International Conference on Occupational Respiratory Diseases

10th ICORD

April 2005, Beijing, China

Organised by ILO and the Ministry of Health of China

Information: www.icord2005.com

World Asthma Day 3 May 2005

Information: www.ginasthma.org



World No Tobacco Day 31 May 2005

Health Professionals and Tobacco Control

http://www.euro.who.int/tobaccofree/Projects/20040903_1

World Allergy Congress

19th International Congress of Allergology and Clinical Immunology (ICACI)

24th Congress of the European Academy of Allergology and Clinical Immunology (EAACI)

June 26 - July 1, 2005, Munich, Germany

Information: Congrex Sweden AB

wac2005@congrex.se

www.congrex.com/wac2005

10th EFA Conference - Breaking through Borders

June 2-4, 2005, Noordwijkerhout, The Netherlands

EFA Annual General Meeting of Members

June 2, 2005, Noordwijkerhout, The Netherlands

Information: EFAOffice@skynet.be

www.efanet.org

Indoor Air 2005 - 10th International Conference on Indoor Air Quality and Climate

Official Conference of the International Academy of Indoor Air Sciences

Organized in cooperation with ISIAQ, will be held in

September 4-9, 2005, Beijing, China

Information: www.indoorair2005.org.cn

European Respiratory Society Annual Congress

September 17-21, 2005, Copenhagen, Denmark

Information: www.ersnet.org

WORDL COPD DAY

15 November 2005

Information: <http://www.goldcopd.com/>



Conference Healthy Buildings 2006

June 4-8, 2006, Lisbon, Portugal

Official conference of International Society of Indoor Air Quality and Climate (ISIAQ)

Organized by Instituto de Engenharia Mecânica -

Faculdade de Engenharia da Universidade do Porto

(IDMEC-FEUP) - Information: <http://www.hb2006.org>

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The complete mailing addresses of the EFA Member Associations can be found on www.efanet.org

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