

**EXPERIMENTAL PILOT PROJECT  
FIRST "YOUTH AND EPILEPSY"  
TRAINING COURSE  
IN THE POITOU CHARENTES REGION**

**CONCEPT**

**PEPS Programme  
(PROGRAMME D'EDUCATION ET DE PROMOTION  
POUR LA SANTE – *HEALTH EDUCATION AND  
PROMOTION PROGRAMME*)  
*"Global health" approach recommended by the WHO***

**PARTNERS**

**POITOU-CHARENTES REGIONAL COUNCIL  
POITIERS DISTRICT EDUCATION AUTHORITY  
MINISTRY OF EMPLOYMENT and SOLIDARITY, via the  
PEPS PROGRAM  
FONDATION DE FRANCE**

## ORIGIN OF THE PROJECT

### The people involved:

- 70% to 80% of epilepsy sufferers maintain good "control" over their condition thanks to their medical care and seizure control, and are able to lead a normal life.
- A proper schooling and a successful integration into a working environment are the key elements in the patient's general well-being.
- This integration is made all the more successful when the work involved is suitable and the disease has been stabilised.

**The development of practices similar to those of another European country, Finland:**

# "YOUTH AND EPILEPSY" TRAINING COURSE

## → THE OBJECTIVES

### LEARNING / MEETING / ORIENTATION

- **REDUCING THE GAP BETWEEN THE OBJECTIVE REALITY AND SUBJECTIVE REALITY OF THE EPILEPSY**
- **YOUNG EPILEPTICS: AN ACTIVE PUBLIC**
- **INVOLVED IN THE FOLLOW-UP OF THE PROGRAMME:**  
each evening, the following day's programme was presented and renegotiated with the young people.

**THE ROLE PLAYED BY THE YOUNG PEOPLE IS AN ESSENTIAL FEATURE OF AN APPROACH THAT IS EDUCATIONAL AND NOT INSTRUCTIONAL (PEPS PROGRAMME)**

## **-> PROFESSIONALS ON HAND TO LISTEN TO THE YOUNG PEOPLE**

- **the neurologist**
- **the school medical officer**
- **the careers adviser and psychologist,**
- **the school nurse**

## **-> PRACTICAL INFORMATION, INCLUDING**

- **the leaflet "careers guidance for epileptic pupils"**
- **the employment manual**
- **the small practical guidebook for employers**

## **RECRUITMENT: THE TIME NECESSARY TO DO**

**→ Entering directly into contact with this young population, taking into account:**

- the fact that epilepsy is a hidden, taboo disease: sufferers therefore avoid declaring they suffer from it and talking about it,**
- the fact that the young people at this level of schooling are for the main part minors, and that it is therefore necessary to first approach the parents,**
- the fact that medical secrecy and professional confidentiality need to be respected and that therefore we need to wait for the young person to contact us or to ask his or her parents to do so**

**→ Explain our approach, by means of the testimony of Finnish young people and of a young French girl who took part in a session organised in Finland in 1998.**

**SO:**

**Because of the obligation we have to proceed via relays made up of a great diversity of professionals**

- The recruitment took several months.**
- A communications operation, as part of the AEPH 2003, and in collaboration with the FEA, was organised in February 2003.**
- A selection seminar was organised, on the training course site, in April 2003.**
- The first training course was organised in August 2003.**

**→ THE GROUP WAS MADE UP OF SEVEN YOUNG PEOPLE, AGED FROM 16 to 23 YEARS OF AGE, including three who are still in, or are reaching the end, of secondary school.**

## **Their expectations in terms of:**

- Medical aspects: a better knowledge of the disease to help them manage it better and to be able to explain it better.**
- Social aspects: meeting other young epileptics in order to share experiences and exchange points of view about the epilepsy.**

# **DETAILS OF THE TRAINING COURSE**

**DURATION OF FIVE DAYS:** divided between collective meetings on subjects aimed to the preoccupations of the participants, excursions, sporting activities and leisure

- Each person introduces himself or herself during the first meeting organised on the first day...**
- ... orientation, on the second day**
- Then on to the epilepsy itself, on the third day...**
- ... before coming back to careers orientation and work, on the fourth day**
- feed back and analysis, on the fifth day of the stay.**

# **WHAT THE TRAINING COURSE BRINGS TO PARTICIPANTS**

**The young people are more than satisfied with what the training course gives them in terms of:**

- Knowledge of the epilepsy**
- Handling of emotions**
- Increasing self-confidence**
- Ideas for solving daily problems**
- Self-understanding**
- Entertainment and relaxation**
- New relationships**
- Discussions and experience-sharing**
- Organisation of their future.**

## **CONCLUSION**

### **→ THE GROUP:**

- **THE YOUNG PEOPLE KEEP IN TOUCH AND WANT TO MEET UP AGAIN:**

**A WEEK END?**

**AN ANOTHER STAY?**

### **→ THE TRAINING COURSE IN FRANCE**

- **OTHER STAYS WILL BE MADE AVAILABLE TO OTHER YOUNG PEOPLE FROM THE POITOU CHARENTES REGION AND NEIGHBOURING AREAS**

### **→ RELATIONS WITH OTHER COUNTRIES:**

- **HOSTING FINNISH YOUNG PEOPLE DURING A FUTURE STAY IN FRANCE**
- **PARTICIPATION OF FRENCH YOUNG PEOPLE IN THE STAY ORGANISED IN Ireland IN 2005.**