

The narrow path to understanding Testimony and role of consumers in allergic matters

Mrs Yanne Boloh
Association Française des
Polyallergiques

The narrow path to understanding

- Discovery of allergy : anguish - Then :
- Anger because medicine is unable to cure
- Afterward, Collecting information :
 - Physician
 - Other specialists, hospital...
 - Mother in law
 - Hairdresser
 - Press ...

The narrow path to understanding

- How to deal with all that ?
- Going out of panic to day-to-day life
- First counsel : do simple

The narrow path to understanding

- Food : more than just a way to fuel the body
 - Medical action (avoid symptoms, how to be sure)
 - Family (how to live together, how to buy and at what price, how to prepare new products, how to learn to do without ready food, easy but too complex)
 - Cultural (a feast : a meal - the french paradox?)
 - Social action (outside home : in the family or with friends, at school, in holidays, at the office, even in shops...)

The narrow path to understanding

- Day-to-day life : healthy way-of-life
 - no-animals, no-carpets,...
 - washing and rinse (twice),
 - humidity but no mould,
 - dresses, cosmetics, medicines,
 - trees and other plants,
 - social activities ...

The narrow path to understanding

A lot to understand : going out of pure emotion

- Reliability of diagnosis (test, inquiry...)
- Symptoms and occurrence (5W)
- Mechanisms of immunity and physiology
- Risks and level of risks
- Reliability of information : who to believe ?
- Natural history of the pathology
- Our own natural history

The narrow path to understanding

From the fear of death to the reality of life

- To be able to mobilize energy, time and other necessities (information, money...)
- To be conscious of our own level of risk
- To be able to adapt to the opportunities (avoiding too many evictions, accept to test again...)

The narrow path to understanding

- Acceptation and understanding : action

But you must avoid over-reactions or under-reactions, as a consumer

The same must become real widely, from the medical world to the society

The narrow path to understanding

- Example of directive 89/2003

A good evolution for all the consumers, not only for allergic people

- no more 25% rule,
- real name of ingredients,
- Focus of food producers on this matter,
- But ...

The narrow path to understanding

- A text only for pre-packaged food
- The annexe III is generally understood as an exhaustive list : 90% of reactions, but... only 90% (what to do with allergies to peas or potatoes?) : in fact, everything is labelled and that is the real good thing
- Some points still to be debated

The narrow path to understanding

- The main excess, out of law : “may contain”
- If the mention exists : the ingredient exists ?
- If not, the ingredient is not here ?
- What to do with this kind of “no-information” ? To buy, not to buy ?
- Go to expensive “without” products with no more guaranties ?

Que Choisir ? Octobre 2005

**SUR LES TRENTE-SEPT
PRODUITS ANALYSÉS...**

**... l'arachide n'a été
décelée dans aucun...**

Que Choisir ? Octobre 2005

Where is the risk ? 37 food products analysed

19 no peanut mention and no peanut inside

18 peanut mention but no peanut inside

19 no hazel nut mention and no hazel nut inside

8 hazel nut mention and hazel nut inside

6 hazel nut mention but no hazel nut inside

4 no hazel nut mention but hazel nut inside

The narrow path to understanding

- We ask for a risk management in food plants and good information, we do not ask for zero cross-contamination
- What are the real risk of those cross-contaminations for atopics ?
- We think HACCP with voluntary thresholds might be enough for the great majority of us
- Our idea : a neutral structure to evaluate

The narrow path to understanding

- April 2005 : our question to Afssa, through CLCV, a consumer association who has the right to ask, with two other associations (Afpral and Afdiag) we are used to work with
- Our president, Caroline Morice, is member of the Afssa working group

The narrow path to understanding

- Very allergic person may receive some help to buy very specific products labelled “without” through national insurance
- But it is anti economic to ask for the same specific products with “label” for all the allergics when the general products can do for the great majority of them

The narrow path to understanding

- What is the risk from non-packaged food ?
Restaurants, shops, market...
- Is a law needed ? Good manufacturing practice as for food hygiene ?
- What is a good information of operators ?
- 5W

The narrow path to understanding

- Recipes are very important and our association does its part to diffuse them (recipes and recommendations for house)
- Important to listen to anguish
- Important to help people to ask themselves questions and to find reasonable answers
- Important to find ways to make consumers voices heard

The narrow path to understanding

- 2000 : we began to work with other associations to understand food production, school organisation...
- PAI
- Classification of children (proposal of a working document actually waiting for improvement from experts of Afssa)
- Afnor Working group for dosage ...

The narrow path to understanding

- If someone do not understand things, his actions may be not adequate and his symptom may come back or increase: he'll become more and more angry and...may go for legal proceedings and trial

The narrow path to understanding

- If everyone think he's allergic, no one will take care of that and... accidents may occur
- Or, everyone will panic and atopics will be excluded ... that means a large number of consumers

The narrow path to understanding

We know that discussion is the best way to go on the narrow path to understanding in the consumer life as the narrow path to understanding in the medical world and, more generally speaking, in the society.

The narrow path to understanding

- Atopics are consumers like others with

Right to the Health

Right to Information

Right to Education

The narrow path to understanding

- Association Française des Polyallergiques
- <http://www.polyallergiques.asso.fr> and
- <http://www.afpada.net>

2 bis, rue du Château - 92 200 Neuilly Sur Seine

Tel : 01 47 22 99 00 - bureau@polyallergiques.asso.fr