



European Federation of
Allergy and Airways Diseases
Patients Associations



European Federation of Allergy and Airways Diseases Patients' Associations

Learn to live with Chronic Respiratory Diseases

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EFA board member

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Clubs

www.efanet.org



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Introduction of EFA

EFA Facts

- Founded 1991
- EFA is a non-profit European network of allergy, asthma & COPD patient organisations: 33 member organisations in 21 countries
- Representing > 500 000 patients & carers



Mission

- Reduce *frequency & severity* of allergies, asthma and COPD
- Minimize *societal implications*
- Improve *health-related quality of life*
- Ensure *full citizenship*
- Pursue *equal health opportunities* in Europe

Objectives

- **Advocacy: Influencing European policy making on**
 - Healthy indoor and outdoor air in Europe
 - Quality and accessibility of healthcare
 - Include people with allergies, asthma and COPD into decision making
 - Adequate funding of demand-driven research on diseases
- **Empowerment of member organisations by exchanging experiences on**
 - Influencing national policymaking
 - Products and services for people with allergies, asthma and COPD
 - Increasing awareness



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Learn to live with Allergies

“May contain traces of peanuts
Made in a facility that also
Processes Peanuts”.

These are two
sentences I hate the
most!

The one sentence I love the most:
“Made in a peanut free facility”

Do you like peanuts?

Well I sure don't because to me,
they are criminals.”

Peanut Allergies by Brenaya Hewlett

<http://www.avoidingmilkprotein.com/Brenay.htm>





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Learn to live with Asthma



experience project



COMMUNITY



SHARE

Mommy, Am I Dying?

A personal story in the experience: I Have Asthma

[...] I started to cough up mucus and wheezing and being 8 I thought I was going to die. [...] I wish I had been diagnosed earlier, but I'm just happy I know now and that **I can manage it.**

By FatChick



[...] Ah me and my asthma, we have a long close relationship. Can't ever imagine myself not feeling wheezy, although I would love to.

By xihearthe80sx



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Learn to Live with Asthma

“ The severity of my asthma means I don't have much of a social life and so I feel very isolated. It's also embarrassing to have to [use] your nebuliser in public. I've lost a lot of friends because of my illness. My relationship with my partner broke down because of my asthma ”
Wendy Williams

Fighting for Breath - A European Patient Perspective on Severe Asthma/ *Results of EFA survey on severe asthma in EU*



“ I would like the air to be cleaner, to make breathing easier, and I would like children with asthma to grow up to have a future without the problem of environmental pollution ”
Soledad Alonso

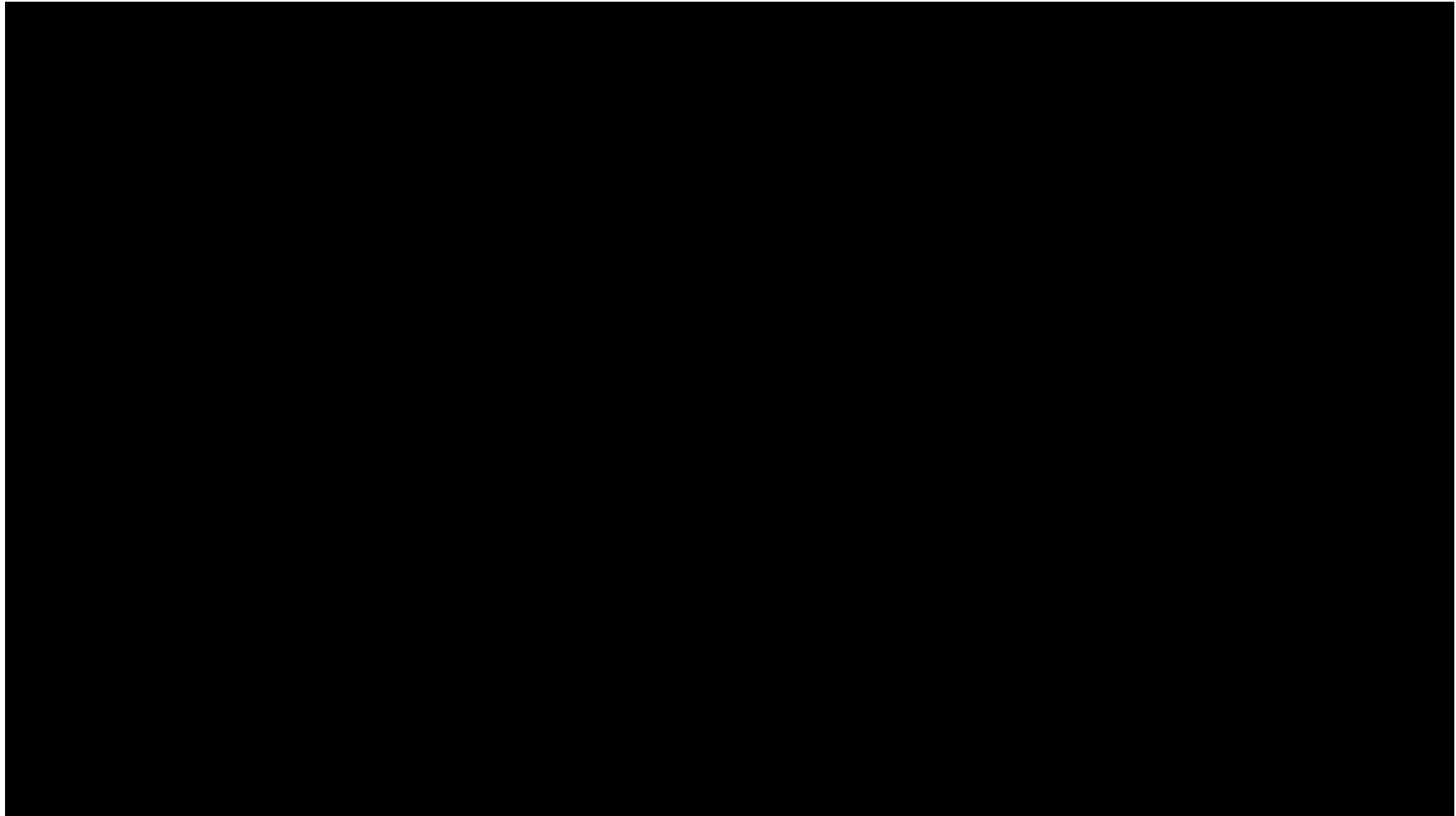




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Learn to Live with COPD: video





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What happens when chronic disease is diagnosed? Patient behaviour:

Patients ideas about their illness are often organized around five components straight after diagnosis:

- Identity
- Timeline
- Cause
- Consequences
- Control/ Cure

These can be thought of as the answers to five basic questions about the illness or health threat:

- What is it?
- How long will it last?
- What causes it?
- How will it/ has it affected me?
- Can it be controled/cured?

People form a mental model of the illness, which is made up of their answers to these questions.

Source: Levendahl, et al.stated 1992

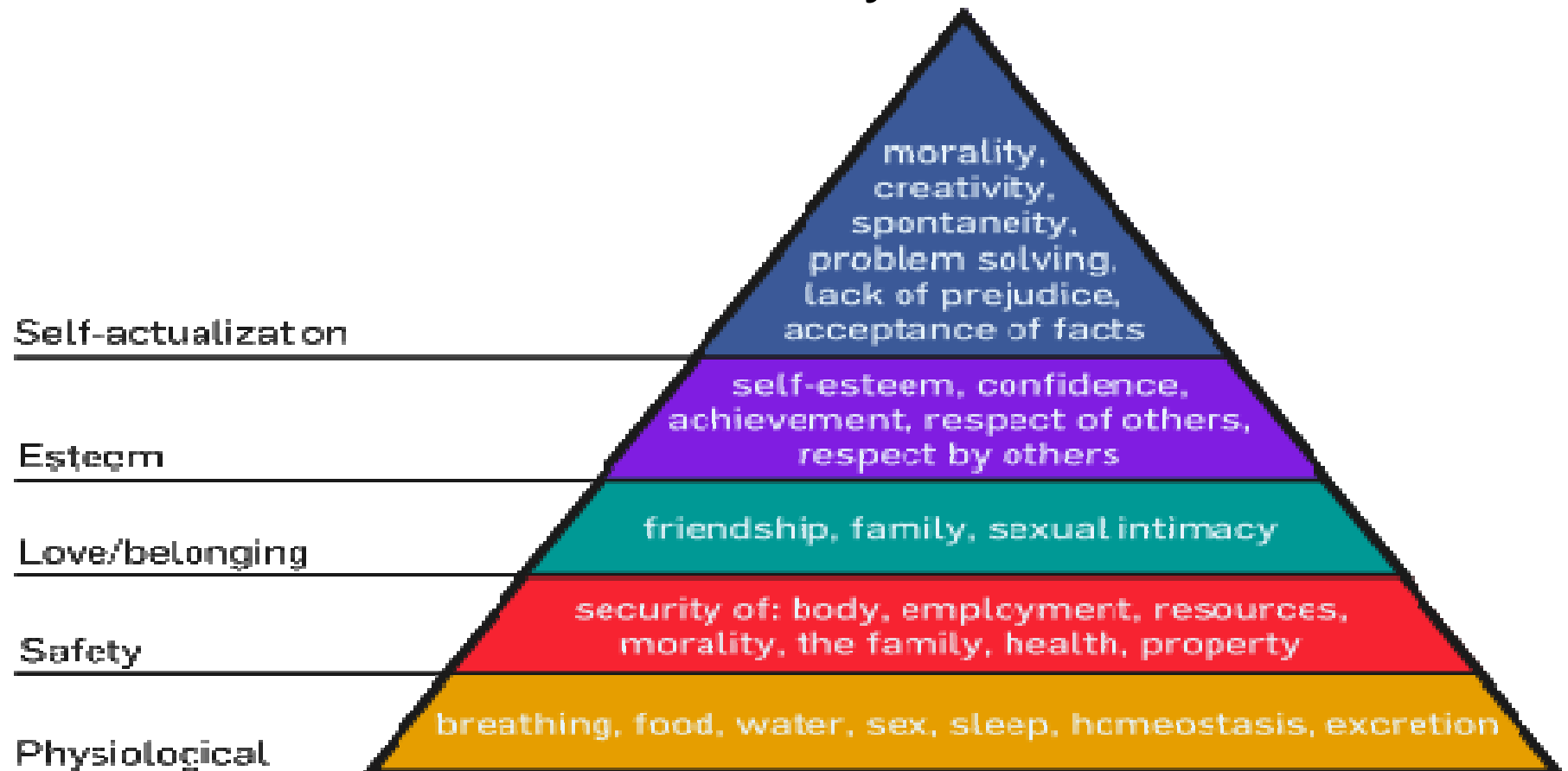


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Why chronic patients are drawn to Peer Support groups?

Abraham Maslow hierarchy of needs





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Why chronic patient education has to be continuous?

- Told, but not heard
- Heard, but not understood
- Understood, but not accepted
- Accepted, but not put into practice
- Put into practice, but for how long?

Konrad Lorenz



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Experienced well educated chronic patients have better control of own disease

Experienced patients

- Are able to participate in treatment planning
- Recognize coming attacks early and in time to prevent them
- Have partnership with doctors on equal level
 - ▶ Better outcomes
 - ▶ Less time for management of disease is needed
 - ▶ Less costs
 - ▶ Better quality of life



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Newly diagnosed inexperienced patients waste time & money if not improving disease understanding

Unexperienced patients

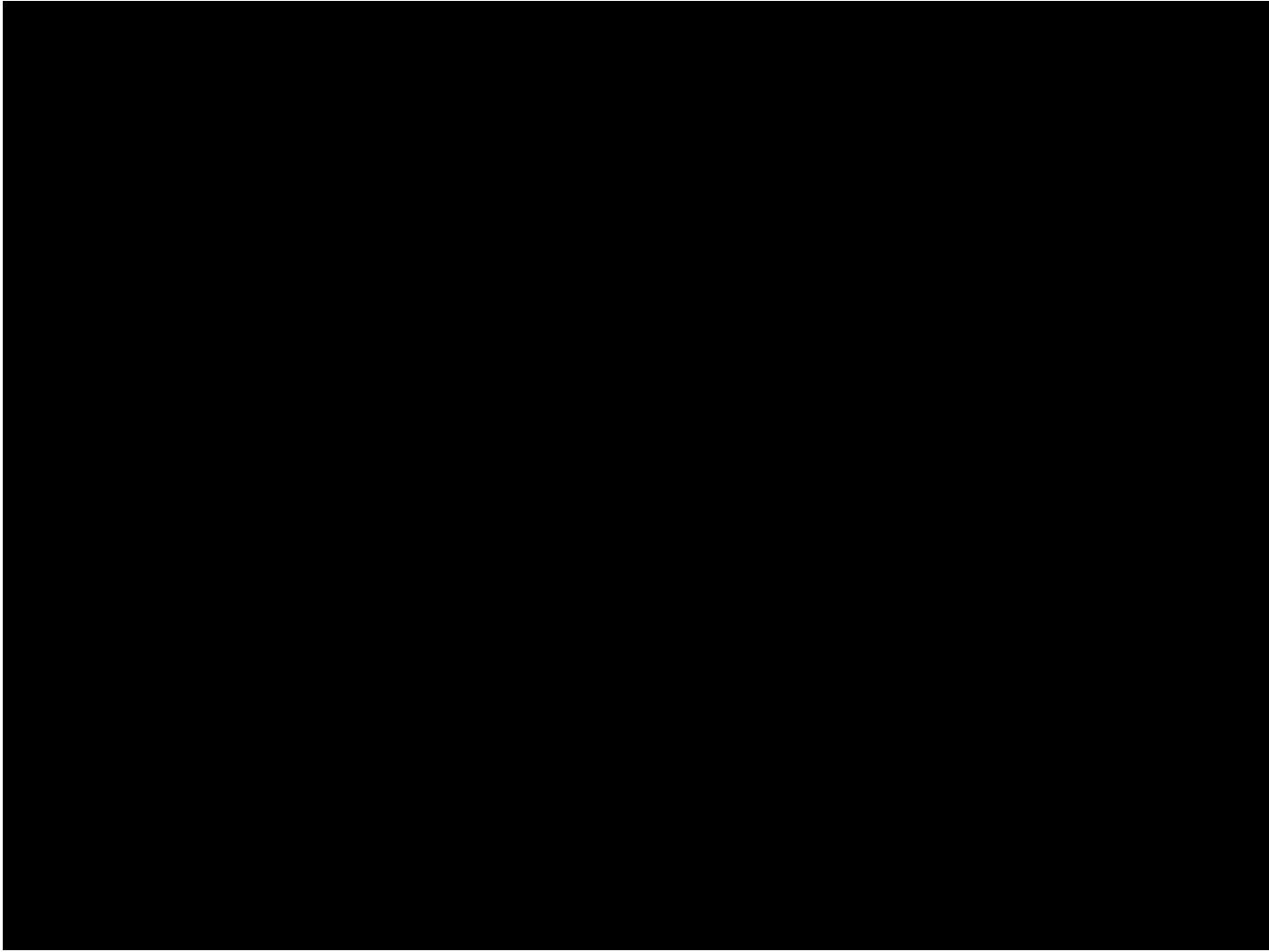
- Can not describe symptoms to communicate with doctors properly
- Expect to be asked by doctor, do not talk themselves, can not or feel unable to ask questions
- Do not know special terms
- Do not know about related diseases
- As the most important take information they are able to understand
 - ▶ Do not follow doctors advise due to missing dialogue
 - ▶ Have one exacerbation behind the other
 - ▶ Are missing school or working hours
 - ▶ Have no concordance and adherence!



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Teaser „Learn to live with asthma“: video





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EFA project „Learn to live with asthma“

- **Goals**
 - Increase newly diagnosed asthmatics adherence (therapy loyalty) by making them partners with their doctors and nurses.
 - Support the work of active (asthma) patient organizations
- The tool can be seen as model for projects of all chronic diseases



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Key message of presentation

- Patients with chronic conditions need **continuous support** to get better understanding of day-to-day life with the disease as pre-condition to **become adherent**: we expect EC to establish patient empowerment and self-management of chronic diseases as a priority in its work plan and health care initiatives
- **Understand doctors and patients as team! Mutual trust between doctor and patient is key** to manage the illness: we expect from EC that all recommendations, methodologies and models take into account the actual patient-self-management activity in the treatment procedures
- Patients have a **right of understandable information**: *we expect from Comission EU-wide structured care models with educational programmes for patients*



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"The most exciting thing that allergy, asthma and COPD associations have done for patients is to change their public image.

It used to be that they were sufferers – bidders – asking for attention to their attacks. Now they have changed into fighters for the freedom to breathe."

Edith Rameckers, founder member of EFA



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Thank you!

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is a Partner of the Year of the Lung
in Memory of Mariadelaide Franchi



2010 | The Year of the
LUNG
Live. Learn. Breathe.