



Presentation
152nd Charity Wine Auction
of the Hospices de Beaune

Sunday, November 18, 2012

Under the auspices of the Fondation pour l'Université de Lyon



INTRODUCTION

As the leading cause of neurological disability in children, affecting 500,000 people in France, epilepsy is a double illness. It does not allow for a moment's respite, neither for the children who suffer, nor for their families, because this particular neurological condition is not only limited to the moments of crisis. Epilepsy is one of those diseases for which the preconceived ideas and judgments of others are as destructive as the disease itself. The seizures often come with the added handicap of social exclusion.

The Chevrier family from Beaune, members of FONDATION IDÉE's Support Committee, have brilliantly supported this application to be part of the 152nd Wine Auction of the Hospices de Beaune. Repeatedly confronted with situations of exclusion, the Chevrier family knows that raising awareness of this illness is crucial. Their daughter, a young 15 year old girl, has epilepsy. In recent years, she has devoted considerable energy to communicating about epilepsy as a major ambassador for FONDATION IDÉE, and is the spokesperson for thousands of children and teenagers with epilepsy in France.

A recent report by the World Health Organization highlights the specific deficiencies in care that affect people with epilepsy compared to all other chronic debilitating illnesses. It is thus urgent that the public becomes fully aware of this particularly distressing situation.

The resolute goal of FONDATION IDÉE is to make Lyon the leading European center for the treatment of epilepsy. Achieving this goal requires additional financial resources; the early detection of epilepsy and timely access to appropriate care are major public health issues. Epilepsy is particularly difficult to diagnose, and is currently the illness with the largest number of errors in diagnosis. 10,000 new cases of epilepsy are reported each year—this alone is a warning bell, calling for us to mobilize all means necessary to fight and overcome this condition.

Supporting FONDATION IDÉE means becoming part of an exceptional project that places Beaune at the center of a regional network for the optimal management of epilepsy, and benefitting from the opportunity to convene in Lyon the best experts in epilepsy.

Fondation IDEE is under the auspices of Fondation pour l'Université de Lyon



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EPILEPSY: A POORLY UNDERSTOOD CONDITION

Epilepsy is a neurological condition and not a mental illness.

The word epilepsy comes from the Greek verb 'epilambaneim' which means "to take by surprise, to attack." Epilepsy is characterized by abnormal electrical activity in the brain and is defined by recurring seizures. There are several dozen different forms of epilepsy, depending on the nature, the frequency, and the kind of seizures, but also depending on the evolution of the disorder over time and its impact on development. We no longer talk about epilepsy in the singular but in the plural.

In fact, epilepsy is like a double disorder: besides the condition itself, which can be very complex, epilepsy is a taboo subject, often synonymous with social rejection, and can lead to considerable psychological suffering for those who are affected. Epilepsy is a disease of exclusion *par excellence*, an atypical illness. Epilepsy can occur at any age, although in most cases it occurs at the two end points of life: it particularly affects children and teenagers, and the elderly.

A report by the World Health Organization (WHO) released in 2010 provides a portrait of the condition and its management: **"Epilepsy is the most prevalent disabling neurological disease in Europe,"** and it is **"one of the most costly illnesses and is responsible for significant mortality, with 33,000 deaths each year in Europe,"** often sudden and unexpected deaths that affect young adults. **"A third of these deaths could be prevented through better organization of care."**

The report highlights serious shortcomings in knowledge, support, and the resources allocated to epilepsy in Europe.

Epilepsy Statistics in France

500,000 people affected, ¼ of whom are under 20 years old

90,000 children suffer from epilepsy

30% of epilepsy patients are resistant to medication

Only 400 patients per year benefit from surgery, of which about 100 children, although there are several tens of thousands of potential candidates for surgery.

Some patients have been on a waiting list for more than a year

THE FONDATION IDÉE

“Because epilepsy affects 500,000 people in France, and is the leading cause of neurological disability in children;

Because epilepsy remains subject to considerable social stigmatization, is largely misunderstood, and has been neglected by major public health plans in our country;

FONDATION IDÉE is actively committed to overcoming this illness by supporting the creation of The Epilepsy Institute.”

OUR MISSION

Founded in 2007, FONDATION IDÉE, under the auspices of the Fondation pour l’Université de Lyon, aims to finance the **construction of the Epilepsy Institute in Lyon, France, dedicated to supporting patients and managing epilepsy** with the following goals:

- **Providing social, psychological, and educational support** to people with epilepsy and support to families through a **resource center** run by patient organizations;
- **Organizing training** for healthcare professionals to improve screening, diagnosis, and management of patients;
- **Supporting research** by creating a multidisciplinary network of leading researchers who will work together on innovative projects, which gives hope to those whose epilepsy affects their intellectual performance;
- **Bridging the gap between research and industry** by bringing together excellent research teams working on future treatments for epilepsy and private companies, who are able to quickly make these discoveries available for patients.

Renowned experts are behind the creation of The Epilepsy Institute and continue to actively support FONDATION IDÉE: **Dr. Alexis Arzimanoglou** and **Professor Philippe Ryvlin**.



Alexis Arzimanoglou

Founding member of the **IDÉE** Institute, Professor, Neurologist –Pediatric Neurologist (Hospices Civils de Lyon), Head of the **IDÉE** Medical Department, Former President of the French League Against Epilepsy (FLEC), and editor of the journal *Epileptic Disorders*.

Philippe Ryvlin

Founding member of the **IDÉE** Institute, Professor of Neurology at the University Claude Bernard in Lyon, Doctor at the Hospices Civils de Lyon, Co-director of **IDÉE's** epilepsy surgery program, Co-director of research team Translational Epileptology Research (TIGER) at the Neuroscience Center of Lyon, and President of the European Association of Video-EEG monitoring units (EEMA).



FONDATION IDÉE functions through the generosity of its donors. Operating costs for 2011 were € 163,000.

In 2011, FONDATION IDÉE received 75,396.29 € of donations.

As a foundation organized under the auspices of the Fondation pour l'Université de Lyon, and a state-approved charity, it can receive gifts, donations and bequests which are tax deductible.

Supporting FONDATION IDÉE will enable thousands of patients and their families to break out of the isolation in which they find themselves, and to have access to better overall care.

THE EPILEPSY INSTITUTE

The Institute will be located next to the **Neurology Hospital of Lyon, the Pediatric and Family Hospital, and the Neuroscience Campus.**

This future site for **the Epilepsy Institute** will bring together several excellent neuroscience research laboratories, including the Institute of Cognitive Science (ISC), the Lyon **Center for Neuroscience Research, and the future Neurocampus**, as well as state-of-the art equipment for exploring the human brain (Positron Emission Tomography, Magneto-encephalography). The CERMEP-Life Imaging research team also groups together several of the most important tools needed for better understand the nature of brain abnormalities that can lead to epilepsy.

The city of Lyon is a national leader in the field of epilepsy. Starting in 2014, its Pediatric and Family Hospital plans to increase its capacity by **doubling the number of children receiving surgical treatment for epilepsy.**

90,000 children and teenagers suffer from epilepsy in France
20,000 children have epilepsy that does not respond well to medication
10,000 children could benefit from surgery to improve their condition

**Surgery enables us to heal
80% of patients resistant to medication**

The Institute thus aims to work closely with the Pediatric and Family Hospital, where two of the Institute's founding members work: Professor Alexis Arzimanoglou, Pediatric Neurologist and Head of the Neuropediatric Functional Exploration Department, and Professor Philippe Ryvlin, renowned Epileptologist.

The Neuropediatric Functional Exploration Department of the Pediatric and Family Hospital focuses on early detection of epilepsy and conducting pre-surgical evaluations, most of which lead to neurosurgery.

In 2011, the activity of pediatric epilepsy service of the Pediatric and Family Hospital was as follows:

- 1378 consultations in epileptology
- 2011 video-EEGs in the laboratory for outpatients
- 2150 video-EEGs in the laboratory or at the patient's bed
- 236 nights (or series of 24h) of long-term video-EEG monitoring on both monitoring beds for 165 registered patients (excluding implanted patients)
- 94 nights (or series of 24h) of STEREO-EEG recordings for 13 implanted patients

At the same time, the Institute's Resource Centre will provide patients and their families with valuable information and advice on all issues related to epilepsy and the day-to-day problems posed by this condition.

Beyond medical care, social support and psychological support often have as many beneficial effects for the patient as the anti-seizure medication itself.

WHICH RESOURCES FOR BEAUNE PATIENTS?

The close ties between the Pediatric and Family Hospital of Lyon and the Epilepsy Institute provide patients and their families better support throughout their journey of recovery.

In its June 16, 2011 edition, the respected French magazine *Le Point* published its ranking of public and private hospitals in France: **the Pediatric and Family Hospital of Lyon (HFME) ranked first in the nation in the treatment of epilepsy.**

Internationally renowned, the Pediatric and Family Hospital of Lyon has become a reference in France in dealing with children and adolescent patients suffering from epilepsy. Similarly, the Neurological Hospital, located on the same site, offers the largest capacity in France for adult epilepsy surgery.

22,000 inhabitants of Beaune

22% of the population under 20 years old

176 people suffering from epilepsy, of which around 30 are children.

Of these 30 children, one third of them suffers from partially drug-resistant epilepsy and could benefit from pre-operative evaluations at the Pediatric and Family Hospital to see if they are candidates for surgery.

Unfortunately, still today, there are many mistakes and misdiagnoses of people with epilepsy—the average time between the first attack and the establishment of a proper diagnosis takes several years. **It is estimated that one out of every four patients with epilepsy is receiving inappropriate treatment.** The consequences of poor management can be severe, both medically (**life-threatening**) and socially, educationally and emotionally, with a risk that children be permanently withdrawn from school.

Making information available, raising awareness, training healthcare professionals about this complex condition, promoting research—all these actions will enable the Epilepsy Institute to improve the overall care of patients.

FONDATION IDÉE is committed to making these valuable resources, developed by the Institute and the Pediatric and Family Hospital of Lyon, easily available to patients from Beaune.

BRINGING TOGETHER A TRADITION OF SECULAR CHARITY AND A GREAT CAUSE

The charity auction by the Hospices de Beaune is an opportunity for the IDEE Foundation to receive valuable support in achieving its goals:

improving the overall, multidisciplinary care of patients with epilepsy and providing support to patients and their families.

By supporting FONDATION IDÉE, you are helping patients and their families overcome the isolation they experience, and you are enabling a larger number of patients, especially children, to benefit from a one-of-a-kind resource center, within an Institute located less than 150 km from Beaune.

By helping to change society's attitudes towards this misunderstood illness, you are helping thousands of families build a better future.

FONDATION IDÉE has a strong commitment to disseminating information about epilepsy as widely as possible, as well as informing the general public and supporting families so that they do not have to face this condition alone.

The Support Committee of FONDATION IDÉE, established in 2009, is made up of parents of children with epilepsy, former patients and patients with their relatives, as well as people interested in this cause.

All members of the Support Committee know how crucial our missions are for the optimal treatment of epilepsy and the future of people with epilepsy.

The commitment of Miss Chevrier, a 15-year teenager from Beaune, and the support of her parents, is a perfect illustration. This teenager's effective involvement in the activities of FONDATION IDÉE makes her one of our key spokespersons.

Help epilepsy patients fight against this disease





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