



# Living with Allergies and Asthma

From Patient Education to Disease Management

IOA-Workshop Berlin 2005



THE UCB INSTITUTE OF ALLERGY

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# Living with Allergies and Asthma

## From Patient Education to Disease Management



### Structured Parent Education in the Management of Atopic Dermatitis

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A blue banner at the top of the page features silhouettes of several people in a meeting or workshop setting, with a bright light source in the background creating a glow.

# Introduction

**Dr. Ulrich Wahn (Germany)**  
Chairman and facilitator

A large, close-up photograph of a human eye with a green iris, looking directly at the viewer, occupies the lower-left portion of the page.

## **A NEW ERA IN THE MANAGEMENT OF ALLERGIC PATIENTS IN EUROPE**

The great physician Professor William Osler once stated 100 years ago “It is more important to know what sort of person this disease has than to know what sort of disease this person has”. Unfortunately the nature of present day medical practice makes us all guilty of allocating too little time to communicate adequately with our patients who suffer with chronic illnesses.

It is a unique part of The UCB Institute of Allergy’s mission to disseminate quality allergy information, and to this end a workshop was convened consisting of internationally recognised allergy researchers. People with a special interest in patient care, allergy education and self management were invited to participate.

It is essential to have a holistic approach to the way we deal with patients who suffer with chronic diseases and successful treatment is far more than merely prescribing medication. Patient education and self-management must not be confused with passive encouragement of self-medication and “over the counter” (OTC) remedies which may actually be detrimental. Self-management or co-management is a mutually beneficial partnership between the doctor and the patient as has been demonstrated with type-I diabetes. Treatment should not be a “one way street” with the doctor directing and the patient a passive bystander, but rather a tailored process structured to the needs of the patient and their parents with the doctor rather acting as a “coach”.

## PATIENTS MUST BECOME EXPERTS IN THEIR OWN DISEASE CONTROL.

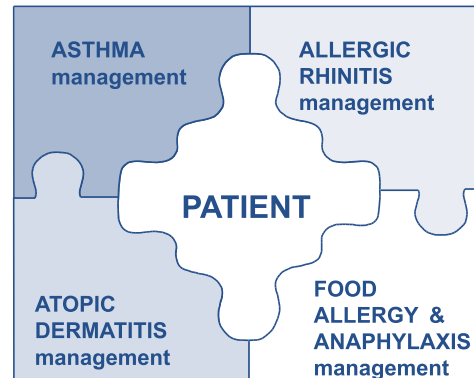
The current education programs including “asthma schools” and “atopic dermatitis schools” were born out a sense of frustration experienced by both patients and their doctors after introspectively asking themselves the question “Are we doing a good job?”. Doctors from different medical disciplines have at last started to interact and have dialogue on programs relevant to patients dealing with chronic diseases. Self management programs for asthma and diabetes which first developed in the USA in the 1980’s have spread to Europe and the first programs began in 1986.

### There was a mutual desire to explore self-management programs that would:

- Increase knowledge and understanding of allergic conditions
- Change attitudes to disease control

### and result in positive outcomes such as:

- Less school and workdays lost
- Less Emergency Room visits
- Greater participation in sporting and normal daily activities



Initially these projects were driven by a few dedicated individuals with vision and enthusiasm. The European Federation of Allergy and Airways Disease Patient Associations (EFA) have been instrumental in defining patient educational and support needs. With an experience that has developed over time, physicians, psychologists, dieticians and all those dedicated to self-management met to discuss and reach international consensus on the standardisation and structure of these programs. After extensive dialogue and comparison of the various options it was decided that a pan-European strategy could be developed. However, this needed to be evaluated in controlled internationally-validated studies to confirm positive health outcomes. Only at that point would health authorities, private health insurers and health economists wholeheartedly endorse the programme and recommend funding for research and implementation.

Many of the delegates at this workshop have been instrumental in providing evidence-based research to show that patient self-management programs are indeed cost-effective. These structured programs produce positive health outcomes and reduce long-term disease mortality and morbidity in the three areas that we will explore in this publication, namely: Atopic Dermatitis, Asthma and Respiratory Allergies and Food Allergy and Anaphylaxis.

## THE EMPOWERED PATIENT - IN THE DRIVER'S SEAT

Our mission is to induce patients to become experts in the management of their disease. This involves empowering the patient by developing their competence to self-manage their disease via education, interaction and understanding. Doctors should change their role to that of a partner or a coach in disease management and no longer dictate complex therapy to an “obedient” patient. This approach with emphasis on interaction and communication will lead to a concordant, more expert and educated patient. Positive outcomes should result in less “doctor shopping” and frustration with treatment. Moreover better insight into the condition could result ultimately in a “cheaper” patient with long term health cost savings and less severe disease.

The expert-patient concept was first developed at Stanford University in the USA where the patient is often referred as being “in the driver's seat” of his/her disease. Patient and parent schools have sprung up across the western world. These programs focus on group interaction with adequate time allocated to explore the following aspects of chronic allergic disease:

- Early disease manifestations
- Living and coping with chronic allergies
- Addressing the extraordinary need for information
- Exploring the lack of acceptance of regular treatment
- Dealing with “corticophobia”

### The Educated Patient

- Will be an expert in management of his/her own disease
- Will be empowered and develop competence
- Will consult with the doctor as a partner and coach
- Will have a better Quality of Life
- Will ultimately be a “cheaper” patient

## THE FUTURE

Successful implementation of these self-management programs into European national health care systems will require many checks and balances.

All programs such as asthma schools, food allergy and atopic dermatitis management programs need constant evaluation of their outcomes. Health insurers will ask us critical questions and they will need hard evidence before releasing funding for these programs. Quality management and standardisation is imperative, and each “trainer” needs regular updating through refresher workshops. Accurate cost/benefit analysis will be a prerequisite requirement from all health economists who will then advise their respective health authorities or insurers on those programmes which deserve support and those which do not.

### Implementation of a Patient Education Program into the Health Care System requires

- Evaluation
- Quality Management
- Cost/Benefit Analysis


## A NEW GENERATION OF PHYSICIANS

The positive spin-off for medical doctors and health care workers will be the creation of a new generation of physicians and health workers. These doctors will develop a more open and democratic communication with their patients and a culture of partnership will follow that will benefit all of those who suffer from chronic allergic diseases.

The UCB Institute of Allergy cannot fund the volume of research that will be required but many new pan-European “Networks of Excellence” and “Integrated Projects” have been established. The European Academy for Allergology and Clinical Immunology (EAACI) supported by the World Allergy Organisation (WAO) are, for example developing the Global Allergy and Asthma European Network (GA<sup>2</sup>LEN) concept. GA<sup>2</sup>LEN and the European Centre for Allergy Research Foundation recently produced consensus guidelines on “Urticaria 2004” and they could facilitate further consensus documents on self-management programs relating to asthma, allergic rhinitis, atopic dermatitis and food allergy/anaphylaxis.

## REFERENCES

- ***European Allergy White Paper.***  
The UCB Institute of Allergy.  
Braine-l'Alleud, 1997; 98-110.
- ***European Allergy White Paper Update.***  
The UCB Institute of Allergy. 1999. 19-26.




# Structured Parent Education in the Management of Atopic Dermatitis

Doris Staab (Germany) - coordinator, Uwe Gieler (Germany), Linda De Raeve (Belgium),  
Alain Taieb (France), Thomas Werfel (Germany), Jean-Francois Stalder (France).

## Section A

### THE IMPACT OF ATOPIC DERMATITIS

#### The scale of the problem



Atopic Dermatitis or Atopic Eczema is the commonest skin disease which affects up to 20% of the European paediatric population. It accounts for 30% of general practice dermatological consultations and 10-20% of specialist dermatological referrals [1]. The fact that atopic dermatitis starts in early infancy and follows a chronic relapsing course places an extra burden on these children and their caregivers. The disease has a profound adverse effect on quality of life (QoL) and causes intense itching, major sleep disturbances and interferes with normal development, education and play. The psychological impact on the child-parent relationships should not be underestimated [2][3]. Mothers of atopic eczema children who lack information and confidence in their treatment will feel more helpless, be prone to depression and become overprotective of their children. The family unit becomes dysfunctional as these children develop “dominant child” behaviour with narcissism and stigmatisation, while in turn the mother becomes increasingly submissive.

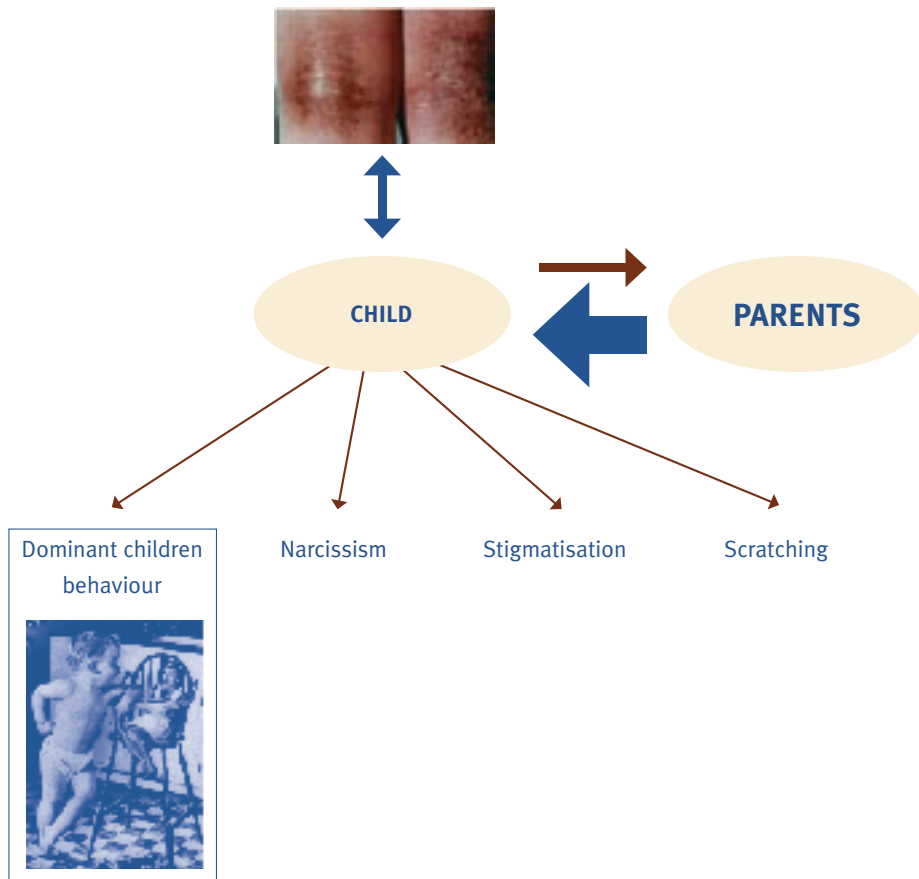
## Specific problems in Atopic Dermatitis

The exact cause of atopic dermatitis still remains elusive possibly due to the multitude of contributory factors and its genetic predisposition. Therefore no single causal treatment can be prescribed to cure the condition, and the emphasis has to be placed on good skin care and avoidance of triggers. As a consequence the disease follows a chronic relapsing course leaving most patients and the carers feeling helpless, impotent and drives them to explore alternative therapeutic avenues. One of the big problems in atopic dermatitis is irrational fear of corticosteroids and non-compliance to therapeutic doses prescribed [4]. Patients confuse topical corticosteroids with oral

anabolic steroids and their General Practitioners may fuel this fear by issuing excessive precautions regarding the regular use of topical corticosteroids and potential side-effects. This is further inflamed by a universal media perception that topical steroids are dangerous and will cause skin thinning and growth retardation. Both of these side-effects have been shown in well- conducted clinical studies unlikely to occur at normal therapeutic dosages with non-fluorinated steroid creams and if they occur, are usually reversible. In a recent study by Charman et al who questioned 200 patients in a dermatology clinic, 72,5% were

### The complex inter-relationship between children with atopic dermatitis and their parents

The complex inter-relationship between children with atopic dermatitis and their parents



anxious about using topical steroids, more than 24% were non-compliant, admitting that they did not use their prescribed corticosteroids [4]. In a similar Australian study, 40% of parents perceived their children's prescribed topical steroids to be dangerous and 20% thought they were too dangerous to use on their children [5].

The consequences of undertreatment including sleep disturbance, social deprivation and family dysfunction may be far more harmful than the remote risk of side-effects from the application of topical corticosteroids.

The parents of children with atopic dermatitis often feel more stigmatised than their children. Patients with atopic dermatitis and their parents experience dysfunction relationships as a consequence of their uncontrolled atopic dermatitis. Parents may feel isolated, helpless and dissatisfied with the doctor-patient relationship. Mothers tend to become withdrawn, develop feelings of guilt and then develop cognitive avoidance of the actual problem of managing the disease (rumination).

This then leads to non-compliance and dissatisfaction with conventional therapies and exploration of unconventional therapies.

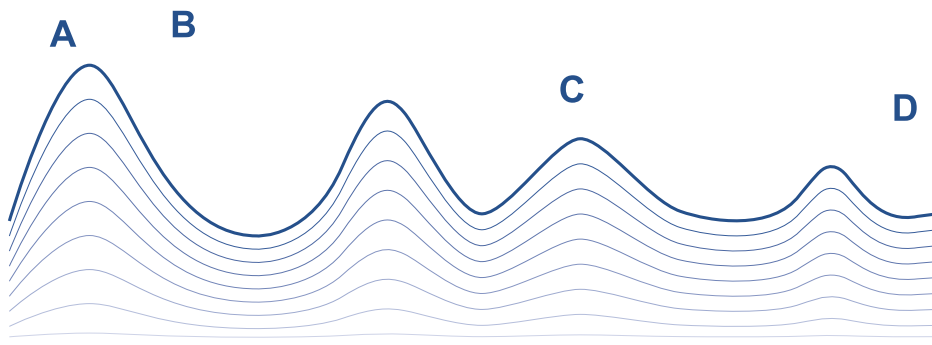
The more severe the atopic eczema on SCORAD evaluation [6], the more likely alternative therapies are to be utilised. Over 60% of atopic dermatitis sufferers try at least one unconventional therapy with about 15% trying three or more of these unvalidated regimes [7].

## Compliance versus concordance

There is growing evidence that the term "compliance" which suggests an obedient doctor-orientated health seeking behaviour should be replaced with "concordance" which suggests a more cooperative partnership between doctor and patient to facilitate better treatment outcomes [8].



### Problems in judging effectiveness of treatment



Légende à communiquer

*Assuming that symptoms of Atopic Dermatitis are spontaneously variable with time, as the wave-line, and that patients are not able to assess the current severity of their disease, it seems that patients have most difficulties in judging the effectiveness of a treatment. For instance, treatment A, administered during a symptomatic attack, will be considered as inactive, while treatment B, given in the recovery phase, will be judged active but deceiving because there is a second attack a few time after remission. Treatment C will be seen as more active than treatment B, because the remission phase is longer. And treatment D has cured!*

## Section B

### STRUCTURED EDUCATION PROGRAMS

#### Current state of the art

Over the years few studies have explored intervention and educational programs to help these parents with treatment and psychological support. Unfortunately most preliminary studies have been single nurse-led interventions which were usually not controlled to assess outcomes [9]. From the recent controlled studies we get the impression that positive outcomes are dependent on the time spent with parents and the qualification of the trainer [10] [11] [12]. Group education programs conducted by Schmidt-Gruber reported that 80% of those parents attending their program felt the program was helpful, particularly the aspect of sharing personal experiences in managing atopic dermatitis [3]. The Germans currently have a large experience in this field of multidisciplinary group education of children and their parents at their “eczema schools” [13].

#### Goals of an education program

- To improve disease perception and self-management skills
- To promote a better outcome for the atopic dermatitis treatment
- To promote a better quality of life for the whole family
- To reduce “doctor shopping” and facilitate a better partnership between doctor and patient/parent
- To reduce the long-term costs of chronic disease treatment

#### State of the Art

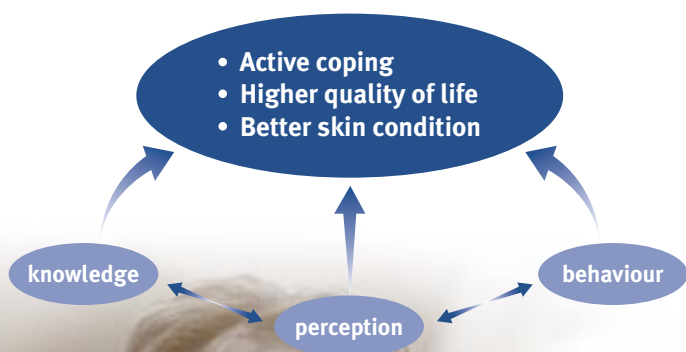
Author	Publication	n	Control group	Intervention
Williams DH	Arch Dermatol 1951	53	no	Single education
McSkimming J	Australas J Dermatol 1984	11	no	Group education
Koblener CS	Arch Dermatol 1988	8	no	Single education
Broberg A	Acta Derm Venereol 1990	41	yes	Single education
Gieler U	Hautarzt 1992	23	no	Single education
Schmidt-Grüber C	Sozialpädiatrie 1996	102	no	Group education
Wenninger	Patient Educ Couns 2000	204	yes	Group education
Staab	PAI 2002	204	yes	Group education
Chavigny	Ann Dermatol Venereol 2002	40	no	Single and group education
Chinn	Br J Dermatol 2002	235	yes	Single education
Boye	Ann Dermatol Venereol 2003	?	?	?
Cork	Br J Dermatol 2002	51	no	Single education
Diepgen	Hautarzt 2003	823	yes	Group education

## Different concepts in patient education

There is a need to reach consensus on which model is the most acceptable for educational programs:

- Information  
the informed patient
- Promotion of compliance  
the obedient patient
- Training  
the capable patient
- **Empowerment**  
**the responsible patient**

The goal must be “Living with Atopic Dermatitis” by means of an empowered patient who can work as a partner with the doctor in self-managing their own or their children’s disease. Education to enhance disease knowledge, psychological improvement in disease perception and scratch control behaviour modification, together with regular daily treatment, will lead to better skin care. This improvement in disease control will restore family dynamics and the patient and family will cope better and have an overall improvement in quality of life.



## Specific aims of patient education

Structured patient education should enable both patient and parent to:

- Have realistic short-term goals
- Enter a process of problem solving
- Accept living with their disease
- Appropriately utilise available social support
- Enhance their own motivation for therapy

## Structure and content of an Atopic Dermatitis Training Program

The current German Model includes 12 hours of training:

- 6 sessions of 2 hours duration once weekly
- Groups consist of 6-8 families
- Interdisciplinary trainers  
(paediatrician / dermatologist / psychologist / nurse and dietician)

Approximately 20-30% of atopic dermatitis sufferers attending dermatology clinics are keen to attend these self management programs [7]. Parents are keenest to attend particularly those with children in the 0-7 age group. Current demand necessitates 6-8 parent groups for every one children’s group. Adolescents present the greatest challenge and are not generally keen to attend, preferring fewer sessions. But if the sessions can be timed to take place over weekends with good facilitators and include age-related attractions such as vacation camps or surfing, then attendance is much better. Different social groups all learn from each other and interact in a positive way.

The sessions have been arbitrarily set at 12 hours as this seems the optimum time for patients and parents to undergo the necessary training, discuss important issues and feel competent in management of the disease. Evidence from other clinical studies show that half or one hour nurse-led sessions are not effective while programs of less than 6 hours



are unlikely to have a positive impact on atopic dermatitis [9] [14]. Similar programs have been highly successful in managing asthma and diabetes. Many parents form their own support groups after the initial sessions which provide ongoing support and useful interaction.

Doctors and nurses attend self-funded training courses to develop their skills, and then are reimbursed for their teaching sessions by Health Authorities. To date about 1000 trainers have completed courses to become atopic dermatitis trainers.

## Group dynamics

Initially the primary goal of the first session should be for the parent to feel comfortable enough to come back for the second session and then to integrate and become part of the interactive group. Didactic lectures may not be appropriate for teaching realistic self-management skills. Developing good atopic dermatitis management skills takes time and one practical approach is to have a multidisciplinary team teaching a select group rather than individual one-on-one interaction. The dynamic interaction within the group is usually the most rewarding aspect, with the health professionals merely acting as education facilitators. Initially some parents come with unrealistic and controversial ideas on treatment, but the whole group interacts in a manner that slowly develop group consensus on appropriate treatment and they all give feedback to each other in a positive environment.

## Specific program content

### Medical Content

- Basic information regarding atopic dermatitis such as epidemiology, natural history of disease and diagnosis (according to criteria Hanifin & Rajka). Structure and function of the skin (to reinforce benefits of skin care)
- Basics of pathophysiology (limited to essential knowledge)
- Common triggers causing exacerbations
- Atopic Dermatitis prevention
- Treating the affected skin



### Psychological issues

- Stress as a trigger as well as a consequence of Atopic Dermatitis
- Dealing with itching and scratching
- Promoting self-management skills in the child
- Social aspects of the disease
- Relaxation technique and behaviour interventions



## Structure of the six (2 hour) sessions

1. Basic medical information and introduction of a relaxation technique
2. Dealing with stress, itching and scratching
3. Basic skin care and disease prevention
4. Skin treatment and dealing with stage-related symptoms
5. Dietetic issues (food allergies and nutrition)
6. Transfer to the daily management and self-management plan

Euro 1.3 million was set aside by the German central government to finance a multi-centre national study into the efficacy and outcomes of these programs.

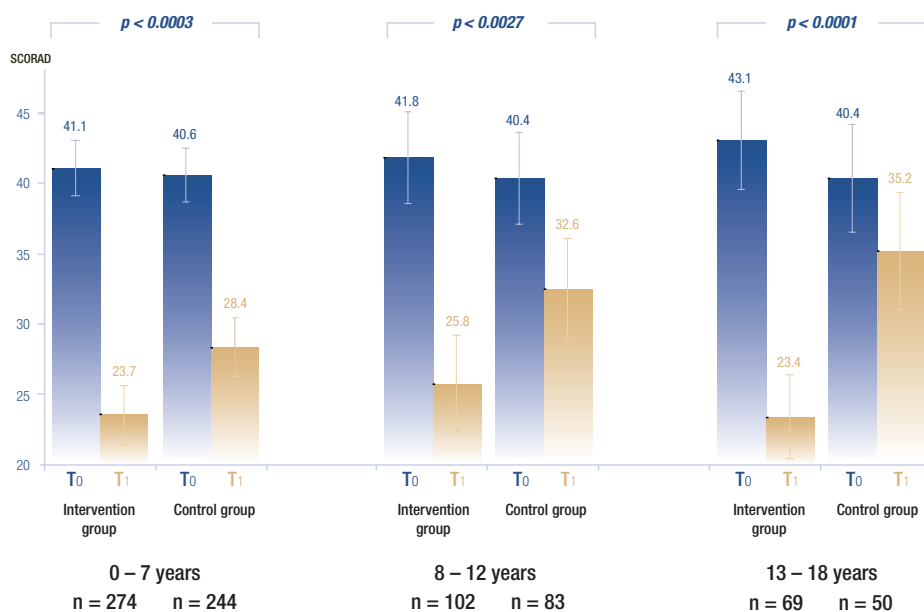


## The German Atopic Dermatitis Study (GADIS)

A major barrier to self-management programs in the past has been a lack of awareness of the scale of the problem and lack of financial support. In Germany, politicians, Health Authorities and private health insurers have been lobbied for funding. Preliminary results from smaller controlled randomised studies with positive outcomes have gone a long way to convince health planners that these programs are indeed valuable and will reduce overall disease morbidity and reduce long-term health costs.

This national study evaluated a large controlled atopic dermatitis intervention program, which was set up after consensus dialogue with all the professionals with experience in this field. This study randomised 820 atopic dermatitis children (SCORAD > 20) aged 0 to 16 years in 3 age groups, each were divided into an intervention group (443) and control group (377). After one year the overall SCORAD measure, quality of life, scratching index and adherence to treatment improved statistically significantly in all three age groups : 0-7 years, 8-12 years and 13-16 years. The greatest improvement in atopic dermatitis scores were in the 0-7 year age group (results still to be published).

### Effects of the AD education program on skin inflammation after 1 year



Staab D, Wahn U et al. (In Press)

## Section C

### KEY ISSUES FOR IMPLEMENTATION

#### Key issues in successful self-management

With the success of the German experience and a growing awareness of the specific problems in managing atopic dermatitis, there is a clear need for further education programs in other European countries. Ethnic and structural differences in individual health care systems preclude one program being transferred to another country without specific modification. The key issues for implementing a program were discussed in the working group.

These included:

- Current experience
- Target population
- Goals of education
- Kinds of intervention
- Education
- Implementation

#### Current experience

All studies done to date indicate that adequate time needs to be spent with the patient or group. From the German experience, 12 hours spent in sessions seems optimal, whilst less than 6 hours does not significantly improve outcomes. The trainers should be a quality controlled multidisciplinary team of psychologist, doctor, nurse and dietician. The ideal population is those children with moderate to severe atopic dermatitis (SCORAD > 20) and their parents. The impact on children with mild eczema still needs to be more fully evaluated.

#### Target groups

Parents of young children (0-7 years) with all grades of atopic dermatitis (SCORAD < 20 and > 20) are the most receptive group attending these sessions and actively seek information and self management skills. School children (SCORAD > 20) are the second most receptive group at the sessions. Those with mild eczema possibly lack motivation to attend, while adolescents and young adult atopic dermatitis sufferers find it difficult to make time available to attend the sessions due to their other commitments. In this group, attendance may improve if special age relevant attractions are included in the program such as sporting activities and vacation camps.



## Goals of education

Teaching knowledge and training skin-care skills are desirable, but enhancing patient empowerment and self-reliance are the most important goals. Adapting treatment to the severity of the skin condition is one of the main themes in the self-management program. Positive outcomes include adequate use of appropriate emollients and topical steroid without fear of side effects and less reliance on unconventional medicine.

In the German experience [13], positive outcomes after one year of using the Berlin Model were: diminished fear of topical corticosteroid cream usage (baseline use increased from 35% to 65% in intervention group versus 33% to 38% in control group) and less reliance on unconventional practices (baseline in intervention group was 56% which dropped to 26%, while in control group baseline was 64% and dropped to 51%). There was a reduction in the use of arbitrary dietary restriction without proven food allergy (baseline 19% in intervention group decreased to 7% while in control group it increased from baseline 27% to 33%).

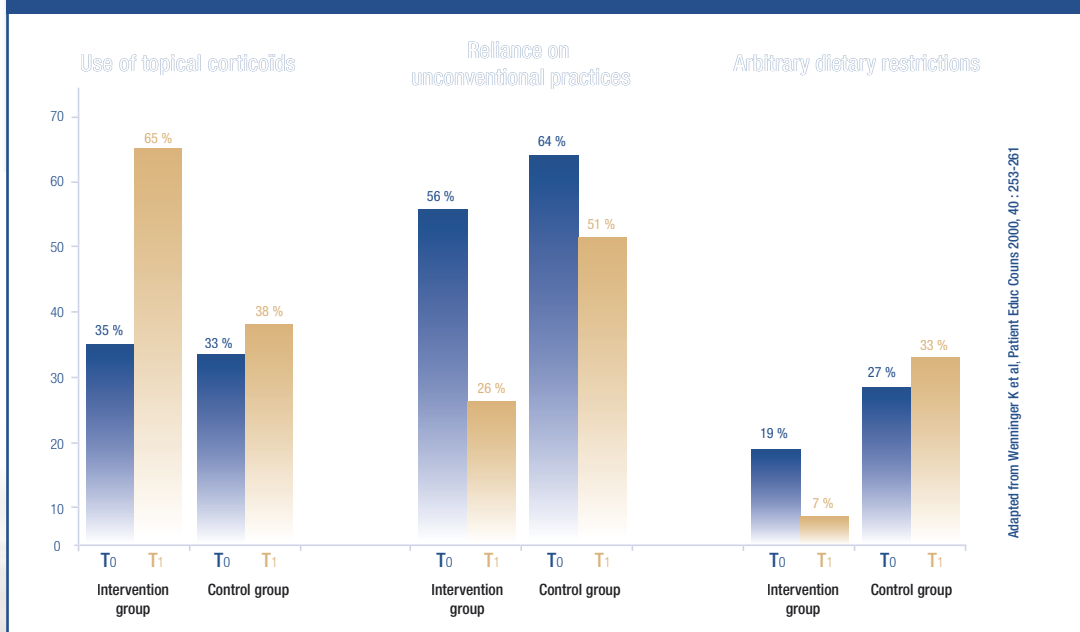
## Modes of intervention

To date the 12-hour interdisciplinary education program has been most successful. Half hour nurse-led consultations and even 6-hour sessions have proved ineffective in improving disease management. In the past, failure to explain the nature of eczema and how to use therapies has lead to patient dissatisfaction, poor compliance and lack of treatment efficacy.

Adequate time should be allocated to listening to the patient and parents concerns, to explaining triggers or causes and to demonstrating correct application of topical therapies. Dietary advice should be included and the nutritional risks associated with introducing arbitrary dietary restriction without proven food allergy in this vulnerable group of children must be explained. In those allergic to indoor allergens, discussing methods of reducing pet and house dust mite exposure is beneficial. Learning to adapt their individual treatment plan to the severity of their skin condition is essential.

The optimal program may extend between 6 and 12 hours, current outcomes seem to support the 12 hour option (six sessions of 2 hours). The program material can be covered in less time, but additional time facilitates assimilation of information and allows time for group discussion and clarification of issues.

### Positive outcomes of 1-year patient's education in Germany



## Qualifications of trainer

The expert multidisciplinary team should consist of at least one doctor (paediatrician, dermatologist or both), a clinical psychologist, dermatology trained nurse and dietician. All members of the team should have experience in dealing with atopic dermatitis and allergology. Standardised curricula are currently being developed for trainer education.

“Second hand” education does not appear to work. Studies show that if a specialist dermatology nurse educates other practice nurses who in turn educate patients about eczema, this is less effective than direct education from the specialist dermatology nurse [14].



## Evaluation of standards

Ongoing multi-centre randomised controlled clinical studies need to be designed to regularly evaluate intervention outcomes and act to reassure health funders that their resources are being put to economically efficient use. Outcome variables should include severity of disease (currently SCORAD), coping with itch, and quality of life parameters for both children and care givers using validated questionnaires. Health economic data to show health cost reduction needs to be provided to ensure ongoing funding. Ideally this should be done over a one year period to get interpretable information and outcomes. Studies will need adaptation for national and cultural differences to be taken into account, particularly with regard to the nature of questionnaires and regional variation in attitudes to health and atopic dermatitis [15].

## Implementation

What kind of intervention would be realistic in each unique health service across Europe? Some interventions may be realistic in one country but not in other countries. Will there be funding available for financial reimbursement of team training, sessions and staffing of the program? Financial support is pivotal and this may come from various sectors such as central government, regional Health Authorities, private health care providers and patient organisations.

**In the Berlin Model, the 12-week education program intervention group showed a surprising decrease in the overall cost of treatment, despite the patients being more concordant with prescribed medication such as emollients, antiseptics and steroids. This is probably explained by fewer emergency consultations with doctors, less need for systemic medication and fewer hospitalisations for eczema exacerbations. If the unknown costs of unconventional treatments (not covered by health insurance) came into the equation then the cost saving in the intervention group would be even greater.**



## APPENDIX

### SCORAD: Index of severity of Atopic Dermatitis [6]

SCORAD is a composite index developed by the European Task Force on Atopic Dermatitis (AD) in 1993. This simple standardised scoring system devised for AD is the sum of various Atopic Dermatitis parameters. The measures are extent (area involved), intensity (erythema, excoriation, etc) and subjective symptoms (sleep disturbance & pruritus). These parameters are scored by the observer and the index calculated. Intensity has the highest weighting. Mild AD is usually indicated by a SCORAD < 20 and Moderate/ Severe AD indicated by SCORAD > 20.

### Atopic Dermatitis Diagnostic Criteria (Hanifin & Rajka 1980) [16],

require all Major and 3 Minor criteria to diagnose Atopic Dermatitis.

#### Major

- Pruritus
- Chronic relapsing dermatitis
- Facial and extensor involvement in infants and children or flexural eczema and lichenification in older children and adults
- Personal or family history of atopy

#### Minor

- Early age of onset
- Course influenced by environmental or emotional factors
- Dry skin
- Scaling, palmar hyperlinearity and thickening of skin on palms
- Dennie-Morgan infra-orbital folds
- Facial pallor or redness
- Nonspecific dermatitis of hands and feet
- Cutaneous infections (bacterial, fungal or viral)
- Anterior subcapsular cataracts

and dermatographism, nipple eczema, cheilitis, pityriasis alba, keratosis pilaris.

**SEVERITY SCORING OF ATOPIC DERMATITIS: THE SCORAD INDEX**

**Erythema (E) or redness**

Mild = E1, Moderate = E2, Severe = E3

**Edema / papulation (P)**

Mild = P1, Moderate = P2, Severe = P3

**Oozing / crusts (O)**

Mild = O1, Moderate = O2, Severe = O3

**Excoriations (Ex)**

Mild = Ex1, Moderate = Ex2, Severe = Ex3

**Lichenification (L)**

Mild = L1, Moderate = L2, Severe = L3

**SCORAD EUROPEAN TASK FORCE ON ATOPIC DERMATITIS**

SCORAD A = E + P + O + Ex + L

SCORAD B = Pruritus (0-3) + Sleep disturbance (0-3)

SCORAD C = Subjective symptoms (itching, burning, stinging, pain) (0-3)

SCORAD = (A + 5 + 7B) / 2 + C

EUROPEAN TASK FORCE ON ATOPIC DERMATITIS

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# Structured Respiratory Allergies and Asthma Education

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## Barriers to patient education

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*


## INTRODUCTION

The principle of self-management should be to make every patient an *expert* in asthma and allergic rhinitis and this can be achieved by gaining skills in:

- Managing the illness on a daily basis
- Minimizing morbidity and
- Maximizing normal daily function

The Global Initiative in Asthma (GINA) goals [1] for successful management of asthma should be integrated into any self-management plan. These being:

- Achieve and maintain control of symptoms
- Prevent asthma exacerbations
- Maintain pulmonary function as close to normal levels as possible
- Maintain normal activity levels, including exercise
- Avoid adverse effects from asthma medications
- Prevent development of irreversible airflow limitation
- Prevent asthma morbidity



“ Successful treatment of asthma and allergic rhinitis is limited without structured self-management.

The Cochrane collaborative reviews (Issue 4: 2002, Issue 2: 2005) confirm that the use of patient education and self-management are associated with the following positive outcomes:

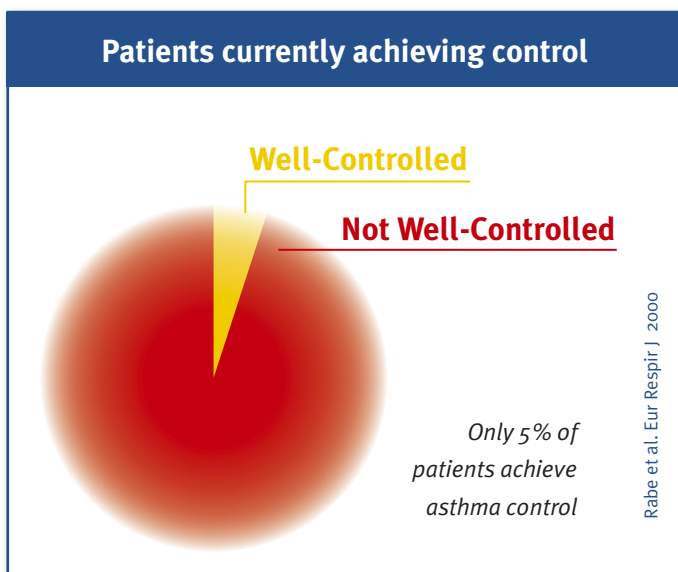
- Reduction in unscheduled GP visits
- Reduction in number of patients who were hospitalised
- Reduction in number of days off work or school
- Reduction in nocturnal asthma

Improvements in compliance (adherence) and a reduction in asthma related deaths were also demonstrated.

## OUR TARGET POPULATION

### Who needs skills in self-management?

All patients with asthma need skills and an individualised self-management plan if they are to become competent in controlling their disease. Some patients require more intensive input than others and adherence to suggested treatment plans varies from individual to individual. Patients are motivated to follow a regime only if it enables them to achieve their own personal goals. Currently only 5% of patients achieve optimal control of their asthma [2]. However less is known about allergic rhinitis control.



“Patients are motivated to follow a regime only if it enables them to achieve their own personal goals.”

*Noreen Clark*

The Asthma in America national population survey [3] in the USA identified some worrying trends:

- 49% of children and 25% of adults with asthma missed school or work due to asthma during a one year period
- 30% of asthma patients reported awakening with breathing problems
- 48% said their asthma limited their ability to take part in exercise and recreation
- 70% of doctors reported using spirometry to measure airflow, but during the same period only 35% of patients reported having a lung function test
- 92% of doctors said anti-inflammatory medication was “essential” or “very important” but only 18% of asthma patients reported using anti-inflammatory medication at this time
- 83% of doctors said they prescribed peak flow meters to allow patients with chronic asthma to monitor their condition, but only 28% of patients had one and only 9% use one at least once in the preceding week
- 70% of doctors said they prepared a written action plan for all, most or some of their patients, but only 27% of patients said their doctor has developed a written action plan for them

A recent UK study showed that almost 60% of patients were content with their asthma control. When shown the GINA goals, satisfaction dropped to 30% [4].

## How do we identify patient-needs in asthma self-management?

The Royal College of Physicians (UK) suggests asking the following three questions referring to symptoms in the last week to month:

- Have you had difficulty sleeping because of your asthma symptoms (including cough)?
- Have you had your usual asthma symptoms during the day (cough, wheeze, chest tightness or breathlessness)?
- Has your asthma interfered with your usual activities (eg housework / school, etc)?

Answering yes to any of these questions should prompt further investigation to identify the cause of the symptoms.

Many asthma scoring tools are available and these include:

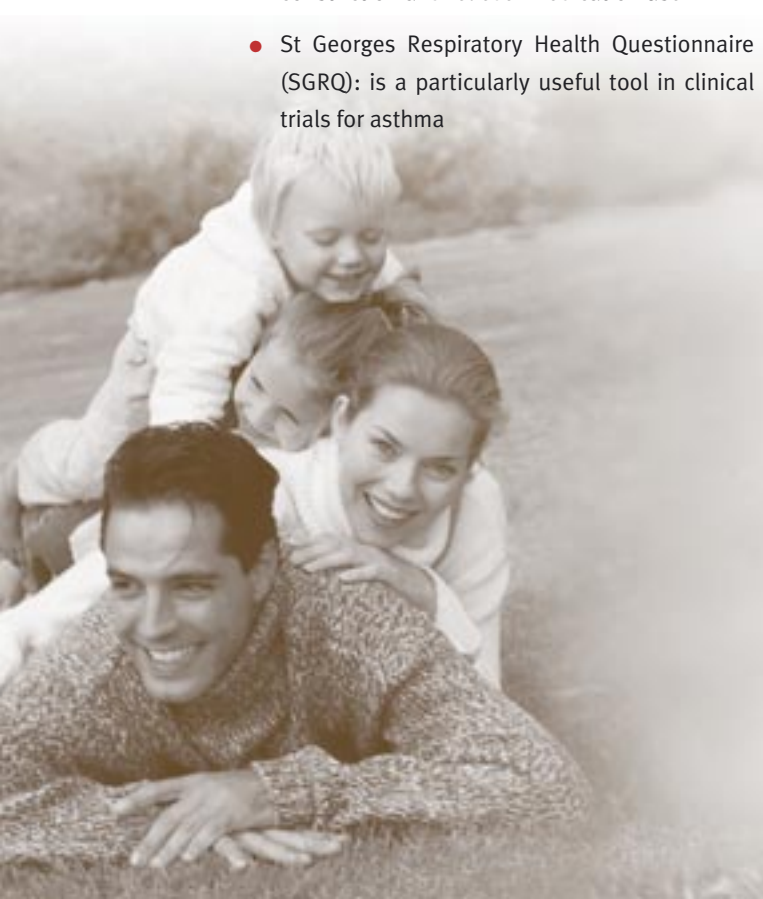
- 30 second Asthma Test
- Asthma Control Test (ACT): global assessment of control
- Asthma Control Questionnaire (ACQ): this 7 item questionnaire, includes minimal day and night symptoms, limitation of activities, bronchoconstriction and reliever medication use
- St Georges Respiratory Health Questionnaire (SGRQ): is a particularly useful tool in clinical trials for asthma

## THE ROLE-PLAYERS

### Who are the team in asthma self-management?

The role-players in the team should always include doctors with a special asthma interest, trained asthma nurses, sports physiotherapists and psychologists. Community pharmacists should not be forgotten as they are often the first port of call in a crisis or for casual asthma advice. The immediate family, the peers, the school teachers and day care personnel make up the secondary team and also require both education and support. “Expert Patient” programs have been developed in the United Kingdom where committed people with asthma undergo further disease education and develop communication skills. They then help others come to terms with living with their disease and offer support on patient orientated strategies for self-management.

Nurse-led follow-up of asthma patients is an area of special note. Over the last 20 years, specialist trained asthma nurses have been taking over a monitoring role in chronic asthma and have been universally successful in this field. A number of studies have identified that asthma nurses are often as good as physicians when it comes to routine asthma management and particularly adept at patient education [5][6][7][8].

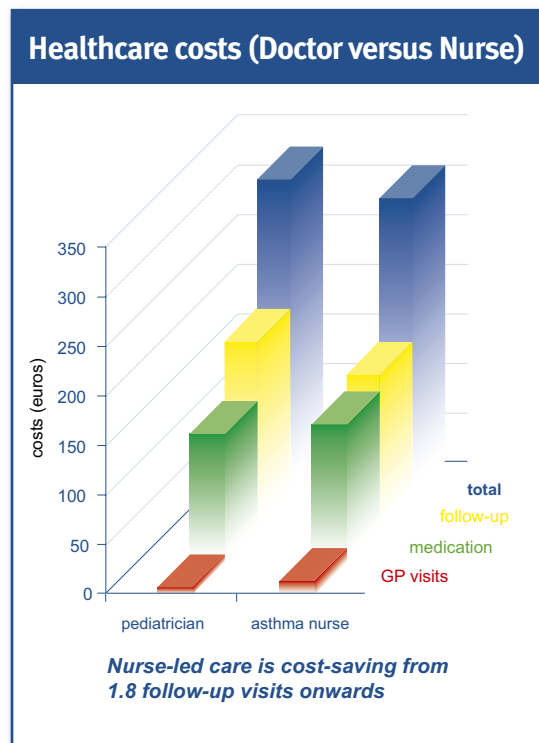


Kamps et al examined the outcomes of nurse-led follow-up of children with diagnosed asthma. In this study, they undertook a 1-year follow-up of newly diagnosed asthma patients who had completed their education protocol. Outcome measures that were assessed included: lung function analysis, inhaled corticosteroid use, number of exacerbations, emergency visits to the GP, absence from school and quality of life issues. It was found that a nurse-led childhood asthma management plan was as effective as that provided by a paediatrician and it cost less [9][10].

## ASTHMA EDUCATION AND SELF-MANAGEMENT STRATEGIES

### Strategies should address:

- Accepting the illness and its needs, which means: an understanding, in simple language, of the basic pathophysiology and correct use of (mainly inhaler) medication in asthma
- Enhancing adherence to self-treatment plans
- Individually tailored instructions and selection of an appropriate inhalation device
- Adapting content to developmental and cultural understanding
- Exploring ineffective beliefs
- Written management plan
- Evaluation and rehearsal



Patients and particularly children find asthma nurses easier to communicate with as they allocate more time and can motivate patients to be more compliant to medication. Nurses appear better able to explain difficult medical concepts to patients, to give practical advice and to supervise inhaler technique compared to doctors [11].

Careful evaluation and quality control of nurse-led programs is most important. Structures need to be in place for asthma nurse training and revalidation. Nurses need to be suitably equipped and skilled to carry out routine asthma management but channels must be in place for early referral of difficult asthma back to the physician or specialist.

### Behavioural aspects

Asthma can induce considerable personal and family stress and anxiety. Asthmatic children may unfortunately perceive themselves as socially inferior and their parents may object to, deny or ignore the diagnosis or even overreact due to anxiety. Frequently patients do not interpret any deterioration in their symptoms correctly. They may even deny typical symptoms until an exacerbation occurs or paradoxically have an unreasonable fear of becoming dyspnoeic. Repeated absenteeism often does not relate to objective asthma symptoms. Incorrect beliefs, cultural bias and a rebellious attitude may all promote non-adherence to treatment.

Adequate self management depends on trust in the treatment, a capacity to communicate with caregivers, social skills and emotional maturity to accept their chronic illness.

## The building blocks of the program

### 1) Factual knowledge is essential

Patients need to understand the basics of asthma and its co-morbid link to allergy and chronic rhinitis. They need adequate information on the treatment options and likely effects of asthma medication.

They must be taught:

- Inhalation technique with instruction and so develop skill with practice.
- An ability to gauge when to adjust prescribed medication up or down.
- To know how to monitor asthma by means of peak expiratory flow diaries, symptom scores and daily activities.

They require clearly written emergency guidelines on how and when to act if the asthma suddenly gets worse.

### 2) Facilitation of this knowledge

Intervention strategies should address the individual expectations of the patient with more clearly defined personal goals. Acceptable and expected outcomes of treatment should be explained. Goals shared by the trainer and the patient should be listed and the reasons for long-term non-compliance should be explored early on.

Once these core knowledge issues have been addressed, then progress and empowerment can be facilitated more easily.

### 3) Integration of asthma in daily life

Developing skills for living with asthma on a day-to-day basis are essential for empowering patients to ultimately become “master of their disease”. They need to improve lifestyle attitudes, general health awareness and explore the emotional effect of living with a chronic disease.

Analogies such as “Skipper of your own ship” “Putting out the fire of asthma” may help patients to understand the reason for interventions and feel more in control of their condition.

### 4) Introduction of a step-wise approach

Although information is always needed, it does not necessarily lead to adequate self-management. Every patient should be offered a self-treatment plan designed to deal with asthma and allergic rhinitis in a step-wise fashion.

This requires basic knowledge about their disease, recognition that it is a chronic lifelong disease and being alert to typical signs of deterioration. Each management plan should be personalised with clearly written instructions specific for that patient.

These instructions should be clear concise and simple [12]. Adherence to the self-management plan will usually follow this process of understanding and empowerment.

### 5) Assessment of program outcomes

Assessing outcomes is usually done after one year. Immediately after a program, the participant may feel saturated with information and temporarily experience a loss of confidence. This is a normal phenomenon and over the next few months, they tend to assimilate the information and put it to practical use with encouraging results. By about six months after finishing the program, they should be deriving maximal benefit.



## Adherence to treatment plans

Adherence, concordance or compliance is a difficult issue and needs special mention. A patient may be prescribed the most effective state-of-the-art medication and treatment plan for asthma, but if they fail to follow it, their disease will be poorly controlled.

A patient's knowledge of the effect of their medication, plus the effect of irregular use and side effects will have an impact on adherence. Treatment instructions should be both understood and agreeable to the individual patient. A culture of open communication about dosage and adjusting this to daily life is important. Tailoring the medication regime to reduce the frequency of dosing and using a small, less conspicuous device improves adherence. A regular routine and the time of day at which medication is taken should fit in with other daily activities.

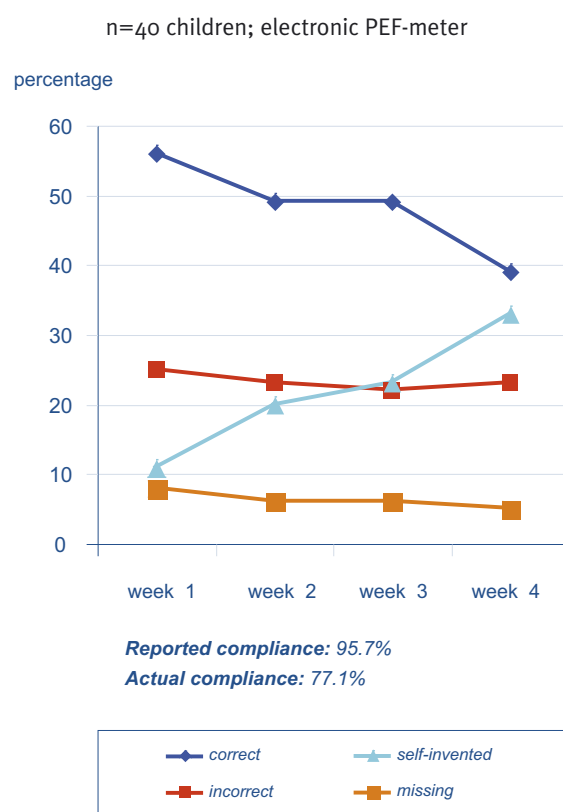
A recent study highlighted the fact that there is a real need for a good patient/doctor partnership with skilful communication, as well as innovative approaches for treatment delivery [13]. This study focussed on patient preference in treatment decision-making and identified facilitation factors and barriers to patient participation. In line with this, efforts should be made to increase patient satisfaction. Patient satisfaction with a particular treatment or decision may well explain most of the positive effects of patient education.

It has been shown that poor inhaler technique is associated with poor asthma control and every patient needs to rehearse and demonstrate their ability to use their delivery device at each visit. Surprisingly, many physicians also have insufficient knowledge of the various inhaler devices and initially demonstrated poor inhaler technique themselves which improved with repeated training and rehearsal [9] [11] [12]. Routinely encouraging the patient to demonstrate their inhaler technique at each follow-up consultation will identify any technical problems they might encounter following instructions.

The value of routine Peak Expiratory Flow (PEF) monitoring in asthma is controversial. On the one hand, a recent evidence-based review demonstrated that an individualised and written action plan based on personal best PEF, using 2–4 action points (as well as recommending both inhaled and oral corticosteroids for treatment of exacerbations) consistently improved the asthma outcomes in patients [14].

On the other hand, another study showed that PEF diaries are unreliable, with 95% reporting compliance in their diaries, whilst actual compliance as measured by an electronic spirometer was less than 77% [15]. Routine PEF monitoring may be fallacious as patients are likely to be non-compliant and then fabricate results for the physician. By contrast, short-term PEF monitoring may be of value if there is uncertainty about the asthma diagnosis or for identifying asthma triggers. Using a personal absolute best PEF as a gauge for asthma control is debatable, as one isolated high reading may be difficult to repeatedly re-attain. It is preferable to rather pitch the “best” PEF as an average level at which the patient is comfortable and symptom free.

### How reliable are PEF diaries?



## Adjusting the program according to needs

### The needs of each age group

Different age groups need innovative approaches to education. For example, young children may feel intimidated by spacer devices while adolescents might resent being seen with bulky inhalers.

To deal with this, each program needs to be adapted to the age-related problems facing each subgroup:

- **0-8 yr:** Burden of disease lies mainly with young inexperienced parents
- **8-13 yr:** Beginning to understand and adhere to treatment which may be helped by role play
- **12-18 yr:** Adherence problems with adolescents independence and rebellious attitudes
- **18-25 yr:** Other life commitments become more important and impede optimal asthma management
- **Adults:** A sense that a lifetime of asthma may lead to feelings of isolation and depression

In the USA and Australia highly effective self-management and asthma education plans have been developed for children [16] [17] and adolescents [18] [19].

### Needs of minority groups

Asthma has an enormous socio-economic and health impact, particularly on less affluent minority groups who tend to under-utilise available asthma educational programs. We need to explore cultural preferences which preclude or impede understanding of asthma and the use of certain devices, tablets or suspensions.

Cultural beliefs and norms need to be integrated into training programs to make them more acceptable. Trainers need to be actively recruited from these minority groups to address cultural differences and promote outreach programs into the various communities. In this way asthma self-education will permeate all cultures in our European Multicultural societies.



One recent study reported on the clinical outcomes and quality of life in a community-based project investigating white European (W/E) and Indian subcontinent (ISC) ethnic groups with asthma living in deprived inner city areas of Birmingham, UK. The authors showed that active intervention did improve clinical outcomes but that, despite delivering this in the relevant ethnic dialect, they were not able to demonstrate the same level of improvement in the ISC patients as in the W/E ethnic group [20].

Nevertheless, socially isolated groups can be reached and this has been shown in another study looking at neighbour-to-neighbour support and their encouragement of asthma self-management among African American children in low-income neighbourhoods. The positive outcome was a reduced acute emergency care utilisation rate and better overall asthma control [21].

## ASTHMA AND ALLERGIC RHINITIS

### The link between persistent asthma and allergic rhinitis

There does indeed appear to be a link between allergic rhinitis and persistent asthma. In addition, the prevalence of allergic rhinitis is increasing and studies show considerable comorbidity with persistent asthma. Research suggest that 78% of asthma sufferers have coexistent allergic rhinitis while those with allergic rhinitis have a 3-fold increased risk for developing asthma [22]. Atopy at an early age appears pre-dictive of respiratory symptoms later while allergic rhinitis precedes the onset of asthma in up to 50% of affected atopic children [23]. The corollary of this is that better control of allergic rhinitis will result in better control of coexistent asthma. Studies now show that uncontrolled allergic rhinitis has a far more negative impact on quality of life than uncontrolled asthma alone [24].

Corren and Leynaert have noted that exposure to an allergen in the nose increases bronchial reactivity in patients with allergic rhinitis (whether or not they have asthma) and treating the nasal symptoms significantly reduces airways reactivity and asthma symptoms [25][26]. Terreehorst found that house dust mite allergy and other inhalant allergic disorders are strongly associated with co-morbid asthma and allergic rhinitis [27]. Although there is considerable debate about the efficacy of allergen avoidance measures in house dust mite allergy, avoidance measures in children seem to be effective. Tailored allergen avoidance measures as part of a self-management educational program was effective for inner-city asthmatic children [28]. Clinical trials on house dust mite allergy show improvement in both asthma and allergic rhinitis after desensitisation immunotherapy.

Further studies show that perennial rhinitis is an independent risk factor for asthma in non-atopic subjects [29] as well as for adult-onset asthma (in both atopic and non-atopic individuals) [30]. Concomitant allergic rhinitis in asthmatic children is associated with an increased likelihood of asthma-related hospital readmissions and greater total days spent in hospital [31].

Children with co-morbid allergic rhinitis incurred greater drug prescription costs and experienced more GP visits and hospitalisations for asthma than did children with asthma alone [32]. Corren found optimal allergic rhinitis control strongly associated with a significantly lower risk of emergency room (ER) visits and hospital admission for asthma care. In addition, treatment of allergic rhinitis with nasal steroids or 2nd generation antihistamine was associated with lower risk of ER visits or hospitalisation for asthma. A combination of both nasal steroid spray and oral antihistamine medication had even better outcomes in rhinitis and consequent asthma control [33].

It therefore follows that educational goals should include acceptance of the interrelationship between allergic rhinitis and asthma. Explaining the beneficial effects of medication on both diseases and promoting understanding of the “single airway” concept will improve treatment adherence. Some authorities advocate promotion of an awareness campaign stressing the link between poorly controlled rhinitis and difficult to control asthma. At the same time consideration of the cumulative load of both nasal and inhaled steroids should always be borne in mind, particularly among children.



## Is there room for an integrated approach?

There is a common co-morbid theme in chronic asthma management, persistent rhinitis management and allergy management - they all share a common pathogenesis. Cost-effective allergy management requires a step-wise approach to managing allergic rhinitis in association with asthma. The Allergic Rhinitis and its Impact on Asthma (ARIA) guidelines formulated by the WHO and EAACI working groups [34] have suggested useful algorithms for treatment and a uniform nomenclature for allergic rhinitis. This new definition with intermittent and persistent allergic rhinitis further highlights the association with persistent asthma.

## THE IMPACT OF SUCCESSFUL ASTHMA AND RHINITIS MANAGEMENT

### Cost effective asthma and allergic rhinitis education

Health care providers and Health Authorities have become increasingly aware that asthma, rhinitis and other allergic diseases, despite their relatively low rate of mortality, have a major impact on direct public health costs. Asthma and associated allergic rhinitis persistently impair the life of affected patients over several decades. These conditions result in a continuous drain on public health resources (as well as a long-term decrease in quality of life), as a result of loss of work days and an array of other indirect costs [35].

The calculated costs for asthma care were over 6.5 billion dollars in the US in 1992 and the largest component of this was attributed to direct costs such as the cost of drugs and outpatients visits. If the indirect costs of poorly controlled asthma were calculated, this figure would probably double.

Little is known about the economic impact of allergic rhinitis, but in the UK there are 5.3 million consultations annually for allergic rhinitis. In addition, several studies suggest that a very large proportion of patients with respiratory allergies, varying from 50-80% are not optimally recognised

or treated and do not comply with prescribed treatment, resulting in a large number of patients with uncontrolled allergic rhinitis and asthma.

## Health economics

It is probable that in the short term, overall health costs may increase with the implementation of screening programs to detect undiagnosed asthma, allergic rhinitis and promote better self-management and follow-up, especially if treated with the newer drugs.

**But the resultant early intervention and better control of asthma and allergic rhinitis will dramatically decrease the chronic drain on healthcare resources in the long term. Emergency Room visits, hospitalisation, work days lost and limitation of quality of life will all be reduced and preliminary studies show that overall health costs will diminish as chronic disabling respiratory diseases become less of a social burden [36][37][38].**

Gallefoss proposes a novel indicator for efficacy of health economic education, and that is Number Needed to Educate (NNE), similar in principle to the well-established concept of Number Needed to Treat (NNT). NNE gives an indication of the number of people with a condition that will need to be educated to get one symptom-free patient. With extended and structured asthma education programs, this may be less than 3:1 (meaning to get one symptom-free patient, you will need to educate three patients) [8].



## THE ROAD TO SUCCESS

### The German and Scandinavian “asthma school” success stories

The remarkable success of these “asthma schools” began with the German asthma education courses which have grown from only 8 in 1992 to a remarkable 1395 by 2002. The initial courses in Berlin in 1987 consisted of 8 teenagers (7 to 13 years) and their parents. These first participants were admitted to hospital for 5 days each, undergoing 30 hours of asthma training for the children and 15 hours training for the parents, by a team consisting of medical doctors, psychologists and sports physiotherapists [39]. There are now over 2000 certified asthma trainers (mostly paediatricians). Asthma Patient Education is now part of the national Disease Management Program (DMP) for asthmatic patients (adults and children). These programs are standardised with similar programs available throughout the country, and all are quality controlled with a set curriculum for trainers. The optimal program duration currently is 20 hours for children and adolescents, 10 hours for parents over a minimum of 3 days, and there is a follow-up session after 6 months. The number of participants who completed asthma training programs between 1992 and 2002 is now in excess of 10000.

The content of the asthma educational programs focus on:

- Increasing knowledge and ability to deal with asthma
- Self-evaluation of lung function (symptoms and spirometry)
- Emergency plans to deal with deteriorating asthma
- Practicing and perfecting inhaler techniques
- Enabling physical exercise and daily activities
- Role-play to learn about handling social situations
- Reflection on coping strategies and resources for the family

In the United Kingdom, the charity organisation Asthma UK runs PEAK adventure holidays for asthmatic children aged 6 to 17 years. These week-long asthma educational holidays are run throu-

ghout July and August each year and activities range from camping to abseiling. Specially trained volunteers including asthma nurses provide supervision with symptom control and asthma education. The group activities (split into two age groups) allow young people with asthma to interrelate, further boosting their confidence and independence.

A measure of the success of these programs can be found in the study by Gallefoss of Norway. In this study, an intervention program involves 78 mild to moderate asthma patients attending out-patient clinics. The control group was monitored by their GP for one year while the intervention group had two 2-hour group sessions and two 40-minute individual sessions with a nurse and physiotherapist. They were given PEF diaries, a written booklet on asthma and a personalised asthma treatment plan. One year later the intervention group reported statistically significant improvement in quality of life and fewer hospital admissions, GP visits and days off work [5][8].

Similarly, Haahtela et al. achieved remarkable goals in the nationwide Finnish asthma intervention study [40][41]. These included:

- Early asthma intervention and recovery from symptoms
- Overall decline in percentage of moderate/severe persistent asthma from 40% to 20%
- Return to age appropriate activity and functionality
- Reduction in hospital admissions by 50%
- Reduction in annual treatment costs of asthma by 50%

Following on this, the National Plan for Asthma Schools in Norway also offered:

- Open dialogue to explore patient attitudes (open ended questions)
- Medical input including asthma risk factors, diagnosis and treatment
- Group education with illustrative slides using analogies to help understand concepts
- Individual education with nurse and physiotherapist
- Patient brochure with personalised action plan for emergencies

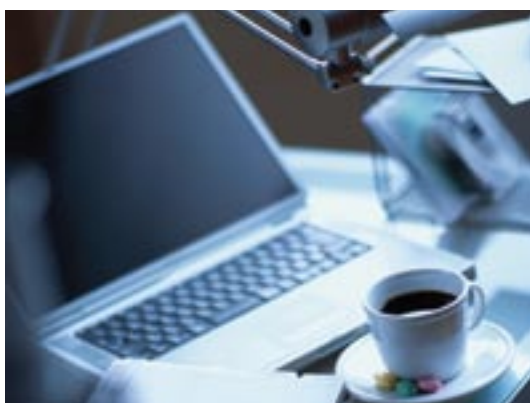
As a result of this valuable research, the key message becomes:

***“A community problem needs community solutions”***

A vital component of the recipe for these Scandinavian success stories was the lobbying of empathetic Health Ministers who could bring pressure on health departments and local Health Authorities to provide support and funding for these programs.

### Future directions

Innovative ways of promoting asthma self-management have been explored in recent years. Compared with asthma self-management, studies on allergic rhinitis self-management are less advanced. To date there has been only one well designed study to assess the effect of education on adherence in rhinitis treatment [42]. Allergic rhinitis education is an area where further research is urgently warranted and structured rhinitis self-management should become integrated into asthma self-management programs.



The number of internet sites with asthma education material and advice has spiralled over the years, but at present there is no regulation of these sites. Organisations such as Health on the Net (HON) offer basic guidelines but do not check website content for accuracy. An international body is necessary for vetting sites and issuing a “Seal of Approval” that a site has been peer-reviewed and the content certified as being both accurate and beneficial to asthma patients. Perhaps the Global Allergy and Asthma European Network GA<sup>2</sup>LEN could take on this regulatory role for validation of material.

The same is true for allergy education material in general. A large number of leaflets are published, particularly for people with hay fever. They are of variable quality and not accessible to all patients because of limited distribution or high reading-age scores. They are often sponsored by multi-national pharmaceutical companies who may principally promote their specific products [43].

Another possibility is that of telecommunication via cellular phone technology attached to ambulatory PEF devices which could be a novel way of monitoring asthma control. Software can download peak flow readings, symptom scores and medication usage and then advise the patient if any medication adjustment is necessary or whether urgent medical attention should be sought [44].

### Using mobile phone technology to adjust medication to asthma symptoms and peak flow readings



Historically pharmaceutical companies have organised and funded asthma and allergic rhinitis education activities. This practice needs to be carefully regulated to remove any agenda to promote specific pharmaceutical products.

Most patients attending allergy and asthma self-management programs are those with insight and motivation and not necessarily the most in need.

Programs should to be tailored to the needs of less affluent groups and to take ethnic and cultural diversity into account when structuring content. Outreach programs to less affluent neighbourhoods and specific training of nurses from diverse cultures would help address this issue. Special attention must be paid to cultural attitudes to disease and treatment otherwise these programs risk not being fully utilised and may not achieve the desired goals.

## CONCLUSION

Self-management in persistent asthma and allergic rhinitis is an essential part of disease control.

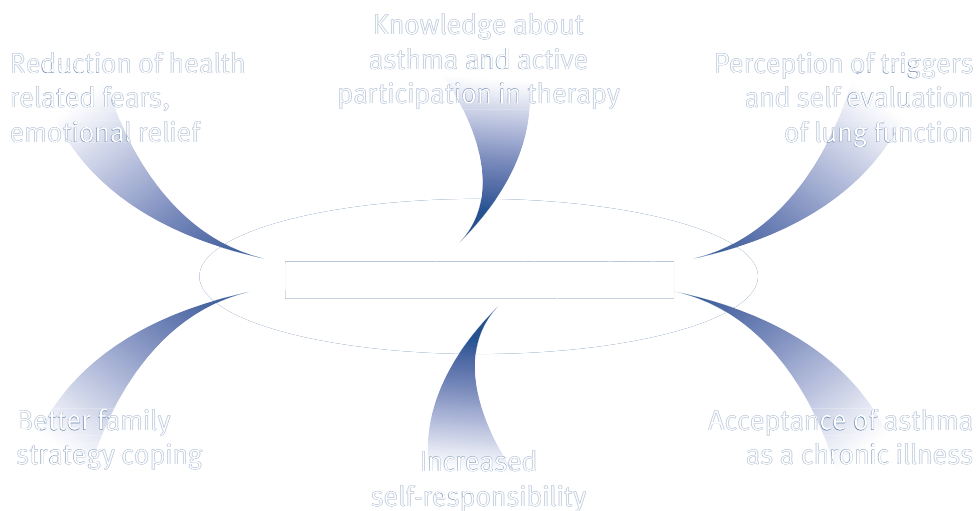
With allergic rhinitis and asthma, both the adult patient and child (or their parents) need to know as much as possible about the nature of their disease and the possible effects of the medication. It is essential that they accept their illness, be free of fear and anxiety and have a realistic perception of their symptoms.

Various clinical studies strongly support self-management and educational programs, which if structured correctly, have a profoundly beneficial effect on the outcomes of asthma management.

Effective self-management requires good communication with the nurse or physician and adherence to the medical advice and treatment plan prescribed [45][46][47][48][49].

Guevara et al., in their 2003 meta-analysis conclude that educational programs for the self-management of asthma in children and adolescents improved lung function and feelings of self-control, reduced absenteeism from school, the number of days with reduced activity, the number of visits to an emergency department, and possibly the number of disturbed nights. They conclude that educational programs should be considered an integral part of the routine care of young patients with asthma [50].

### Goals of Patient Education



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# Food Allergy and Anaphylaxis

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## Section A

### THE PROBLEM OF FOOD ALLERGY

#### Defining food allergy and anaphylaxis

The umbrella term food hypersensitivity is used to describe all adverse reactions to food and it includes both food allergy and non-allergic food hypersensitivity [1].

Food allergy may be subdivided into IgE or non-IgE-mediated food allergy. Most IgE-mediated food allergic reactions involve the skin and upper respiratory tract, whereas most non-IgE-mediated food allergic reactions (involving IgG or T cells) affect the gastrointestinal tract. Food allergy can occur as an immediate reaction within minutes or up to two hours of consuming a particular food, otherwise as a delayed type reaction after two hours. Symptoms of food allergy may involve one or more organ systems, such as the skin, the gastrointestinal and/or respiratory tract resulting in symptoms such as urticaria, angioedema, worsening of eczema, asthma, rhino-conjunctivitis, vomiting, or diarrhoea.

A non-allergic food hypersensitivity reaction does not involve the immune system and covers pharmacological reactions to vaso-active amines (serotonin, tyramine and histamine), lactose intolerance due to deficiency of gut digestive enzymes and reactions to food toxins which, for example occur in schromboid fish and mushrooms.

Anaphylaxis is an immediate systemic allergic reaction which is potentially lethal and characterised by symptoms affecting the respiratory tract, cardiovascular system, gastro-intestinal tract, skin and neurological system. This disorder should be graded according to Sampson's criteria (2003) [2]. Anaphylaxis can affect any age group. Food allergy is the most common cause of anaphylaxis and in the USA, food allergy accounts for 33% of cases of anaphylaxis (resulting in an estimated 200 deaths per year). The next





most frequent causes include reactions to insect stings (14%) and medication (13%). Sometimes the term anaphylaxis is used for mild symptoms but this leads to confusion and an accurate definition of anaphylaxis is therefore essential [3]. However, sometimes mild symptoms, such as tingling in the mouth may be the precursor of an anaphylactic reaction.

### The extent of the problem

The whole issue of food allergy is fraught with confusion and public misconception. Approximately 25% of the general population claim to be allergic to one or other foodstuff, but on careful evaluation only 2-3% of adults and 6-8% of children will exhibit true food allergy [4]. The most common food allergens are cow's milk, hen's egg, peanuts, tree nuts, seeds, wheat, soy, fish, and shellfish [5][6].

#### 39 cases of anaphylaxis caused by food in 29 children

- **M/F:** 20/9
- **Age:** 3 months – 9.5 years (mean 2.4 years, median 1.5 years)
- **Causal food:**
  - cow's milk (CM) 12
  - peanut 8
  - egg 6
  - fish/ shellfish: 3
  - wheat: 2
  - potato: 2
  - hazel nut: 1
  - kiwi: 1
  - probably: fish 1, peanut and/or hazel nut 1, "Sharon" fruit 1, additives 1
- **Mean age at anaphylaxis caused by:**
  - CM / potato: 1 year
  - other foods: 3 years

Data from L. De Swert, Belgium 2005

Physicians need to be able to readily recognise the patients who are most at risk for food allergic and anaphylactic reactions. These patients need urgent specialist referral for a full diagnostic work-up and confirmation of their allergy. Once the diagnosis has been confirmed, food allergic patients should undergo thorough instruction and training with regard to diet and emergency management [7][8]. Intervention should always include education on appropriate avoidance diets and an easy to

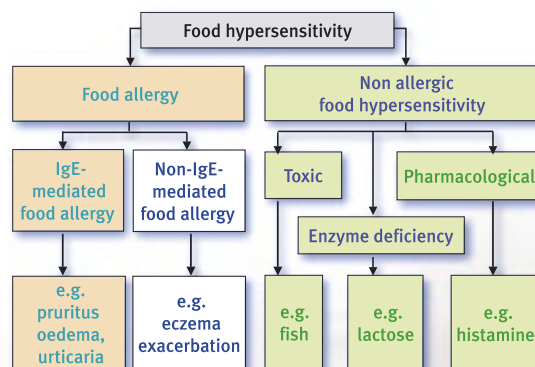
understand action plan for managing food allergic emergencies [9]. The patient or parents should be informed about the expected natural history of the particular allergy. For example, cow's milk allergy is inversely related to age, with two thirds of patients becoming tolerant by three years of age. By contrast, peanut allergy is only outgrown by 20 percent of children and the majority of patients will remain allergic until adulthood.

Those who are not shown to be allergic on testing should be counselled and reassured that they have no evidence of food allergy. This is important in order to prevent a lifetime of unnecessary food avoidance, which could hamper their quality-of-life and perhaps lead to malnutrition.

### Those at risk in the community

Most clinical reactions involving food allergy occur in the community where immediate medical assistance is not readily available. It is necessary therefore to prepare each patient, who is at risk or who has a documented food allergy, for an anaphylactic reaction and to become an expert in dealing with their allergic reactions whenever and wherever it might occur. Fortunately, most reactions involving food allergy do not result in severe anaphylactic reactions. However, we need to be able to identify those patients who are especially at risk in order to ensure prompt intervention.

Recent research has highlighted that one third of fatal food allergic reactions occurred while eating at a restaurant while another third occurred at home [10]. In both situations no professional treatment is immediately available and this highlights the need for proper patient education to deal with these emergencies.



Modified from Johansson SGO et al. Allergy 2001; 56: 813-824

## Recognising severe food allergy and anaphylaxis

In general, the knowledge and experience of general practitioners in diagnosing, treating and guiding food allergic patients is poor [11]. Even specialists such as paediatricians appear to know only the basics of food allergy and anaphylaxis. Moreover, the psychological and social impact on the patient and their families is considerably underrated. A comprehensive and systematic history of symptoms is therefore essential to identify those individuals with suspected food allergy in order that they may be referred to a specialist physician for accurate diagnosis and treatment. Every physician should be able to recognise those signs of food allergy and anaphylaxis which make appropriate specialist referral mandatory.

Signs of food allergy may involve the skin with features of urticaria, flushing, angioedema, pruritus and/or eczema. Gastro-intestinal symptoms may include vomiting, abdominal pain, dysphagia and diarrhoea. Respiratory signs may be in the form of wheezing, dyspnoea, stridor, rhinitis and conjunctivitis. Patients with cardiovascular signs may exhibit tachycardia and arterial hypotension, while neurological signs may manifest with extreme agitation, a “feeling of dread” or even loss of consciousness. Every physician should know that patients who have pre-existing bronchial asthma are a special high risk group for fatal anaphylaxis especially if they are food allergic. Fatal reactions involving food allergy are most commonly associated with a respiratory mode of death rather than cardiogenic shock [10].

Patients who present with suspected food allergic symptoms after having ingested, or had contact with or inhaled food allergens need urgent referral to a specialist who is experienced in food allergy and anaphylaxis. Once correctly diagnosed and a management plan has been set up, they should be followed up by the specialist on a regular basis until stable after which education leading to self-management should take place.

### The specialist’s diagnostic work-up

A full medical history should explore particularly: time of onset of symptoms, the kind of foods implicated, associated exacerbating factors at the time of relapse of symptoms, pre-existing medical conditions, history of asthma, atopic eczema and infant feeding problems.

A family history of first degree relatives with atopy is a significant risk factor for developing food allergies.

Also, environmental factors should be explored and a note should be made of those factors which amplify food allergic reactions such as simultaneous intake of alcohol and intake of specific medication (e.g. aspirin, codeine, ACE-inhibitor and beta-blockers). Exercise, stress and hormonal changes during the menstrual cycle may be important and some reactions may be exacerbated by taking a hot shower.

## Typical symptoms associated with food induced anaphylaxis

Symptom	n=39 cases	
	n (%)	1st Symptom
skin	39 (100)	34
respiratory: upper airways	12 (31)	11
laryngeal oedema	4 (10)	3
lower airways	14 (36)	6
gastrointestinal	13 (33)	6
cardiovascular	7 (18)	1
neurological	5 (13)	0

## Appropriate allergy testing is essential

Suspected food allergy should be confirmed using appropriate diagnostic tests [12][13]. Skin prick testing (SPT) and measurement of serum specific IgE will demonstrate sensitisation to the offending food. In case of delayed hypersensitivity atopy patch testing (APT) might be informative. Specific elimination diets, guided by a dietician experienced in food allergy and implemented over a one to six week period may help identify trigger foods which were not immediately apparent. The “gold standard” in food allergy diagnosis is still the double-blind placebo-controlled food challenge (DBPCFC). However, the procedure is time-consuming and therefore expensive and it poses a potential risk to the patient. Open challenges may be performed if subjective symptoms or day-to-day variations of allergic symptoms do not play a major role. Oral food challenge tests should always be done under medical supervision. Indications for hospitalising patients for a test such as an oral food challenge include previous life-threatening events or challenges with highly allergenic foods. Oral food challenges including exercise testing should be performed if exercise is considered to play a role as an amplifying factor.

## Avoid tests of no proven value

Certain diagnostic practices of unproven value are constantly being promoted to the public via the media. Specific food IgG testing has not been shown to be indicative of allergy as most individuals will naturally produce IgG antibodies to food independent of being allergic. Bioresonance, hair analysis, VEGA testing, Kinesiology, Iridology and blood cytotoxic tests are of no proven diagnostic value in allergy [13][14]. All of these tests have at some point been evaluated in the medical literature and found to lack reproducibility and diagnostic validity. Unconventional practitioners use these tests to incorrectly label people with food allergies and food intolerance. This results in the unnecessary prescription of food exclusion diets, possibly resulting in malnutrition. In addition, it results in food-related anxiety and negatively impacts on quality of life for the whole family.

## Section B

### FOCUS ON ANAPHYLAXIS

Current guidelines for treating anaphylaxis are based on expert opinion but there is little evidence-base regarding what to use and when to administer treatment such as epinephrine, bronchodilator, antihistamine and corticosteroid medication.

### Anaphylaxis is a rapid reaction

The rapid onset of most cases of anaphylaxis has been emphasized previously. The interval between eating the offending food and fatal collapse is usually about 25-35 minutes and the dose required to trigger a reaction can vary from a mere trace of allergen to over 100g [10]. Asthma is a major component of fatal food anaphylaxis, especially when the asthma is poorly controlled. Over 50% of the documented USA anaphylaxis fatalities were due to peanut allergy and 96% had associated asthma symptoms as a major factor in the symptom complex.

Reviewing both fatal and near-fatal food anaphylactic reactions showed that very few patients had epinephrine available at the time of their reaction. Of great concern was the fact that the vast majority had had previous allergic reactions but were still not adequately prepared for anaphylaxis [10][15]

Grading of food-induced anaphylactic reactions					
Grade	Skin	GI Tract	Respiratory tract	Cardiovascular	Neurological
1	Localised pruritus, flushing, urticaria, angioedema	Oral pruritus or tingling mild lip swelling			
2	Generalised pruritus, flushing, urticaria, angioedema	Any of above plus nausea and/or emesis	Nasal congestion and/or sneezing		Change in activity level
3	Any of above	Any of above plus repetitive vomiting	Any of above plus sensation of throat pruritus or tightness	Tachycardia (increased > 15 beats/min)	Change in activity level plus anxiety
4	Any of above	Any of above plus diarrhoea	Any of above plus hoarseness, "barky" cough, difficulty swallowing, dyspnoea, wheezing, cyanosis	Any of above plus dysrhythmia and/or mild hypotension	"Light headedness", feeling of "pending doom"
5	Any of above	Any of above plus loss bowel control	Any of above plus respiratory arrest	Severe bradycardia and/or hypotension or cardiac arrest	Loss of consciousness

All symptoms are not mandatory. The severity score should relate to the organ system most affected.

adapted from H. A. Sampson, Pediatrics 2003, 111: 1601-1608

## When should epinephrine be prescribed?

This has been a contentious issue because of differing views on aspects such as a fear of inappropriate use, dosage, method of administration and the important aspect of proper training. Although each case should be carefully evaluated, this consensus group feels that epinephrine auto-injectors should be issued to at least the following food allergic individuals:

- any patient with a history of a previous generalised severe reaction
- cases in which the reaction appears to be getting progressively more severe
- those who are confirmed allergic to peanuts, tree nuts and sesame seeds
- patients reacting to minute amounts of allergen, and
- patients with co-existent mastocytosis

Epinephrine should be administered in a weight-related dosage of 0.01mg/kg. It may be repeated within 5 minutes if symptoms worsen or severe symptoms persist [16]. Currently only two strengths of epinephrine (150 micrograms and 300 micrograms) are available in the form of EpiPen and Anapen auto-injectors. Using a dose of 0.01 mg/kg the 300 micrograms auto-injector is just optimal for a 30 kg patient while the 150 micrograms auto-injector is appropriate for a child weighing 15 kg. Problems

arise especially in children of less than 10 kg for whom even the 150 micrograms dose is too high, as well as children who weigh between 20 and 25 kg for whom a decision has to be made as to which dosage is best. Similarly, in heavy adults a dilemma arises because the 300 micrograms dose will not be strong enough and sometimes 2 or 3 auto-injections of the 300 micrograms have to be given simultaneously. A wider range of fixed dosage options or an adjustable device needs to be developed.

A prescription-in-isolation of injectable epinephrine given to patients at risk for an anaphylactic reaction is not adequate treatment. The issue of epinephrine auto-injectors with little or no other emergency management training may have the adverse effect of heightening anxiety and confusion. Therefore, extensive training with clear, written instructions for emergency management has to be given to these patients.

In a community setting epinephrine is best administered via the intramuscular using the antero-lateral thigh. This leads to better absorption than the subcutaneous route [17]. Adequate systemic levels of epinephrine cannot be reached using the inhalation route and this is not recommended. Epinephrine by inhalation should be used only when localised laryngeal oedema is evident. In a hospital setting epinephrine can be used intravenously, but cardiac monitoring is important as inadvertent excess dosages can lead to cardiac arrhythmias. Alternative

routes such as sublingual administration have shown promising results in animal models [18], but further studies are needed in humans as problems with salivary oxidation of epinephrine in the mouth may occur.

All patients with anaphylaxis should be carefully observed for at least 12 to 24 hours in case a biphasic reaction occurs. They should be referred to an allergy specialist for review after each anaphylactic episode.

## Proposed management plan

### Mild anaphylactic reactions

A mild anaphylactic reaction will manifest with symptoms such as generalised erythema, urticaria, angioedema, abdominal pain and/or vomiting.

Management of this type of reaction involves the following:

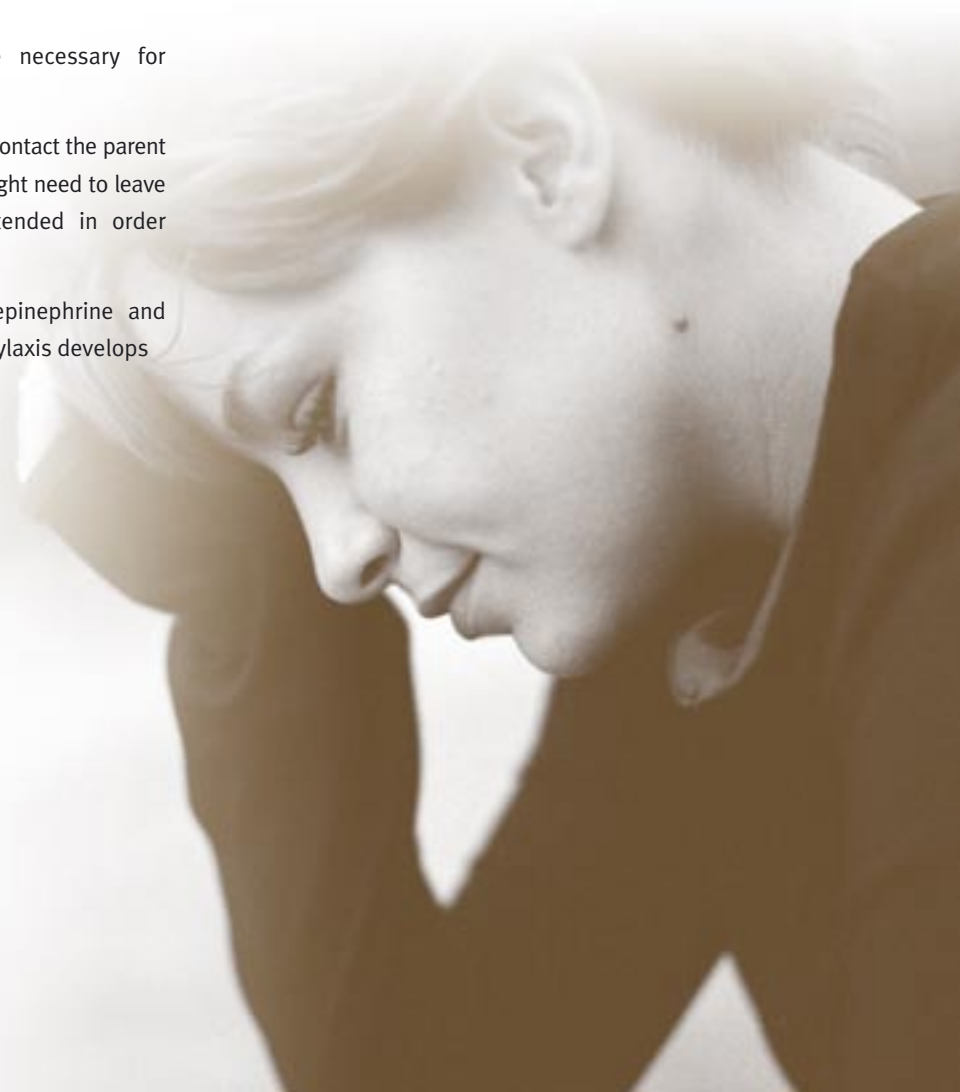
- Monitor the patient for worsening of anaphylaxis
- Try to keep the patient calm and give antihistamines and corticosteroids
- Beta-2-agonists may become necessary for respiratory symptoms
- Call for medical assistance and contact the parent or carer (if you are alone you might need to leave the patient temporarily unattended in order to call for help)
- Locate or obtain injectable epinephrine and keep on standby in case anaphylaxis develops

### Moderate-to-severe anaphylactic reaction

Moderate-to-severe reactions which necessitate the administration of epinephrine are those cases associated with noisy breathing, swelling of the tongue, tightness in throat, pallor, difficulty in talking, wheeze and/or persistent cough. At this stage:

- Administer injectable epinephrine into anterolateral thigh muscle (if not already given)
- Administer beta-agonists if available
- Give oral antihistamines and steroid medication (if not already done)
- Call emergency ambulance explaining that anaphylaxis has occurred and contact the parent or carer (if not already done)

Reactions involving the cardiovascular or cardio-respiratory system or combined with neurological symptoms are regarded as very severe and should prompt even more urgent intervention [19].



## Section C

### FOOD ALLERGY INTERVENTION

Food allergy is a classic model of a disease where the principle of disease management is synonymous with self-management.

#### Patients are badly prepared for emergencies

The vast majority of food allergic patients are poorly prepared for an unexpected anaphylactic reaction. Sicherer et al [20] identified that less than 20% of anaphylaxis sufferers have epinephrine at hand. In addition, less than 25% of pediatricians could demonstrate the correct use of an EpiPen. This is compounded by the finding that only 25% of pediatricians have prepared a written action plan for patients in the event of anaphylaxis [20]. Clark et al noted that in North America only 40% of patients who were treated for food allergy in an emergency department had had previous instruction on which foods to avoid. Furthermore, only 16% were prescribed injectable epinephrine. Moreover, only 12% had been previously referred to an allergist for diagnosis and management planning [21].

From the above findings on what appears to be a widespread failure of proper management, it is clear that injudicious epinephrine prescription will never replace a thorough allergy evaluation and accurate diagnosis by a competent specialist. Over-prescribing of epinephrine can also result in an increase in food anxiety and may actually reinforce the psychological fear of an unexpected allergic reaction. Similarly, unnecessary dietary precautions can lead to social exclusion and isolation of individuals and further stunt education and emotional development. It is also clear that all patients with epinephrine as well as their families, teachers and care givers need thorough instruction on how and when to use injectable epinephrine [22]. This has led to calls for a European multilingual step-by-step treatment plan for food allergy and anaphylaxis which can be applied in an agreed manner, according to symptom severity.

#### Recognising hidden food allergens

There is no cure for food allergy and consequently, there is no effective therapy other than avoidance. In practice, many cases are informed of the diagnosis and simply instructed to avoid the allergen without any further education or support. This common practice is wholly unacceptable and has led to many of the recommendations in this text.

Identification of food allergens in day-to-day foods is extremely difficult for the unwary as common allergens may be labelled with unfamiliar names. Therefore, better food labelling and patient education is mandatory. Every patient with food allergies should see a dietician with specialist training in food allergy for dietary advice and supervision of any elimination diet to ensure that it is nutritionally adequate. The dietician should also help the patient to understand food labelling and be aware of hidden allergens or alternative names for known allergens. For example, milk allergic patients need to know that whey and casein are other names for cow's milk products.



A major breakthrough assisting patients to recognise hidden allergens has been the recent European Union legislation that food labels shall clearly declare whether any one of 12 allergenic substances is present [23]. This abolishes the old «25 percent rule», whereby known allergens had to be incorporated in the label only if the food contained more than 25 percent of that allergen. Now all foodstuffs that contain substances such as cereals (including gluten), crustaceans, hen's eggs, fish, peanut, soybeans, cow's milk, nuts, celery, mustard, sesame seeds and sulphur dioxide must be labelled as such.

## Major allergenic foods listed in EU draft directive on labeling of foods

- Cereals containing gluten (i.e. wheat, rye, barley, oats or their hybridized strains) and products thereof
- Crustaceans and products thereof
- Eggs and products thereof
- Fish and products thereof
- Peanuts and products thereof
- Soybeans and products thereof
- Cow's milk and products thereof (including lactose)
- Nuts (i.e. Almond, Hazelnut, Walnut, Cashew, Pecan nut, Brazil nut, Pistachio nut, Macadamia nut and Queensland nut) and products thereof
- Celery and products thereof
- Mustard and products thereof
- Sesame seeds and products thereof
- Sulphur dioxide and sulphites at concentrations of more than 10 mg/kg or 10 mg/l expressed as SO<sub>2</sub>.

There is mounting pressure to ban the labelling of allergen free foods with the disclaimer “may contain traces of nuts” or “processed in a factory that prepares nut containing products” as these statements do not help the patients to decide whether or not a food is safe to eat. Clear-cut labelling is essential. However, we still do not know precisely how much allergen is “too much”. The Lowest Observed Adverse Effect Level (LOAEL) of the various allergens needs to be investigated in highly sensitive individuals [24]. These levels will be critically important for food regulatory agencies in assessing anaphylaxis risk.

## Three places of risk for those who are food allergic

Studies have emphasised that food allergic patients experience the greatest risk :

- When out-shopping for food
- when ordering food in a restaurant or from a caterer
- when eating food prepared by friends or relatives at home, or by caretakers at day care centres and schools

A number of countries now have anaphylaxis registers to record reactions. All emergency room staff and primary care physicians should be encouraged to become involved and accurately report all cases of anaphylaxis.

## More food allergy awareness

General knowledge about food allergy can be reinforced using written instructions, videos, DVDs, telephone help lines and via internet chat forums with trained allergy facilitators. Action plans need to be individualised but should contain common basic first aid measures. Many experts advocate a “food allergy passport” with an individualised written emergency action plan which will be very helpful for carers, colleagues, teachers and medical personnel who may be faced with emergency situations.



## Training and education for the community

A number of European hospitals, clinics and allergy support groups now offer courses to instruct patients with allergies. These courses have been extended to parents, schools, factories and other institutions. There is mounting evidence that if patients are more aware and proactive in their own management, then they are less likely to have accidental adverse allergic events. On average, a minimum of 6 hours needs to be spent in a self-education group environment to get real benefit. There should be regular contact with the group in the first year and this is continued with “support-on-demand” thereafter. Ethnicity and cultural differences should be taken into account when setting up these courses to gain maximum impact and best outcomes. These courses have proved extremely popular with patients and their parents and in some European countries health insurance companies now offer financial support for these programs. Courses in allergy self-management are still not widely available tending only to be accessible in larger cities in the European Union. Unfortunately, training courses specifically focusing on food allergy self-management are much rarer.

## Uniform action plan in simple language

Every patient with a history of anaphylaxis and severe food allergy should carry an Action Plan card. This must include essential details of the patient (height, weight, age, concomitant medication and associated illnesses) of their allergy (allergen, severity and medication they carry), as well as contact details for their physician, carer and local hospital.

Use of injectable epinephrine, beta-agonist inhalers, oral antihistamines and corticosteroids must be clearly explained. Concomitant medication that might interfere with treatment must also be identified (such as ACE-inhibitors and beta-blockers which interfere with epinephrine action). The action plan should include graphic visual cartoon's showing exactly how to administer treatment in a step-wise manner.

## Effectiveness of education programs

A question which is often asked is “do education and self management plans make any difference or alter behaviour in the community?” Various clinical studies have been performed to assess the effectiveness of these patient education programs.

Kapor et al showed significant improvement in three parameters after patient education: these included the patient's knowledge of how to avoid a specific food, the family's understanding of how to manage a reaction and finally critical steps in effective EpiPen/ Anapen administration [25].

Follow-up with a contact group and having a permanent designated “contact person” will improve support and help patients and their care givers. Food allergy cook books with local cuisine are very useful and reassuring, but not yet universally available.

## Support networks are essential

The Food Allergy Organisation in the Netherlands has introduced a uniform international plastic ID card which identifies the patient's allergies and contains specific information for doctors, care givers and restaurant staff. Self-help food allergy groups such as the Netherlands Stichting Voedselallergie and Nederlands Anafylaxis Netwerk, UK Anaphylaxis Campaign and the French Allergy Vigilance Network provide educational brochures, “safe” restaurant guides, arrange family education days and outings to safe amusement parks. This helps parents regain their confidence and begin to socialise and bond with other parents with similar food allergic children. Ideally these food allergy and anaphylaxis support networks need to be extended across Europe.

Other sources of trustworthy information such as the internet and booklets, will hopefully soon carry a “seal of approval” indicating that the information has been reviewed by experts and found to be accurate and appropriate. Regrettably, many unregulated publications and internet sites may heighten anxiety by “scare mongering” or just offer inaccurate information which then leads to confusion and poor disease control. Reading this conflicting information makes it difficult for the patient to decide what information is correct and what should be ignored.

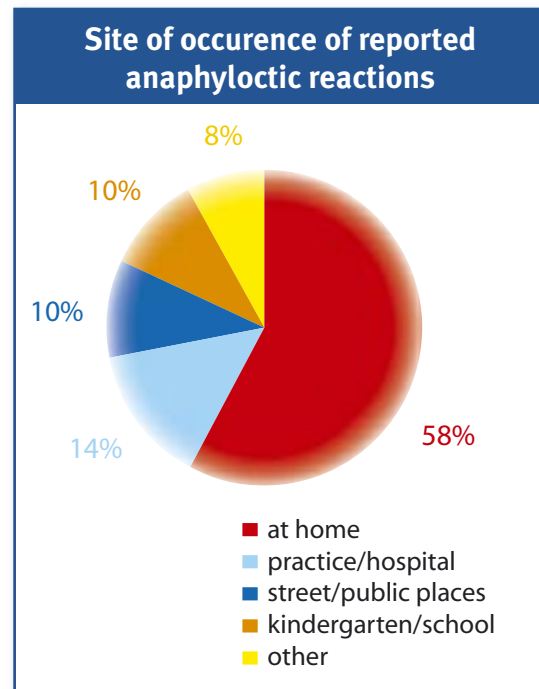
### Many aspects need further research

Epidemiological studies will help assess variations in the distribution and frequency of reactions to the principle food allergens in different countries. For example, the preponderance of allergy to peanut in the USA and Western Europe, rice in China, fish in Scandinavia, sesame in the Middle East and poppy seed in Eastern Europe.

Opinion leaders need to encourage countries to set up National Registers of Anaphylaxis to get a clearer idea of the scale of the problem and so plan further appropriate intervention. Near fatal anaphylactic reactions can cause severe psychological consequences to the survivor and their family.

In addition, unnecessary dietary restrictions can result in a nutritionally unbalanced diet and lead to resentment and depression in sufferers and their care givers. Young children may be excluded from kindergarten because staff are unwilling to take responsibility for the child or administering the epinephrine. Studies to assess the social impact of this are a priority in the coming years and government and health care organisations should be encouraged to support these initiatives.

There is also a necessity to study the pharmacology of epinephrine further, to clearly identify the therapeutic window for this drug and to assess the best route for administration. The development of new multi-strength devices is a priority and needs to be explored as a matter of urgency.



### Innovative developments

Anti-IgE antibody therapy is not a cure but certainly may play a role in reducing severe reactivity associated with exposure to food allergens [26]. Although it may act as a “safety net” in the short term, it is expensive and needs to be administered by injection. Unfortunately, the original tested drug TNX-901 was prematurely withdrawn and the studies have to be repeated with Omalizumab which to-date has not been widely tested in food allergy. Promising new “engineered” recombinant vaccines using modified protein allergens for food allergy are in the process of being developed [27].

Hypo-allergenic foods can be genetically modified to produce pan-allergen (profilin and LTP) free foods but adverse public opinion regarding genetically modified foods is a major obstacle to this. Hypo-allergenic cultivars of certain mass produced crops can be selected and farmed instead. However, whether these will be successful in reducing food allergic sensitisation remains to be seen.

In the interim, there is currently no cure for food allergy or anaphylaxis. It is therefore essential that we educate the patients, their caregivers and physicians in a structured manner, so that they can adequately manage their food allergies and prevent food induced anaphylaxis.

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## THE UCB INSTITUTE OF ALLERGY

Division of UCB S.A., The UCB Institute of Allergy (IOA) is an independent, European and not-for-profit organisation, created in 1987 to combat allergy.

In response to the international epidemic of this disease, the Institute's objective is to implement all the resources necessary to raise awareness of allergy as a major health issue amongst the general public, patients, health care professionals and public authorities.

Under the supervision of a Scientific Advisory Board made up of eminent European specialists in the field of allergy, IOA has initiated many actions. These aim to inform and educate about allergy, to improve prevention, to promote research, to analyse the current situation and to define key actions to be taken over the coming years. Moreover IOA favours cooperation between various allergy related organisations. The Institute is present all around Europe with 20 national sections and in South Africa.

The Institute's web site (<http://www.theucbinstituteofallergy.com>) and central membership library provide members with current relevant information and publications about allergy. For the general public, schools and children, IOA has produced videos (e.g. "Who's sleeping in your pillow?", "Allergic: to be or not to be?...Rhinitis"), educational games and other information material. IOA also organises and holds meetings, symposia, conferences, panel discussions and offers "Travel Grants & Scholarship Awards" to young researchers.

As a result of these activities, The UCB Institute of Allergy hopes to forestall the sobering prediction of certain epidemiologists: *In 30 years' time, everyone may be allergic...*

*Unless we act now!*

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