The first international conference on Therapeutic Education in Atopic Dermatitis was held in Toulouse on 23, 24 and 25 June 2010. The conference, organised by the "Foundation for Atopic Dermatitis" which is part of the Pierre Fabre Group, brought together paediatricians, dermatologists and nurses from France, Belgium, Spain, Poland, Greece, Italy, Canada and the United States. It was more than just a conference; it was a time for exchanges of techniques and methods but also cultural exchanges.

Opening ceremony on 23 June 2010 - Natural History Museum - Toulouse

The conference was opened by Mr Jacques Fabre, President of the "Foundation for Atopic Dermatitis", Mr Yves De Prost, Head of Dermatology at the Necker Hospital in Paris, Mr Carle Paul, Head of Dermatology at the Larry Hospital in Toulouse and Mrs Chantal Segard, "Foundation for Atopic Dermatitis" Project Leader, who presented the programme of the event.

Jacques Fabre officially opened the conference, recalling its main objectives: fruitful exchanges and the necessity of reaching a scientific consensus, underlining the importance of the manifestation in the face of the difficulties that atopic dermatitis represents.

Mr De Prost insisted on the need for Therapeutic Education in atopic dermatitis for three reasons: the chronic character of the disease, the clinical efficacy of the education and finally its reinforcement as it is now regulated by the HPST (Hospital, patients, health and territories) law.

Carle Paule focused more on the doctor - patient relationship, looking back at the evolution of the patient object over the past decades, to the patient today who plays a leading role in their treatment.

The objectives of the conference were presented by Dr Chantal Ségard, project leader of the Foundation for Atopic dermatitis: The first objective was of course the exchange of experiences between the teams from the countries represented (France, Italy, Belgium; Spain; Poland; Greece, Canada; USA; Columbia; Mexico) with an additional originality: the presence of therapeutic education teams, that is to say doctors, nurses and psychologists. The second objective was to draw up a position paper containing the international guidelines of a therapeutic education programme for AD.
A summary of the presentations is presented below by theme and not in chronological order of presentation (cf. programme)

Sébastien Barbarot, dermatologist at the University Hospital Hôtel Dieu in Nantes, presented the origins of TPE in atopic dermatitis as well as its evolution. It all starts with one observation: the disease became more and more frequent in the 90s, leading to a phobia of steroids, false beliefs about eczema, or bad compliance. The consequence: a disappointment in the treatment of atopic dermatitis, whilst chronic diseases like asthma were well understood by the medical profession.

At the beginning of the 2000s, the idea was to create multi-professional teams to enrich the diagnoses and the long term treatment of the patient, making it more qualitative and giving a positive value and more weight to TPE.

In 2002, collective sessions began, bringing the recognition of the unavoidable character of this therapeutic education.

In view of these satisfactory experiences, the foundation worked to build atopy schools all over Europe. And today it can be considered as done, with centres in 7 European countries and soon there will be more.

Therapeutic Patient Education, a topical subject

In July 2009, the HPST law actually integrated this notion of therapeutic education. Admittedly it is not new, but it is now structured. The French National Authority for Health has shown great concern for chronic diseases, notably atopic dermatitis. The number of cases of this disease is continuously rising, more particularly in industrialised countries. Beyond the consequences on health, there can be economic consequences to be taken into consideration.

Indisputable benefits

There is a prevalence of therapeutic education in chronic diseases, linked to bad compliance. This observation makes the active participation of the patient necessary in the treatment of their illness.

But TPE does not just come down to compliance with the treatment. The objective is for the patient to acquire the skills and knowledge to give them more independence and responsibilities in order to manage their pathology and its treatment. The patient learns to demonstrate their needs, to spot and analyse when at risk, to solve daily therapeutic problems, do what is necessary for their treatment, etc. The benefits of therapeutic education are well known. It helps limit the risks of complications, relapse or hospitalisation and noticeably improve the quality of life of the patients as well as compliance, the need for treatment and the doctor-patient relationship. These indisputable benefits in terms of public health are coupled with real health savings for the community.

The experiences of TPE throughout Europe and worldwide
Experiences in the face of atopic dermatitis vary from country to country. The differences in the systems, whether health or economic as well as cultural, can influence the treatment.

Consequently, various apprehensions can be noted. In the United States for example, according to Dr. Eichenfield, Therapeutic education is traditional and incoherent. The problem is that there are no standardised recommendations, which is why the two American colleagues recognised that they "had a lot to learn at this conference".

It seems crucial to develop this Therapeutic Education, through doctors and professionals, but also with the help of tools and promotional resources.

In Poland, Dr Malaczysnska, from Polanski Hospital - Gdansk, organised an atopy day, where children and parents got together over games and other fun tools.

For the Spaniard Antonio Torrelo (Nino Jesus Children's hospital in Madrid), a consensus on the disease is necessary, and the contact between the doctor and the patient needs to be reinforced. To strengthen this relationship, it is necessary in particular to use brochures, or a website. It is also necessary to work hand in hand with the different specialists, dermatologists and paediatricians.

Despite the differences between the countries, the professionals agree in terms of a therapeutic education programme. Indeed, it is generally divided into 4 main phases, used amongst others by Gisèle Kanny at the school in Nancy.

1. Elaborate a diagnosis

In this phase, the objective is above all to identify the needs of the patient, their expectations, apprehend the different aspects of their life, their background and the way they react. Following this identification, a first diagnosis will be drawn up.

2. Contract: personalised programme plan

This phase concerns drawing up a contract with the patient, formulating the skills they must acquire in order to set up a personalised programme.

3. Planning of TPE programme

In this education programme, the content to be proposed during the TPE sessions, the methods and participatory learning techniques need to be selected and the sessions carried out. It is generally on this point that there is the most divergence in methods. Even though they follow a common line of learning, each country brings a little extra, an idea, a particular way of doing things that is specific to their culture.

In Italy for example, Carlo Gelmetti explained that they use creative tools like the calendar, the atopy clock, the house and the different seasons. Furthermore, a significant increase in the commitment of the Italian teams in the management of these tools can be noted.

Marie-Anne Morren, dermatologist in Louvain (Belgium), is more focused on the group approach. In the Atopy school in Louvain, the techniques vary according to the age groups and are thus adapted to the abilities of each little patient.
Danielle Marcoux in Canada goes by the German model for the organisation of the sessions, developing them around six themes: knowledge of the disease, the psychological aspect, aggravating factors, the treatment, food allergies and observance of the treatments.

The Atopy institute in Greece opened a month ago. Panagiota Emmanouil and Alexandra Katsarou-Katsari presented the three modules used: the education of the patient, the information on the disease and the psychological aspect, also with significant interaction with the parents.

Everyone agrees on this multidisciplinary approach, with the credit granted to the association of multiple professional bodies that can be part of the set up of the therapeutic education. In the United States for example, the psychological side carries significant weight. In view of that, on top of the atopy schools, support centres have been created to support and help adults affected by the disease in order to provide them with psychological support.

4 Evaluation of skills

The evaluation concerns a round-up with the patient on what they know, what they have understood, what they can do and apply. With Atopic Dermatitis, the PO SCORAD (presented by JF Stalder) was created by the ETFAD to enable patients to evaluate themselves in order to benefit from an adapted, personalised treatment. The tests are also carried out at the end of the education programme to see if the patient has acquired the necessary skills.

All the speakers insisted on the necessity of this evaluation. In Poland for example, the parents are evaluated twice a month.

Essential points:
- Power of group sessions: group cooperation also teaches the doctor and enables information and experiences to be exchanged.
- Need of training for teams who wish to teach TPE
- Need of information for patients
- Importance of the multidisciplinary approach
- The PO SCORAD as an unavoidable evaluation tool
- Education in parallel of doctors and patients with the aim of working together.
- Importance of diets, even if the colleagues from the United States think that the diets are too restrictive.
- Idea of integration of patients as instructors: this question was tackled thanks to the curiosity of Mr. Stalder. Even if this integration can be effective, eczema remains an individual disease. In Italy, a mother helped write the FAQ on a website. In conclusion, for the time being it appears to be easier for the patient to be a part of patient associations as integration in medical staff is extremely complex.
SCORAD is a tool that measures the disease at a given time and does not give the patients point of view, whereas the PO SCORAD provides a score based on the objective evaluations made by the patients themselves. The principle is a self-assessment of the disease. This tool aims at improving knowledge of Atopic Dermatitis as well as its symptoms, and improving communication with the doctor. The PO Scorad uses a group of pictures representing the symptoms and graded according to severity. A major multicentric international study enabled the correlation with the Scorad to be verified. It is therefore a tool which will be very pertinent in improving patient monitoring between consultations but also to help patients monitor themselves better. This tool, developed by the ETFAD, the Foundation for Atopic Dermatitis and Aderma, exists in paper format. A software version is also available. A version is currently being developed by the Foundation to create an educational and evaluation tool in group sessions.

The economic impact of TPE

For the time being, the studies do not really prove the importance of therapeutic education. It would therefore be necessary to design studies which would accentuate the fact that TPE, by reinforcing the abilities of adaptation to the disease by the implementation of skills and appropriate processes, would enable: on the one hand, to reduce the need for treatments linked to the general treatment of the disease in the short or medium term and on the other hand, limit or delay incidents and complications linked to the disease.

This is what was done for the Asthma schools. Numerous worldwide studies have proven the influence of asthma on daily life, but above all the positive consequences of therapeutic education, as Pr Michel recalled sharing his experience in Asthma schools. He also insisted on the necessity for studies which prove the need for education, this long term interest in the quality of life. Asthma was only studied thanks to Therapeutic Education, a decrease in hospitalisations, absenteeism and the need for treatment was observed. Furthermore, in general, although it depends on the towns, hospitals... the cost is free for the patient. It is in this perspective that it seems primordial to develop an interest in Atopic Dermatitis, to enable recognition and thus increase the grants for better functioning.

Furthermore, each country has a different social security system, and there was a discussion on this theme, the funding. In the United States for example, the resources are generally made up of donations and financial support of the hospitals; there are a lot of financial constraints making it difficult to keep TPE "alive". In Belgium, there is still no refund but Doctor Morren hopes this will change rapidly. In Poland, part of the cost is financed by the hospital.

*It has emerged from these discussions the need for more studies to prove the impact of therapeutic education. However, a considerable problem persists: severe forms of Atopic Dermatitis, needing hospitalisation, do not account for the majority. The challenge is therefore to prove the economic interest despite its weak impact, to reinforce the interest of the ministry.*

The solutions proposed and discussed:

- Play on the quality of life and the indirect economic consequences: absenteeism, increase in hospitalisations, sick leave...
- Empower the Therapeutic Education units in the hospitals with the aim of obtaining budgets, as well as recognition.
- Insist on the consultation activity
- Focus on the multidisciplinary approach: constructive exchanges.
- Lobbying on education.
- Integrate TPE in outpatient care.

*The idea would be to have a European result to attempt to standardise the TPE, to reach a scientific consensus.*
According to Sébastien Barbarot, it is necessary to be cautious of the medico-economic approach, to focus essentially on the quality of life of the patient and the impact TPE can have. However, for the results to have a real impact, they must prove that there is a significant effect on the quality of life.

For therapeutic patient education to be a quality approach, it must:

- focus on the patient: orientation towards the patient is the future.
- be an integral part of the treatment of the patient.
- be structured and governed by specifications documents
- take into account the daily life of the patient: social, psychological, environmental factors.
- be carried out with a multi-disciplinary team: dermatologists, paediatricians, psychologists... with TPE training, for an all-round treatment
- take into account the identification of the needs of the individual, and thus adapt the treatment
- have a real organisation as well as varied content and tools
- contain an evaluation concerning the progress of the TPE programme

Internet: key tool for tomorrow?

In the United States, Internet has become an extremely widespread tool in the treatment of Atopic Dermatitis. Moreover, the two American professors insisted on the increasing power of the web. Lawrence Eichenfield affirmed recommending Internet from the 1st consultation, in the aim of completing the patients' questions.

Peter Lio presented a very interesting subject concerning the use of the internet in the TPE process. Internet has become a very important tool at all levels, the medical field being no exception. The patient can gather passive information on the Internet to learn, but the fact that they have to search gives them an active role.

Web 2.0 - social groups, social networks such as Facebook or others - is also booming. P. Lio insisted on the creation of an online community. For him, it is necessary for the patients to talk about their problems amongst themselves, exchange their experiences over the web. The important thing is to choose a moderator to filter all unsuitable information.

Going even further, he puts forward the idea of having applications on mobile phones that enable patients to set alarms when a drug needs to be taken or a cream applied. Here it really concerns creating the need in patients, but in the end it could prove to be an easy to use and very useful tool.
Summary of the workshops and the “position paper”

After putting together all the information gathered, here is what Therapeutic Education sessions could contain.

**Workshop: General content of sessions**

*(JM Chavigny-A. Lasek-C. Chiaverini/D. Dupré-C. Debons)*

1. **Introduction Module**
   - Presentation of experience, meeting the patient
   - Exercise such as photo expression
2. **Knowledge Module**
   - Knowledge of the disease
   - Knowledge of the treatment
3. **“Technical” Module**
   - Management of aggravating factors
   - Demonstrations of treatments
4. **Social Module**
   - Management of situations
5. **Recognition of participants**
   Medals, certificates of participation.
   
   Additional tools suggested:
   - Flyer in form of bank card with department number, the website, main contact.
   - Medals
   - Songs: summary of methods of treatment used in Poland and in Belgium
   - Small Punch and Judy style show with a child and a “doctor” who summarises at the end of the session for the children all the elements addressed.

**Workshop: Organisation and Methodology**

*(J. Mazereeuw-S. Balika / S. Barbarot -C. Bernier)*

1. Inclusion criteria: distress of patients, parents. In general, these are the most subjective criteria. It is necessary to be cautious and to use more objective criteria for selections.

2. The sessions can be group or individual.

3. When talking of the TPE programme, it is necessary to insist on the fact that it is to learn about the disease, but also that it is an opportunity for exchanges.

4. As for the organisation, the most practical seems to be to set the dates in advance and divide the groups up according to age. The question concerning the presence of parents remains a free choice according to the countries. In Belgium for example, it is not a problem to receive the parents as well during a group session. In France, it is more of a problem.

5. The TPE training is carried out in teams

6. It is also necessary to find the right balance between formalisation and creativity.

7. For teenagers, developing internet seems to be the key to success in increasing attendance of TPE programmes.
Proposal for a position paper by S. Barbarot

Plan

• Introduction
  – Context
  – Why recommendations?
• Method:
  – position paper based on authors experience (gathered during an international workshop) and data from literature
  – Answering questions.
• Results: recommendations with practical tables
• Short discussion
  – Conditions for use
  – Perspectives
• International editing committee
• Journal: Pediatric dermatology?

Questions

1. How is TPE defined?
  – WHO definition
2. What are the objectives of TPE for DA?
  – Health-economic approach
  – Quality of life improvement, coping
3. Who is the target population for TPE?
4. Who are the TPE actors?
  – Need for a multiprofessional team
5. How to start TPE (What to do beforehand, how to build a programme)?
6. Keys for success
7. How to assess the impact of TPE?
8. Is TPE possible in private practice?
9. How to fund TPE in Dermatology?

Practically speaking

• Review the existing literature
• Form an editing committee (but with only 1 editor)?
• Choose the journal
• Establish a 6 month plan
What they thought about the conference (interview)

Professor Stalder: "With so many countries taking part, the event wasn't a foregone conclusion and so we must congratulate the quality of the organisation and the scientific content drawn up by the Foundation represented by Mrs Ségard and Mrs Passerini. It is extremely encouraging to find people as motivated as us, and this conference came at just the right time: 50% of products prescribed are not used and there is an unimaginable waste, particularly in terms of results. This conference has a great future as it is just the beginning”.

Marie-Anne Morren: "The meeting was a great success, we will return home full of ideas and hope that it continues”.

A nurse: "It was a friendly exchange between the different teams and of everyone's experiences. To sum up, it was a really constructive encounter”.

Danielle Marcoux: "This conference was really enriching at all levels”.

Antonio Torrelo: “This conference is necessary as we must be structured, meet with others and come to a consensus on the disease”.

Many thanks to all the speakers, workshop leaders and all the participants!

.............To be continued............